

THE ENTITLEMENT MENTALITY

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

It begins very early: professionals tell the parents of a baby with a disability what rights, assistance, and services the child and/or parents are entitled to under federal and/or state laws and programs. This exercise—“these are your rights”—continues throughout the person’s life, and in the process, the Entitlement Mentality is born.

Entitlements for people with disabilities are many and varied: early intervention services, special education services, therapies, vocational-rehabilitation, day programs, housing/residential, SSI (Supplemental Security Income), and more. While some of these may not fall under the “legal entitlement” category, they’re loosely lumped together for this article.

Few in Disability World—parents, people with disabilities, activists and advocates, service providers—are exempt from the Entitlement Mentality. Parents and people with disabilities are basically told, “This [the system] is the way...” And, actually, deciding whether or not to enter the system *is* a choice, but that’s not usually on the table for discussion. Instead, “recipients of services” are often led to believe they *must* agree to the services offered (and they’re often made to feel guilty if they don’t eagerly sign up). Thus, the slide into to the Entitlement Mentality happens so easily that we often don’t realize it’s happening. In the process, we often lose our common sense, autonomy, personal responsibility, and more.

When parents/people with disabilities enter the system, or when they move to a different arena in the system, they’re usually not told about other options (more about these in a moment), but that’s to be expected. Service providers are in the *business* of—what else? Providing services! Expecting them to share information about other options would be like a Chevy dealer telling a customer to look at a Ford!

In the case of activists/advocates, newsletters and other publications routinely scream about the need to “end the waiting lists” for services. In some cases, the waiting lists are full, so people with disabilities can’t even get *on* the waiting list. Yes, our federal and

state governments need to follow their own laws and fund the programs and services they’ve mandated. But are entitlements the best we can do for people with disabilities? Why aren’t advocates/activists spending their time, for example, helping people with disabilities learn how to get real jobs so they can get *out* of the system? The Entitlement Mentality frequently sabotages our common sense.

Entitlements are good, yes? Maybe, maybe not. They can be helpful if they enable people with disabilities to live the lives they want. They can be harmful when they lead to dependency, helplessness, social isolation, physical segregation, and other unintended negative consequences.

We take the *system* for granted, as well as the *value* of the system. But what if we question this? Despite all the progress that’s apparently been made in the last 40 years or so (beginning with the Deinstitutionalization Movement in the 1960s), today’s system is, in many ways, simply a variation of the institutional model (from the late 1800s and much of the 1900s). Under that model, and over many decades, it was variously believed that (1) the presence of certain medical diagnoses and/or characteristics were “problems” that needed to be “fixed;” (2) families were not competent to take care of their children with disabilities and/or a child with a disability could ruin a family’s life, so parents should abandon their children to the expertise of professionals in the institutions; (3) people with disabilities needed to be protected from the community; *and* (4) communities needed to be protected from the “menace” of people with disabilities. Of course, different labels were applied then (such as feeble-minded, idiot, imbecile, moron, and others) which fueled negative attitudes, devaluation, abuse, and more. While the intentions of many of those who supported the institutional model may have been benevolent, we know the extraordinarily negative outcomes of this model.

We can also see that the premises of this model were not accurate! Yet despite all the apparent

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progress, it seems the system still operates from these antiquated and erroneous paradigms.

In general, we no longer put babies or young children in institutions; today, we have early intervention services in the home—parents are still thought to need the assistance of professional services to raise their young children with disabilities. In addition, our babies are seen as a potential burden on society, as evidenced by one of the purposes of early intervention from Part C of IDEA: “to reduce the educational costs to our society, including our Nation’s schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age.”

For school-age children, the institution has been replaced with segregated special education classes in the public school system. And this segregation is often justified by the archaic beliefs that (1) children with disabilities should be sheltered and protected from the larger school community and/or (2) general ed classes should be protected from the “disruptions” of students with disabilities.

In the adult arena, large state-run institutions have generally been replaced by smaller congregate settings. But as Paul Castellani writes in *From Snake Pits to Cash Cows*, “At the beginning of the twenty-first century, the overwhelming majority of individuals living in so-called community services were in congregate residential and day programs that replicated the highly routinized patterns of daily life typical of the downsized state institutions. Individuals living inside and outside formally designed institutions still received elaborately prescribed and monitored clinical-therapeutic services rather than supports for daily living most needed and would likely prefer.”

