



independence^{INC}
for people with disabilities

**House Committee on Children and Seniors
Rep. Connie O'Brien, Chair**

**Testimony on Independence, Inc.
Stacey Hunter Schwartz, Ph.D., Executive Director
February 12, 2013**

Thank you, Chairperson O'Brien and members of the Committee, for the opportunity to provide information today on Centers for Independent Living (in general) and on Independence, Inc. (specifically). I am the Executive Director of Independence, Inc., a Center for Independent Living in Lawrence, Kansas, serving people with disabilities in Jefferson, Douglas and Franklin counties. Our mission is to maximize independence for people with disabilities through advocacy, peer support, training, transportation, and community education.

My background. I grew up in California in a household with a younger brother with a developmental disability. My whole family was affected by Craig, as we teamed up to train him in how to be as independent as he could be. My parents were teachers and both found themselves in the roles of advocates, not just for Craig but also for other local children with disabilities. I suppose my career path was sealed.

I went on to earn a Ph.D. in Counseling Psychology, counseled and taught people with brain injuries at a community college in Orange County, California, became the dean for special programs at that college and published a book and some textbook chapters about traumatic brain injury. For many years, I referred my students to the independent living center in Orange County without any awareness of the rich history and fascinating philosophy underlying the independent living movement.

Independent Living Movement and Philosophy. Once I came to Lawrence and to Independence, Inc., I learned that Centers for Independent Living are the outcome of the national civil rights and Independent Living Movements. The Independent Living

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philosophy creates a new social paradigm and emphasizes that people with disabilities are the best experts on their own needs and that they have crucial and valuable perspectives to contribute to society and are deserving of equal opportunity to decide how to live, work, and take part in their communities.

The 403 Centers for Independent Living (or “CILs”) in the U.S. are an offshoot of the Rehab Act of 1973. The state of Kansas currently has 10 CILs. The Kansas Association of Centers for Independent Living (KACIL) is our professional organization.

Kansas Centers for Independent Living (CILs)	
Coalition for Independence	Kansas City, KS
Independent Connection	Salina
Independence, Inc.	Lawrence
Independent Living Resource Center (ILRU)	Wichita
LINK, Inc.	Hays
Prairie Independent Living Resource Center (PILR)	Hutchinson
Resource Center for Independent Living (RCIL)	Osage City
Southeast Kansas Independent Living Center (SKIL)	Parsons
Three Rivers Independent Living Resource Center	Wamego
Topeka Independent Living Resource Center (TILRC)	Topeka
The Whole Person	Kansas City, MO (serves residents of some Kansas counties)

What are CILs? Centers for Independent Living are community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities. CILs are unique in that they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization. That means that a majority of our staff, our management and our Boards or directors are themselves people with disabilities.

A tenet of the independent living movement is “Nothing about us without us.” People with disabilities want to make their own choices about how to live their lives. And they are often in the best position to teach others with disabilities how to succeed. I might have years of education and experience working in the disability field, but I sure wasn’t taught that a great way to get new tires on a wheelchair is to arrange with the local bicycle shop staff to jump in your van, wheel out the chair, replace the tire, and wheel it back—pitcrew style—and save money on the tire at the same time.

CILs use their resources to best meet the needs of people of all ages with all kinds of disabilities in the counties they are assigned to serve. But their state and federal Independent Living grants, which originate in the Department of

Education’s Rehabilitation Services Administration do specify some specific “core services” they must provide.

The Five “Core Services” of Kansas CILs	
Peer Support	Peer mentors with disabilities serve as role models and provide moral support and creative solutions for issues of life via 1:1 counseling and/or support groups.
Information and Referral	Provide information on any subject related to living independently with all disabilities. Refer individuals to other agencies to assist in gaining independence.
Individual and Systems Advocacy	Individual and systems advocacy to promote positive change for and with individuals. Work with individuals on self-advocacy/assertiveness to promote personal empowerment. Systems advocacy activities in partnership with individuals and community members to affect attitudinal and environmental change.
Independent Living Skills Training	Trained staff members provide innovative approaches to performing basic tasks that lead to independence, such as cooking, budgeting, resume writing, application assistance and employment readiness.
Deinstitutionalization (not a “core service” in all states)	Assistance with avoiding admission to or facilitating release from institutional settings like nursing homes or mental hospitals by providing community supports so people with disabilities can live in less restrictive settings.

