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

## Brief #2: The Independent Living Model vs. Parent-Led Model

One of the terms used in the Rehabilitation Act, as amended, to define the philosophy of the Centers for Independent Living (CILs) program is familiar to families as well as to CILs: *self-determination*. That word was introduced in the “normalization” movement of the early 1970s which applied primarily to individuals with intellectual disabilities to mean the power to use one’s own will in life choices. The term became more well-known over time and has been adopted by service delivery systems.

There’s another term in the Rehab Act definitions that is not so well-known in family programs: *consumer control*. That term created a more radical shift in how services are planned and delivered. First, CIL staff and governing boards are made up of a majority of people with disabilities. Services are provided through peer sharing and staff and board members serve as role models. They are tangible proof of what may be possible for the consumer. Second, the consumer chooses and leads the services. This includes home and community-based services such as health care, personal assistance, counseling and therapies, Person-Centered Planning, etc.

Family members who accompany their transition-age youth to an appointment at a CIL are often surprised when the CIL staff asks the family members to wait outside the interview room while they meet with the consumer privately. Family members who have been involved in the Parent-Led Model of advocacy for their disabled child may be used to being in the driver’s seat regarding services or education. At CILs, the consumer is the individual with a disability, philosophically and in practice—not the family. CIL services are consumer-directed regardless of the type or severity of the disability. While CILs provide information, resources, and referral to non-disabled individuals such as families, policymakers, and the public, it is the individual with the disability who is preparing for transition to adulthood who will have the option to create an Independent Living Plan and set goals of their own choosing.

Sometimes family members are needed to facilitate communication but are asked to allow their youth to speak for themselves. Also, families from some cultures define independence differently than CILs might and prefer to participate as a unit. Independent Living Advocates should always be sensitive to cultural preferences while continuing to support the consumer in naming their own life goals.

As the world becomes more accessible and inclusive because of federal legislation, youth with disabilities are recognizing that they have a right to be heard and to make choices. But having the capability to make those choices won’t happen suddenly when a disabled child arrives at transition. Decision-making is a skill that develops over time as a child matures. IL Advocates can assist families to enable their child or youth by informing them of youth leadership development opportunities, such as directing one’s own IEP meetings, participating in peer groups where self-advocacy is taught, serving as members of committees and boards, and meeting with policymakers to give them first-hand information about disability issues.