

Elbow Room

(or Nothing About Me Without Me!)

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Literally, I want and need elbow room on an airplane. A middle seat is the pits when your seatmates hog the armrests. I also want elbow room on a bus or airport tram.

Metaphorically, I need elbow room in my day-to-day life—to live my life my way. At the same time, I need to live cooperatively and respectfully with family members, co-workers, and others. Day in and day out, it's a balancing act to maintain the elbow room I need without also poking others with my elbows! The same is true for most other people without disabilities.

Unfortunately, the same is not usually the case for children and adults with disabilities. Ruled by their “plans/programs” (ISFP-Individualized Family Service Plan, IEP-Individualized Education Plan, ISP/IHP-Individualized Service/Habilitation Program, PCP-Person Centered Plan), many people with disabilities are not allowed to make choices in their lives, to take risks, to follow their dreams, and so forth. The simplest decisions are made for them: what to eat, when to eat, what to wear, when to get up, when to go to bed, how and where to spend their time, and much, much more. Their lives may be programmed to the nth-degree.

They have no elbow room. So we shouldn't be surprised by the mantra many are embracing, “Nothing about me without me!” And when a person's privacy, autonomy, and self-direction are threatened, we shouldn't be shocked when he throws his sharp elbows at us—verbally, physically, or in some other way.

The “system” that essentially permits paid providers to be “in charge” of the lives of children and adults with disabilities is partially responsible. Family members may bear responsibility if they surrender their authority to professionals. And families and professionals alike are accountable when “helpful interventions” become “harmful interference.” In

addition, we shouldn't be misled by efforts that are supposed to represent “progress.” Many states now require that a “person-centered plan” be written for adults with disabilities who receive services, yet they may not require the person with a disability to be at her own meeting! How can it be “person-centered” if the person is not present and engaged in the process? *Whose life is it anyway?*

How can we expect a person with a disability to ever be successful if others are in control? From the earliest moments in a person's life (yes, we need to start when children are very young), we need to spend less time trying to control and more time listening and asking. Then our efforts should be focused on understanding and respecting; providing the needed assistive technology, supports, and accommodations; and/or doing whatever it takes to help the person live her life her way.

Ed Roberts needed a power wheelchair and a portable ventilator and he could move only two fingers on his left hand; he was also the father of the Independent Living Movement. Ed needed help doing just about everything, but he was in charge of his life because he made decisions about his life, including what type of help he needed, who would provide the help, and how the help would be provided. Ed once said, “The quality of my life is related to how free I am to make my own choices.” *You* want to decide how to live your life; so do I; so do children and adults with disabilities.

Let's question what we're doing. When does help cause harm? When does support actually smother? When does assistance become control? Are we nurturing self-direction or learned helplessness? How do the people with disabilities in our lives *feel* about what's happening in their lives? Shouldn't we care?

Everyone needs elbow room. Remember, “Nothing about me, without me!”

**Elbow room is
positive freedom...
Individuality is
freedom lived.**

John Dos Passos