

# The Disability-Industrial Complex

Revolutionary Common Sense by Kathie Snow, [www.disabilityisnatural.com](http://www.disabilityisnatural.com)

According to “talk on the street,” more money is the solution to the “problems” faced by people with disabilities. Voices from both sides (those who provide services and those who receive services) say the same words: more funding is the answer. Yet *billions* are already being spent in what we should recognize as the Disability-Industrial Complex.

Many of us, regardless of which side we’re on (provider/recipient), don’t see disability services as a business. In the big scheme of things, they represent “human services,” provided by government entities, for-profit corporations, and/or non-profit charities. But make no mistake, it *is* big business, *and people with disabilities are the raw material that fuels the growth of this behemoth industry.* And, unfortunately, disability services have adopted the for-profit business model used by companies that sell products.

In that traditional model, SuperMart (a fictional company) constantly focuses on adding new products/services, lowering prices, opening new stores, expanding its coverage area, increasing its customer base, and more—all to make more money and grow the business. So this model is fine for consumer products. Unfortunately, many believe it’s also fine for providers of disability services: the more “clients” served, the better. But there’s a huge difference between consumer products and human services—especially in the areas of consumer choice and supply and demand.

We may *choose* to go to SuperMart for things we *want* (a new TV) or things we *need* (food), or we may choose to shop at a different store. We may also choose to put off buying a new TV/DVD combo until we can pay cash instead of using a credit card, or we may decide to get the old TV fixed and buy an inexpensive DVD player. We may buy meat and veggies at SuperMart, but shop at a different store for canned goods. We can freely make these choices.

In most cases, the same is not true for people with disabilities. In general, there are few choices in disability services. Most parents can’t shop around to find the best early intervention, special educa-

tion, and/or other services for their children. Ditto for adults with disabilities. In a free-market society, competition drives businesses to continually improve in order to maintain and increase their customer base. If customers aren’t satisfied, they go elsewhere, and the business goes under.

But there is little or no competition in disability services, so there’s no market push to continually improve. Unlike other companies, service providers don’t stay in business because they’ve satisfied their customers. They’re *allowed* to stay in business because they meet the rules and regulations mandated by the government bureaucracy—whether or not they please their customers!

In fact, service providers can outright fail their customers, yet they stay in business! Just look at the dismal outcomes for students who receive special ed services: the low graduation rate and second-rate education, which takes us to the shameful estimated 75 percent unemployment rate of adults with disabilities (and this number is higher for those with significant developmental disabilities). And *that* takes us to Voc-Rehab and other providers of employment assistance for people with disabilities. If the unemployment rate of people who *don’t* have disabilities was 75 percent, a national outrage would ensue, followed by massive changes in the general educational and employment fields. But the educational system and employment services for people with disabilities continue to fail—and nothing is done!

What about supply and demand? In general, customer demands dictate supply. Businesses work hard to meet the demands—not less and not more. Either extreme (too many products or too few) could lead to financial losses and failure of the business. Routinely, businesses perform research to determine what customers want, and needs are driven by the end-user. But again, the same is not true in the Disability-Industrial Complex. There, providers of services (in conjunction and collaboration with their government overseers)—not customers—“create the

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demand,” by first identifying the “problems” of people with disabilities, turning problems into needs, and then deciding how to meet those needs.

*Disabling Professions*, a book of essays compiled by Ivan Illich, explores this state of affairs in illuminating detail. First published in 1977, it describes the seduction of the public by a variety of “professional” services. (And many of us have willingly been seduced.) This book was out of print and hard to find for years, but it was republished in 2000 and its wisdom is needed now more than ever. In Illich’s essay on “Disabling Professions” he writes:

Professionals tell you what you need and claim the power to prescribe. They not only recommend what is good, but actually ordain what is right. Neither income, long training, delicate tasks nor social standing is the mark of the professional. Rather, it is his authority to define a person as client, to determine that person’s need and to hand the person a prescription... Professionals assert secret knowledge about human nature, knowledge which only they have the right to dispense. They claim a monopoly over the definition of deviance and the remedies needed.

Then in John McKnight’s essay, “Professionalized Service and Disabling Help,” he writes:

...every modernized society...is marked by the growing percentage of service in its Gross National Product, not only of services such as postal deliveries, catering, car repairs, etc., but social services such as marriage guidance, birth control, counseling all that falls under the general heading of social help.