Finally, the belief that conditions we call disabilities are “problems” that need be “fixed” has *expanded*, as evidenced by the explosive growth of remedies, therapeutic services and other interventions such as: diet regimens; pills; social skills programs; music, horticulture, art, horseback riding, behavioral, and other therapies; and more. And many of us want still more. But more services and programs don’t necessarily equate to better lives for people with disabilities.

Removing the faults in a stage-coach may produce a perfect stage-coach, but it is unlikely to produce the first motor car.

Edward deBono

So, in the 21st Century, many are still operating under 19th Century paradigms. How much progress has really been made? We could say that great strides have been made in *where* people with disabilities receive services (in the community instead of institutions). But what about *outcomes*? People with disabilities are still isolated and segregated, still under-educated, still marginalized and devalued, still on the receiving end of efforts to fix/change them, and still unemployed and living below the poverty line.

So why do families and people with disabilities embrace a system that still doesn’t lead to the outcomes we want? It seems that we (initially, at least) trust the system. We quickly realize we need to learn to “navigate the system.” We don’t always like it, but we’ve been brainwashed to believe that entitlements represent the best and/or only way to “do everything possible” to help a child/adult with a disability.

This brainwashing is complete when the very *presence* of the system causes many of us to look no further. We don’t, for example, routinely explore whether the needs of a person with a disability/family could be met by sources other than the system. Much of what the system offers may, indeed, be helpful. But the system’s methods are not the only way, nor, based on outcomes, are they necessarily the path that will get people where they want to be! A variety of other options can be explored:

- Using therapists/professionals as consultants to teach people with disabilities, families, and/or others how to incorporate valuable activities in inclusive settings, throughout a person’s day;
- Replacing traditional therapies with ordinary and beneficial activities (swimming at the “Y” with family or in the family’s hot tub instead of water therapy, infusing music in a person’s life instead of prescribed music therapy, etc.);
- Helping an adult with a disability learn to access existing employment services (the same ones used by people who don’t have disabilities) instead of depending on “special” VR/employment services.

These are just a few examples we can consider (more are in my books and other articles) if and when we no longer let the Entitlement Mentality cloud our vision.

In many cases, it seems some parents still embrace antiquated perceptions: that their child's disability is a terrible burden, a fate worse than death, and more. As a result, they feel they're "owed," and someone should "pay" for their difficulties. (And what does this do to the child?) If all entitlements are received, they're pacified, even if or when those entitlements do little or nothing to actually make things better. And maybe their mindsets aren't too far off the system's mentality, for it seems the system often operates from the cornerstone belief that human services are the "solution" to the "tragedy/problem" of a disability.

Many parents receive entitlements for their children that are not really needed. "Mary" and "Steve" live a good life in a two-story home. When "Bobby," their teenage son with a disability, grew too big for them to carry him up and down the stairs, they began receiving in-home services for him: a variety of people who were, essentially, strangers came into the home to carry Bobby up and down the stairs. Why didn't they just move to a one-story home? How does this make Bobby feel? Does he like strangers carrying and touching him? Was he asked what he wanted and were other options considered? No, because his parents said he was "entitled."

What would Mary want if it were her? When/if she can no longer walk up the stairs, will she want her husband to hire strangers to carry her? Or will she prefer they move into a one-story home or turn a downstairs room into the master bedroom?

"Larry" and "Donna" live a middle-class life, with "Amy," their 12-year-old daughter with a disability and two older children, and they qualify for family support services. Every weekday, an assistant picks Amy up at school and stays home with her until her parents arrive home. On Saturdays, an assistant takes Amy to the mall. This program allows Donna to hire the assistants, and she tells Amy they are her new "friends." What 12-year-old is surrounded by friends who are adults? Who *pays* to have a friend? Was Amy asked if this is what she wanted? Why can't she stay home with her brother/sister or even alone (with a phone in hand and neighbors close by)? Or why can't she go to a friend's home, the teen center, or after-school program? These options are used by

families without a child with a disability. But they weren't considered, since an entitlement for special services was available.

"Carly" and "Dan" are another middle-class couple. When "Ryan," their son with a disability, turned 18, his parents signed him up to receive SSI (Supplemental Security Income). Yet neither Ryan nor his parents actually need this money from the government. Ryan's 22-year-old sister, Sara, is still living at home and is supported by her parents, while she attends college and works part-time. Why are Carly and Dan willing to support Sara, but not Ryan?