Deinstitutionalization and Medicaid waiver programs. Just as studies show that the vast majority of people want to “age in place,” or remain living in the community, in their own homes for as long as possible, people with disabilities also prefer to live in the community in *their* own homes. One method by which people with Medicaid eligibility for nursing home residency can stay in their own homes is by accessing Physical Disability and Frail/Elderly Medicaid waiver programs. Such programs allow people with disabilities to self-direct personal care attendants who assist with such tasks as feeding and bathing.

Until KanCare was instituted, Kansas CILs provided eligibility assessments and case management as well as payroll services for attendants in the PD waiver program. Currently, the assessments are provided by the Aging and Disability Resource Center (ADRC), run by the Area Agencies on Aging (so-called “triple

As”), while the case management is provided by the managed care organizations (MCOs). CILs (and other providers) continue to provide payroll and related services called Fiscal Management Services (FMS) under contracts with the MCOs.

What happens at Independence, Inc.? In addition to providing the Core Services of CILs and serving as an FMS provider, Independence, Inc. also has the following programs:

1. **Youth Employment Program.** Our fantastic independent living specialist Ranita Wilks became paralyzed when she was four years old. As if it were yesterday, she recalls asking her mother what would happen to her when her mother got too old to care for her. Her mom said Ranita could accompany her to the nursing home. Ranita made a conscious decision to avoid that path. Instead she got a degree at KU.

For over a decade, she has worked tirelessly to see that youths with disabilities don't fall into a trap of thinking that their goal in life should be getting on SSI and avoiding earning too much money. Instead, through our Youth Employment Program, Ranita arranges for them to complete 80-hour paid work trials. By paying the wages and worker's comp insurance, we relieve the employer of risk and help the youth start on the employment path.

Our outcome data show that at the end of the trials, one-third of the students in the program are offered permanent positions, one-third are told they would be hired if a position opens up, and one-third need to try a different trial.

Now Ranita works with school personnel and parents to help these youth find jobs, arrange any necessary accommodations for their disabilities with their employers, research bus routes, receive their first paychecks, learn to budget the money, and start on the path towards becoming contributing members of society.

CILs helping people with disabilities to become gainfully employed represent great bang for the buck. Studies show that getting people with disabilities on the track to employment rather than to government dependency can save society \$132,000 per person per year indefinitely.

And Dr. Jean Hall and her colleagues at KU have tracked over 800 Kansans with disabilities. In their study, they found participants with any level of paid employment had significantly lower rates of smoking and better quality of life; self-reported health status was significantly higher, while per person per month Medicaid expenditures were less.

Employment, even at low levels, was associated with better health and health behaviors as well as lower costs. Yet participants reported being discouraged from working by medical professionals and federal disability policies.

How I wish my younger brother Craig could have had access to these creative, cost-effective employment opportunities to become independent, rather than spending his working years in a sheltered enclave at a large corporation, always afraid to jeopardize his SSI by earning too much money.

2. **Transportation.** Independence, Inc. also has a transportation program. We provide accessible transportation for Douglas County residents with and without disabilities who need to go to work, shopping and medical appointments. For many people who live in rural areas surrounding Lawrence, our transportation service, for which we receive some KDOT funding, is their only means of getting to their doctors in Lawrence, Kansas City and Topeka.
3. **Loans of medical equipment.** We receive donations of durable medical equipment like wheelchairs and walkers and loan them out to the public for little to no charge.
4. **Braille services.** We provide braille services to government and private companies at reasonable rates.
5. **Accessible Housing Program.** We work with the City of Lawrence to administer a community block grant program that enables people with disabilities and low incomes to make needed accessibility modifications in their rental housing. Examples include an entrance ramp, widening doorways, installing an accessible sink, roll-in shower, and grab bars. In the vast majority of these projects, the modifications remain to benefit future tenants.
6. **Accessibility consultations.** We share our expertise on how to make buildings accessible, and we provide accessibility surveys at a reasonable rate.

Conclusion. The State of Kansas Department of Children and Families' Rehabilitation Services pays Independence, Inc. \$29,000 a year for its state independent living grant. We are fortunate that we also receive a federal independent living grant, a Douglas County grant, some private grants from foundations and a small amount of private donations. Leveraging that money and utilizing a team of dedicated volunteers and committed staff, Independence, Inc. served 845 individuals with disabilities last year who strove to increase their

independence. Kansans are getting a great deal and they should feel proud to their centers for independent living.

Thank you for your time and consideration.