

Great efforts are expended to help or treat the *bodies and brains* of children and adults with disabilities. But do we give much thought to their *hearts and minds*? Do we ever wonder if all the “help” may actually be harmful to the *whole person*?

When my now 19-year-old son was diagnosed with cerebral palsy at the age of four months, I embraced CONVENTIONAL WISDOM (the dictates of physicians, therapists, and early intervention providers), and Benjamin began physical and occupational therapies. This, I was told, was best for Benjamin, so we did as much therapy as possible! Like many others, I mistakenly equated *effort* with *progress*.

I also gave little or no thought to my son’s heart and mind. By accepting the wisdom of EXPERTS, *no more thinking on my part seemed necessary*. Thankfully, however, when my son was three, my comfort zone was challenged by adults with developmental disabilities I met in the Partners in Policymaking leadership training program. Hoping to learn from them, I asked about their childhoods and was shocked by their collective responses. “I wish I could have made my parents happy...They always wanted me to walk [or talk or achieve some other functional skill], so they took me to therapy for years. But I wasn’t able to walk [or whatever], so I know I let them down...and I wish they could have loved me just the way I am.”

Whoa—this eye-opening experience helped me understand the *message of therapy* to a child: “You are not OK the way you are,” and this message is sent each and every time a child’s body is “worked on” in the traditional manner. Yes, therapy can be fun and therapists are usually nice, caring people, *but the message is still there*. It may rear its ugly head in children, who respond with tears, resistance, or anger, or it may lie dormant, then rise up years later, in a firestorm of painful memories. And this message can permeate a person’s entire life, for if he’s not good enough for *his own parents* (who are supposed to love him unconditionally), how can he ever be good enough for anyone else later on—friends, neighbors, teachers, employers, and others?

Even worse, the stories of some adults with developmental disabilities indicated that years of

HEARTS AND MINDS

REVOLUTIONARY COMMON SENSE
by Kathie Snow

therapy and interventions might have increased their chances of being sexually or physically abused. Some attempted to resist the hands of therapists or even their parents during “home programs,” and when their “No’s” or tears or anger were ignored, they learned that they had no power *then*, and no power *later* to stop the “bad touches” of others. And many of us are aware that the rate of sexual and physical abuse of

adults with disabilities is said to be double that of the general population.

With a lump in my throat and pain in my heart, I *heard* the words of these adults. But they were too painful to *embrace*. To do so, I would have to question the value of therapies and the wisdom of EXPERTS—and none of *them* ever said therapy could be anything but helpful. The empathetic part of me heard the pain of these adults, but my *ego* didn’t want to deal with the frightening possibility that I might have been less than diligent in investigating what was really best for my son. My ego won. I pushed their stories deep inside and pretended they weren’t there. Benjamin’s “therapy career” (*it really can be like a job for kids*) continued.

Three years later, six-year-old Benjamin was successfully included in first grade and in typical community activities. His life was grand, I thought, until my perceptions were shattered by his passionate words and buckets of tears as we drove to therapy after school one day: “I don’t want to go to therapy any more—I just want to go home and play, like my friends. I’ve been doing this *all---my---life*, and going to therapy doesn’t make me feel like a *regular person*.” For he *was* a regular person in first grade, and on the T-ball team, and in Scouts, and at home—but not at therapy.

His words and the raw pain and anger meshed with the stories from the adults three years before, and I finally embraced them. Benjamin never went to therapy again. The therapists read me the Riot Act, concerned about his body, but I had finally realized that protecting his heart and mind were more important. And my son’s reaction? “Mommy, thank you for listening to *me*.”

The expertise I had learned from therapists helped us create more natural ways to provide the assistance Benjamin needed, in our home and the community,

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using techniques that didn't send Benjamin the soul-crushing YOU'RE-NOT-OK message: playing in the hot tub replaced water therapy; a shoulder massage morning and night during the dressing/undressing routine replaced the therapist's weekly arm/shoulder therapy; and more. We've never looked back, and the dire predictions of therapists ("Stopping therapy will ruin his life...") did not come true. Today, Benjamin is enjoying his second semester at community college; his power wheelchair, service dog, laptop computer, classroom accommodations, and a little help from his classmates ensure his success. He believes in himself and envisions a great future as a film critic!

The well-meaning efforts of health care and service providers, educators, and others—including parents—may lead to less-than-desirable outcomes when we are not *intentionally mindful* of the potential consequences to a person's heart and mind. And unintended, negative consequences abound across the continuum of services. Professional help is not inherently harmful, but the *way* it's provided can generate long-term harm to people's hearts and minds—and we can change this!

Therapists can become valuable consultants, instead of direct hands-on providers, helping parents, teachers, and others learn how to incorporate beneficial activities within inclusive settings, including sharing ideas for assistive technology, supports, and modifications. And while providing therapy in natural environments (like at home instead of a therapy clinic) seems like a step in the right direction, this strategy *can* prove harmful if it causes a child to feel NOT-OK. For example, if an in-home therapy session creates stress in a child, making her feel unsafe or unprotected *in her own home*, where *can* she feel safe and protected? Some parents meet therapists at playgrounds or other neutral locations in order to protect their children's sense of well-being and security in their own homes.

In many school districts, children with disabilities are in segregated special ed classrooms (including preschools), while others are pulled out

of regular ed classrooms for "special services." These practices demonstrate little regard for the hearts and minds of students, as they send YOU'RE-NOT-OK *and* YOU-DON'T-BELONG messages. Isn't the purpose of education to prepare students to succeed as adults? How can we expect this outcome if "special help" for children's bodies and brains causes potentially *irreversible harm* to their hearts and minds? At inclusive schools, students with disabilities are in regular classes, and extra assistance is provided *in* those classrooms, by regular ed and special ed teachers, therapists, and even classmates, in ways that are respectful of their hearts and minds.

"Special" (segregated) sports teams, youth groups, etc., also send the YOU'RE-NOT-OK *and* YOU-DON'T-BELONG messages. Yes, participants receive the message that they *do belong*, but only in those special environments—and these do not represent the real world!

Children in such environments may become adults who are comfortable only in similar sheltered settings, dependent on others. In their hearts and minds, they learn they're not good enough for the real world—they settle for a blue ribbon in a second-class world.

The hearts and minds of adults with disabilities may have been deeply scarred as children, and more harm may come via adult services. While an employment counselor is working to find you a job, for example, what does such help do to your heart and mind? It reinforces the notion (probably learned as a child) that you're incompetent and unable. What if adults with disabilities were taught *how to get their own jobs*, so they can believe in themselves and their abilities? Ditto learning to live on your own with whatever supports you need. More importantly, what if parents helped their children learn these skills so adult services aren't needed?

Our good intentions are no longer good enough. Isn't it time to critically examine if services and/or help have the potential to harm a person's heart and mind, and then make changes? We can be guided by the ancient, timeless, valuable wisdom of the "first physician," Hippocrates, who said, "First, do no harm."

**The hearts of small children
are delicate organs.
A cruel beginning
in this world can twist them
into curious shapes.**

Carson McCullers

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