They're hoping Ryan will have a job and be able to support himself one of these days, but they didn't

***Minds are like parachutes—
they only function when open.***

Thomas Dewar

consider the downsides of Ryan being on the government dole: the disincentives to work under current SSI rules; that Ryan will be seen as "needy and helpless" by others; that they/Ryan will need to maintain accurate records of how the SSI funds are spent in the event of an audit (there's no such thing as a free lunch); and the eligibility for receiving SSI is, essentially, that Ryan is unemployable. How does Ryan feel about this? Was it his decision? Carly and Dan made the decision because Ryan is "entitled," and they've been paying taxes all these years, so why not get some of that back?

In these examples, parents are simply following the conventional wisdom of today's system. But are entitlements the best we can do for our children?

Have we considered that there are other conditions/situations that might be considered "problems," but there's no system to meet the needs? How are these situations handled? People who want to lose weight join a weight-loss program, find support through a peer group, and pay for the services; others go it alone, watch what they eat, and exercise. Men and women who want to get in shape join a health club or take walks every day. People who want to quit smoking, drinking, gambling, etc., join support groups, "work the steps," and change their behavior. And there are many other ways individuals take responsibility for themselves, make changes to their lives, work to find creative solutions, and more: they have to, since there is no system for them.

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But Disability World is different: people with disabilities and/or their families are not expected to be responsible and/or find their own solutions. For example, many parents who willingly pay for child care for their children without disabilities insist that the state pay for “respite care” for their children with disabilities. Simultaneously, people with disabilities and their families are often expected to maintain their proper place of dependency and helplessness. However, positive change *is* happening at a few schools, service providers, and other entities, as people with disabilities/families are encouraged to use natural supports and generic services, to become more self-reliant, etc. But the response is not always favorable: “recipients” may accuse “providers” of shirking their responsibilities, and then threaten to sue!

Taking legal action—even when it can make matters worse—is another characteristic of the Entitlement Mentality. Yes, some lawsuits are absolutely necessary, but others can be very detrimental. “Susan” wanted “Joshua,” her four-year-old son with Down syndrome, to receive speech therapy services from the school’s special ed preschool program. But she did not want him enrolled in the segregated preschool class. The school insisted (incorrectly) that Joshua must attend class to receive therapy, so Susan was preparing to sue the district to resolve the issue. When questioned, it became apparent that Susan had an otherwise great relationship with the school, where her two older children attended. She expected Joshua to be included in kindergarten when he turned five. What would a lawsuit do to her relationship with the school? Was there another solution? Yes, Susan could get Joshua private speech therapy that would be covered by her husband’s insurance policy! Susan dropped her plans to sue, and was relieved that she wouldn’t ruin the good relationship she had with her children’s school. “How could I have been so stupid,” she asked, and

The best years of your life are the ones in which you decide your problems are your own. You do not blame them on your mother, the ecology, or the president. You realize that you control your own destiny.

Albert Ellis

then realized that her common sense had been corrupted by the Entitlement Mentality.

Are there exceptions to the scenarios in this article? Of course. Are service providers the “bad guy” in all this? No, they’re doing the best they can within the rules and regs of the system. And those who receive services are just doing what the system says to do. The problem is that the system operates from antiquated and erroneous paradigms. And, yes, the system needs to be changed. But people with disabilities and/or families don’t have to wait until the system changes for positive changes in their own lives. They can explore other options and take a different path.

The system can be helpful in some cases. But it is not the total solution, nor is it the only way. As demonstrated by some of the examples previously described, the Entitlement Mentality can result in:

- The perpetuation of antiquated paradigms;
- Rational people behaving irrationally, and loss of our common sense;
- People with disabilities and families ceding personal responsibility and autonomy to professionals;
- Dependency on the system and a concurrent victim mentality;
- The isolation, segregation, and devaluation of people with disabilities.

People with disabilities and family members can move beyond the Entitlement Mentality if we decide to use the system as the last resort, instead of the first choice. We can choose to view the system as a safety net to turn to *if and when* all of our other resources (family, friends, churches, community, and other natural supports and generic services) are tapped out. *What if there was no system?* Would we really let the people with disabilities we love go without, or would we find what they need in any way possible? Finally, we can recognize that the most important “entitlement” is having the freedom to live an autonomous, self-directed life of your dreams!