



NCCD

Nebraska Consortium for Citizens with Disabilities

COMMUNITY INCLUSION
FOR PERSONS WITH DISABILITIES

Policy Brief on Community Living

By

Nebraska Consortium for Citizens with Disabilities

Introduction

For decades in the not-too-distant past, persons with physical, behavioral, and cognitive disabilities were typically excluded from life in the community through placement in institutions such as large hospital facilities, insane asylums, orphanages, and nursing homes, usually at great financial cost to state government and at great cost to the humanity of those who experienced the disabilities¹. Many such individuals became wards of the state because parents and/or other relatives could not afford to pay the cost of their care.

However, in more recent times, we've learned that including persons with disabilities in the community outside of institutions through Home and Community-Based Services (HCBS) not only preserves the humanity of persons with disabilities, but such inclusion carries with it a number of advantages, not the least of which is the possibility of employment. With the passage of the Ticket to Work and Work Incentives Improvement Act (TWWIA) in 1999, people with disabilities began to learn how they could earn an income without fear of losing their federal health-care benefits (e.g. Medicaid) by using incentives delineated in the Social Security program².

Here's the sequence of the logic: institutional care is typically and greatly more expensive than HCBS³ --> people with disabilities in institutions can't get a job if they remain in the institution --> people with disabilities remaining in institutions, therefore, will not be employed --> state government will continue to pay higher costs for that care without any hope of a return on their investment.

The alternative logical sequence follows: if government pays for HCBS --> government and taxpayers will experience a reduction in expenditures for institutional care --> more people with disabilities, now living in the community, have the opportunity to learn how to work and obtain employment --> successful employment of people with disabilities breeds more people with disabilities being successfully employed --> successfully employed people with disabilities are now able to pay taxes and have greater purchasing power --> more people are now paying taxes and commercial businesses are now paying more taxes because of having higher sales volumes --> state government now has a return on its investment!

From anecdotal experiences people have observed that because of contact by including people with disabilities they feel they are more responsible, have more sense of direction and more focus on what is important.⁴

What Community Living Looks Like

People with disabilities should be welcomed and included in all aspects of our society. This includes public activities, programs and settings, and private establishments which are open and accessible to members of the general public.

¹ http://archive.adl.org/education/curriculum_connections/fall_2005/fall_2005_lesson5_history.html

² <http://www.socialsecurity.gov/work/>

³ http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf

⁴ http://www.uni.edu/inclusion/benefits_of_inclusion.htm

People with disabilities should receive the supports they need to participate actively in community life without having to wait. Services should be freely available to all to alleviate stress: to enable them to meet their needs. Stress factors can include poverty, poor housing, isolation, illness and any sort of discrimination or harassment.

The disabled and their families are entitled to timely and accessible information. Support should be provided in the way that the person prefers, should promote the development of independence/interdependence, should not frustrate the development of relationships between peers and should not substitute for the relationships with those living in their community.⁵

Overall, People should have the opportunity to:

- Live in and participate in their communities;
- Have satisfying lives and valued social roles;
- Have sufficient access to needed support;
- Have control over that support so that the assistance they receive contributes to lifestyles they desire; and
- Be safe and healthy in the environments in which they live

Children should have the opportunity to:

- Live in a family home;
- Have access to the supports that they need;
- Grow up enjoying nurturing adult relationships both inside and outside a family home;
- Enjoy typical childhood relationships and friendships; Learn in their neighborhood school in a general education classroom that contains children of the same age without disabilities;
- Participate in the same activities as children without disabilities;
- Play and participate with all children in community recreation; and
- Participate fully in the religious observances, practices, events, and ceremonies of the family's choice.⁶

Adults should have the opportunity to:

- Have relationships of their own choosing with individuals in the community, in addition to paid staff and/or immediate family;
- Live in a home where and with whom they choose;
- Have access to the supports that they need;
- Engage in meaningful work in an inclusive setting;
- Enjoy the same recreation and other leisure activities that are available to the general public; and
- Participate fully in the religious observances, practices, events, and ceremonies of the individual's choice.⁷

⁵ <http://sixbyfifteen.org/category/community-living/>

⁶ <http://www.thearc.org/page.aspx?pid=2353>

⁷ <http://www.thearc.org/page.aspx?pid=2353>

According to the National Council on Disability:

“For example, the per capita HCBS Waiver figure includes people living with their families as well as people receiving both residential and day services from paid providers. Since providing care to people living with their families is usually less costly than providing residential services in the community, such as congregate living or shared housing, a state with a higher proportion of people living with their families will have lower average HCBS Waiver costs. However, this type of variation in HCBS Waiver costs underestimates the cost of providing community care to former institution residents, who will usually transition to residential services.”

In Nebraska as of 2013 the per capita cost of institutional care per year is \$397,352.00 as compared to \$26,653.00 to \$77,104.00 for HCBS, depending on type of service.⁸

Next Steps

In July of 2013, the HELP Committee released a report that stated: State and federal efforts should focus on helping people live in their own homes. Virtually all people with disabilities can live in their own apartment or house with adequate supports.

Accordingly, for virtually all people with disabilities, the most integrated setting appropriate is their own home.⁹ American citizens are now living longer than ever before, so, as the aging process produces more disabling conditions and with the "Baby Boomer" generation's desire to continue to live in their own homes and communities, there will be an increase in the need for accessible, affordable housing. More housing means more people with disabilities can find places to live outside of institutions. More housing means more investment in construction and a boost to the nation's prosperity.

However in Nebraska we don't seem to embrace these concepts. According to the Medicaid Annual Report for 2013 Nebraska continues to spend the largest portion of the Long Term Care Budget on facilities rather than Home & Community Based Service (HCBS). The Federal Government has encouraged states to rebalance their long term care budgets to focus more on HCBS.¹⁰

This has resulted in missed opportunities in Nebraska. One such opportunity was the Community First Choice Option made available under The Affordable Care Act (ACA). This is a state plan option that states can apply for that can provide increased matching funds for attendant services and supports to Medicaid beneficiaries to those that would be institutionalized without a waiver or waiting list.

Community inclusion is not only a good idea, it is a necessity.

⁸ <http://www.stateofthestates.org>

⁹ <http://www.harkin.senate.gov/documents/pdf/OlmsteadReport.pdf>

¹⁰ <http://dhhs.ne.gov/medicaid/Documents/2013-Medicaid-Annual-Report.pdf>