This state of economic development is distinguished by its unlimited potential since service production has none of the limits imposed by goods production—limits such as natural resources, capital and land. Therefore, the social service business has endless possibilities for expansion as there seems to be no end to the needs for which services can be manufactured... [Managers] recognize that if there is no need for service, it is possible to manufacture a need. If the popular perceptions of need do not fit the service, social service managers have developed techniques that can persuade people to fit the service...

In a Real World business like SuperMart, success and continued growth occur only when a company provides what *customers* say they want/need. But as

described above (and as many know from first-hand experience), the human service industry expands because professionals—not customers—continue to define and create the need. For example, music, art, swimming, or gardening may provide a variety of benefits to our lives. But it’s been determined (by professionals) that simply adding these things to our lives or taking an art or music class isn’t enough. No, we need true professionals, not just an art or music teacher. So these things have become “therapy,” and we think professional therapists can solve people’s problems. That’s one way new industries are born.

So the Disability-Industrial Complex grows, and in the process, many service providers get rich. Of course, like many other businesses, those on the front lines may be overworked and underpaid. Nevertheless, those who own/operate human service agencies are making money; if they didn’t, they’d get out of the business. Similarly, state and federal bureaucracies continue to grow, and their employees enjoy good wages and health benefits—yet the people with disabilities they serve have little or none of either.

While some of the funding of the Disability-Industrial Complex comes from donations, the vast majority is taxpayer dollars—in the form of SSI, Medicaid, school system funds, and more. We all know about “government waste,” and the financial shenanigans in the Disability-Industrial Complex may be greater than in any other arena (like the \$600 hammers in the military made famous years ago).

For example, have you considered what services for people with disabilities actually *cost*, as compared to the *reimbursement* that states and their agencies receive from the Federal government (in the form of Medicaid, Social Security, and/or other tax dollars)? In *From Snake Pits to Cash Cows: Politics and Public Institutions in New York*, author Paul Castellani writes:

...Unofficial estimates by long-time budget and fiscal experts [show] that the *per diem costs* for each developmental center resident were substantially lower than the [Federal] *per diem reimbursement rate*...As the *per diem* developmental center rate topped \$2,000 by the end of the century, unofficial estimates of [New York’s] actual costs per day for each developmental center resident were around \$200. Similarly large gaps exist between the *rates* and *costs* in small ICFs/DD, Day Treatment, and other Medicaid programs. By 2000, it was unofficially estimated that Medicaid was

generating at least a \$300 million a year surplus [for the state of New York] of costs versus rates...

Are you shocked? Castellani's book was published in 2005 and included the most recent statistics (2001) available at the time. What about today? Make sure you're sitting down: according to New York sources, the current Federal *reimbursement* for residents in one state-run developmental center is about \$3,100 per day—that's over \$1 million per person, per year! The actual *cost* of the services is about \$300 per day. (And while these figures are from New York, other states behave in a similar fashion.)

So what does this sky-high reimbursement actually pay for? According to the source: salaries and benefits of the entire staff (not just those who work at the developmental center); purchase and maintenance of properties (group homes, day programs, etc.); and repayment of long-term municipal bonds that were originally used to purchase, create, and/or maintain buildings and land (for segregated settings, no less). So what's the incentive for this agency to move people with disabilities out of the developmental center and into community settings? None! Most people served by the agency are *not* in the developmental center, so the few hundred "residents" of the developmental center are being used as the cash cows to keep the *entire* agency afloat (and maybe even the state of New York via the surplus of funds). We can assume these individuals will likely "need services" (*while being held hostage*) until the long-term bonds are repaid!

Similar outrageous situations exist in many human services agencies. Tax dollars (SSI, Medicaid, and/or other funds) are "redistributed" up and down the food chain: paying for salaries and benefits (while people with disabilities go without either), marketing and other operations, buildings and grounds, and more. Why don't we "cut out the middleman"? In the New York example, what if we simply *gave* the \$300 per-diem cost of services to each of the people with disabilities in the developmental center? That's \$109,500 a year! With that money, a person could *get off* SSI and Medicaid and out of the developmental center. He could get his own place to live and buy whatever supports he needed (personal assistance, assistive technology, and anything else) on the open market. He could probably purchase insurance through a high-risk pool. He wouldn't have to work,

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if he didn't want to, and he'd still be able to donate to his favorite charity! Instead, he's forced to keep others employed, while he's considered a "charity case."

Public schools are not exempt from this "funny business." Even though special ed law requires schools to provide a variety of services for students with disabilities, some schools have figured out how to preserve their funds (taxpayer dollars) and tap into Medicaid funds to pay for these services. And in one district, the parent of a child who *did not qualify for or receive* Medicaid was asked if she needed anything for *her* son, since the school had "extra Medicaid dollars left over" which were not spent on the children who *were* entitled to Medicaid.

