Benevolent Services

Dangerous Messages

Revolutionary Common Sense by Kathie Snow
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Today's service system attempts to address the "problems" of children and adults with developmental disabilities via interventions, treatments, therapies, special programs, and other services and entitlements. But hidden within all this "help" are unspoken messages that can harm those who receive the services. The messages vary, depending on the program or service, but they all share one commonality: "messages of incompetence" about children and adults with disabilities and family members. Under the cloak of benevolence, the service system presumes that medical personnel, educators, therapists, service coordinators, and others in the field have superior knowledge and expertise about the needs of children and adults with disabilities. But this is really a long-standing myth. People with disabilities and family members are the true experts!

In early intervention, the ***spoken message*** is: "Your baby is at such risk, he is entitled to the special help of professionals and services in order to minimize the effect of developmental delays and help him reach his potential." The ***unspoken message*** is: "Loving your baby, playing with him, and helping him learn—just like all parents do—is not enough. You're just a parent and your child needs more than you can give him. And even if you *have* successfully raised other children, you still don't have the knowledge or skills to handle *this* situation." And we, the people who know our children best, believe the myth.

Worse, however, is the damage done to the hearts and minds of children and adults with disabilities when the unspoken messages of today's service system tells them, over and over and over again,
"You are not OK."

In early childhood education, the ***spoken message*** is: "Your three, four, or five-year-old child with a disability is so far behind and so unprepared, she is entitled to special ed preschool where trained professionals will help her get ready for public school. Further, with enough help, the child's disability may be ameliorated in special ed preschool and maybe she won't need special ed services by the time she reaches kindergarten."

The ***unspoken message*** for stay-at-home moms is: "Keeping your child at home is not an appropriate option. You don't have the skills to maximize your child's development, nor are you competent to meet your child's special educational needs. Sending your son or daughter to the neighborhood preschool two or three days a week is also not appropriate. Regular preschools are not competent to handle your child's needs; only we have the skills to meet the needs of children with disabilities."

The ***unspoken message*** for working moms is: "The daycare center cannot provide all the special care and education your child needs, even *if* it's the place where your other children have been (or are being cared for), and even *if* the center's employees know your child because they've been caring for him for a long time. The daycare staffers have not been trained in how to help children with developmental disabilities. Your child needs to attend the special ed preschool for part of the day, and then we can bus your child to the center for babysitting." And parents, along with experienced daycare/preschool staff, believe the myth.

In special education, the ***spoken message*** is: "Because children with disabilities have so many problems and special needs, and because they are so different from typical children, they need specialized help from specially trained teachers in special settings. The ***unspoken message*** is: "Children with disabilities are not competent to be in regular classes. Furthermore, regular education teachers are not competent to teach children with disabilities, the regular educational environment is not appropriate, and even the combined wisdom of parents and educators is not enough to meet the child's unique needs." And experienced parents, along with educators, believe the myth.

In the lives of young adults, the ***spoken message*** is: "Because of their disabilities, teenagers are entitled to receive help from the special ed system and the voc-rehab agency. These experts will determine what kind of careers are appropriate and will place students with disabilities in part-time jobs (most likely without pay) in the hope they'll be successful in entry-level positions. Students who are not employable at the present time will attend special programs to help them get ready for a real job—one of these days."

The ***unspoken message*** is: "Your teenager is not competent to find a job or determine her future on her own. Even if she has the support of her family and even if she has dreams, she needs the expertise of professionals who will determine what she's capable of doing." And parents, along with their budding young adult children, believe the myth. The same dilemma faces many adults with disabilities: they wait in line (often, for years) for a vocational counselor to "place" them in an "appropriate" job (appropriate from the system's perspective), because it's assumed a person with a disability is incompetent to get a job on his own (the way most adults get jobs!).

In the area of living arrangements, the ***spoken message*** to adults with disabilities is: "You're entitled to habilitation services, so we'll help you learn how to live in the community." The ***unspoken message*** is: "You're not capable of living on your own or finding your own supports in the community, so we'll decide where and how you should live (in a group home or some other facility that may or may not be where you want to live). And we'll tell you if and when we think you're ready to live on your own."

And for individuals with disabilities of all ages, the ***spoken message*** of therapies and other interventions is: "We're going to help you learn to walk, talk, feed yourself, control your behavior, and achieve a variety of functional skills." The ***unspoken message*** is: "You are not-OK the way you are, and we're going to work on you—with or without your cooperation—until you can be the way we think you should be."

With the best of intentions, good people work in the service system and provide "help." *But the underlying premise of the service system is flawed:* it's based on the paradigm that the "problem" is within the person with the disability. Thus, even good people can inadvertently do harmful things, such as sending negative messages that create dependency and erode self-determination, autonomy, self-reliance, and more.

In truth, the "problem" of disability does not reside in people with disabilities. The real problem rests in societal attitudes and social policies that define people with disabilities as "abnormal" individuals who (pick one or more): need to be made "whole" or be "fixed" via therapies and other interventions; are incompetent; are unable to succeed without expert help; are not expected to live "normal" lives; and...(insert your own experiences).

Parents and people with disabilities (again, with the best of intentions) step into the jaws of the service system, and unintentionally relinquish their autonomy, free will, and choice, and accept the notion that others know best. In most cases, they end up becoming angry and frustrated, and uncomfortable with the paternalism of the system and the lack of real assistance. Worse, however, is the devastating damage done to the hearts and minds of children and adults with disabilities when the unspoken messages of today's service system tell them, over and over and over again, *"You are not OK."*

If we want children and adults with disabilities to lead natural, ordinary, and fulfilling lives, we must be aware of the hidden messages of today's conventional wisdom, and we must reject the philosophies that marginalize people with disabilities and family members. When we recognize disability is a natural part of life, we'll know success and inclusion for people with disabilities will *not* come from the system and its efforts to "normalize" people. We'll understand success and inclusion arise when individuals with disabilities live real lives in their communities, with help from natural supports and generic services.

Today's social policies have the best of intentions: to help people with disabilities. But the system is misdirected: it's not the bodies and brains of people with disabilities that need to be changed—it's the attitudes and perspectives of society (that's us) that need to change.