# A close-up of a logo Description automatically generatedA green and white logo Description automatically generatedThe Independent Living Advocate’s Toolkit for Mentoring Families of Children with Disabilities

## Brief #1: Teaching Vocabulary

Words matter. They matter in life generally. They matter in the world of disability. Words have meaning given to them by individuals and by society. Parents and families of children and youth with disabilities are aware of this reality constantly as they navigate the domains of education, health care, accessibility, transportation, technology, finances, and a host of other life areas where barriers can spring up that prevent equity and inclusion.

The Independent Living activists who were architects of the Rehabilitation Act, as amended (the Act) understood this fact. When Centers for Independent Living (CILs) were created by the Act, the activists made sure that the words that were used to describe people with disabilities and the kinds of services and advocacy that CILs provide were empowering and leveling. CILs are non-residential services and advocacy organizations. The first guiding principle of the independent living movement is that disability is an ordinary life experience. It’s not a tragedy, a punishment, or a failing. The person with the disability doesn’t have something “wrong” with them and they are not a “victim.” With that in mind, it was essential to elevate people with disabilities from the role of perpetual patient or client to that of consumer or customer. Consumer means “user” of services or products. In the consumer market, the consumer has the right and the power to make choices about what they want. It moved the narrative about people with disabilities a long way from the old “handicap” which meant cap in hand, begging for money.

The word consumer is the official term that’s embedded in the Act, along with a string of other words and phrases that define the independent living philosophy:

…a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society…. (Sec. 701)

The person with the disability always gets to choose how they want to describe themselves, but advocates can help families understand the power that different words have to shape the self-image and self-determination of the disabled child as they mature into adulthood. Imagine, for example, the impact that teachers can have if they talk about strengths, interests, and goals rather than deficits. When parents speak with teachers and other professionals, they don’t have to use the same vocabulary the professionals are using. They and their child with the disability can choose their own words and set the tone for how they expect to be respected and listened to in any setting.