On a regular basis, just like businesses in the Real World, those in the Disability-Industrial Complex proudly crow about their growth: an increase in the number of people receiving services and/or number of programs/services offered. And while this may represent success for the organization, it certainly does not symbolize success for the people on the receiving end of services. Instead, it represents an increase in the number of people who have been made *dependent* on the organization! Think about it: every goal written in those ubiquitous IFSPs, IEPs, IHPs, ISPs, is supposed to help a child or adult with a disability move closer to a successful, interdependent life (my words, not the words of the system). Why is it that few individuals "meet their goals" and/or "make progress"? Why are so many said to need *more* services, not less? Is it because people with disabilities *are* failures, or because the system *needs* them to fail so they'll stay helpless and dependent on service providers?

The mission statements of human service agencies, schools, and others who provide services are invariably focused on helping people with disabilities live better lives—not on the organization growing and making more money! So if they really want to live up to their mission statements, shouldn't they do whatever it takes to ensure people with disabilities move beyond dependency (and therefore, have better lives)? If so, they would adopt the *opposite* of the Real World business model and success would be measured by fewer customers, not more!

For example, a service provider could help a woman with a disability learn how to network, make



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connections, and find her own job, instead of trying to place her in a job (and making her look incompetent in the process). If her first job didn't work out, she would know how to find her next job, and wouldn't need the service provider. Therapists could become consultants, instead of providing hands-on manipulation of a child's body. They could help parents, day care staff, and/or others learn how to incorporate beneficial activities into a child's day and/or how to use ordinary activities (swimming, karate, dance, etc.) to meet the child's needs. There are many ways to truly assist people with disabilities, instead of providing "special services" which result in dependency, segregation, and other negative consequences.

Alas, the situation with today's community-based services is not much different than what occurred during the Deinstitutionalization Movement in the 1960s. The biggest barrier to closing and/or downsizing institutions and moving people with disabilities into the community was not concern about the lives of people with disabilities, but about (1) the employment of those who worked in the institutions and (2) the economic impact on the community! Unions and others fought tooth and nail to maintain the status quo, so employees wouldn't lose their jobs, and civic leaders screamed about the economic hardship on the community. Real concern about the lives of people with disabilities—if there ever was any real concern—was lost in the hysteria over the economic harm to employees and communities. Never was it more clear that people with disabilities were commodities—income-generating cash cows to be used at will.

Despite the apparent progress of community-based (instead of institution-based) services, people with disabilities are still commodities. And the more needy they're made out to be (by archaic laws/policies and professional expertise), the more valuable they are to those who are economically dependent on them. Imagine that: people with disabilities are seen as dependent, but in truth, everyone in the Disability-Industrial Complex is dependent on people with disabilities!

But what if professionals in the field took a principled stand, and got out of the dependency-business? They could put their valuable skills to work in other careers. A Voc-Rehab counselor could work in human resources in the private sector, and ensure the company hired employees who have disabilities. *That* could decrease the shameful unemployment rate!

A teacher in a segregated classroom could become a general ed teacher and ensure children with disabilities were included in her class. If she liked working with very young children, she could open her own daycare/preschool and ensure children with disabilities were included. The skills of any job in the system can be utilized in other arenas. And jobs *outside* the system provide more opportunities to help create a more inclusive society than any job *in* the system!

I'm skeptical of the service system's willingness to change on its own. There are too many who are too heavily invested in maintaining the status quo of the Disability-Industrial Complex. Simultaneously, I'm an eternal optimist about what's possible for people with disabilities and their families: Benjamin, my 21-year-old son who has a disability, is attending college, living the life of his dreams, and, by choice, hasn't received any services since he was six.

People with disabilities and their families can choose to ignore the negative prognoses and laundry-list of problems which professionals dole out to us. We can reject the services that result in dependency, isolation, and devaluation. We can determine our own needs, and then use our own resources and the bountiful supply of natural supports and generic services in our communities to meet those needs. We can choose to use the service system as the last resort instead of the first choice. And, then, when the customer base of the Disability-Industrial Complex begins shrinking, human service businesses may finally recognize the obvious: they need us more than we need them. Some organizations will fall by the wayside, and others will realize that to stay in business—just like any other company—they must let their customers define their needs, and then they must meet those real needs via high quality customer service. What a concept!