

Independent Living in New York State: A Needs Assessment

SUMMARY

February, 2009

Prepared for:
New York Association on Independent Living (NYAIL)

Prepared by:
Donald Pryor, Ph.D.
Project Director

1 South Washington Street
Suite 400
Rochester, NY 14614
585.325.6360

100 State Street
Suite 330
Albany, NY 12207
518.432.9428

www.cgr.org

SUMMARY

The New York Association on Independent Living (NYAIL) is a membership organization representing Independent Living Centers (ILCs) and satellites located in 45 counties throughout New York. The Association advocates on behalf of people with disabilities, promotes the philosophy and vision of independent living, provides information and technical assistance to members, and advocates for the resources necessary to support ILCs and related services. In this context, NYAIL contracted with the Center for Governmental Research Inc. (CGR) to conduct a needs assessment to determine how ILCs can more effectively meet the needs of people with disabilities throughout the state, to determine service gaps and barriers that interfere with the provision of services, and to determine the resources Centers will need in the future to best meet the needs of their constituents and how those resources should be best allocated.

It should be noted that this needs assessment was undertaken prior to the full onset of the current economic crisis affecting NYS and the nation. As such, it did not explicitly address issues or ask specific questions concerning how ILCs should respond to the current budget crisis facing the state, its jurisdictions and nonprofit agencies of all types throughout the state. On the other hand, the issues raised in the needs assessment have direct relevance to the crucial questions of what services are most critical to provide in a crisis environment, and how scarce resources should be most effectively and efficiently allocated to obtain the best possible return on the public's investment.

Key Findings

Independent Living Centers are mission-driven non-profit agencies that have demonstrated their ability to help position people with disabilities to become more economically self-sufficient and independent in their daily lives. They have been effective advocates in the lives of individual persons with disabilities and their family members, and have also advocated effectively for systemic changes in statewide policies, legislation and regulations.

And they have been cost effective. Data collected and analyzed by VESID (NYS Vocational and Educational Services for Individuals with Disabilities) over the years have indicated that ILCs have conservatively saved New York taxpayers more than \$9 in deinstitutionalization costs for every state dollar invested in ILCs and satellites throughout the state. ILC services contribute to a net savings of upwards of \$110 million each year as a result of avoided institutionalized care for people with disabilities, and the actual savings may prove to be higher when all ILCs begin to consistently report such information beginning within the next year. A

recent national study has confirmed similar cost savings attributable to ILCs outside of NYS.

The numbers of people served by the Centers in 2006-07 were at least 19% higher than at the beginning of this decade. More than 71,000 persons were served by 36 state-funded Centers and satellites in that year, not counting thousands of additional people with disabilities served by 14 additional Centers and satellites that do not receive state funds.

Consumers of ILC services express overwhelming support for the services they receive, with systems and personal advocacy, special education and service coordination representing needs that are especially well addressed by the Centers. More than 9 of every 10 consumers would recommend the Center that serves them to other persons with disabilities, with another 7% saying they would make such a recommendation “depending on the need.”

Information supplied by NYAIL and ILCs indicates that the Centers have historically been influential in helping shape and pass pivotal legislation strengthening the self-sufficiency of persons with disabilities and helping save the state money by reducing nursing home and other institutional costs associated with people with particular types of disabilities.

Despite the demonstrated successes and accomplishments over the years of ILCs and their statewide association, there are currently significant gaps in services and underserved geographic areas which need to be addressed. For example:

- 17 counties have neither an ILC nor satellite located within county borders. The gaps are particularly acute in the Southern Tier and Finger Lakes regions, where there are no Centers or satellites in half or more of the counties.
- Given the sheer volume of numbers of residents with disabilities living in the New York City and Long Island regions, even though each county has an ILC or satellite, very small proportions of people with disabilities are able to be served by those facilities.
- There are significant inequities in the operating costs and resources available to Centers and satellites across regions. Two very different types of regions—New York City and the North Country—both have low levels of dollars spent per facility and low levels of expenditures per person receiving ongoing services within their facilities.
- People with disabilities in rural areas and in various immigrant communities, as well as racial/ethnic minorities in some communities, are particularly vulnerable in terms of access to services available through ILCs.

- More targeted emphasis is needed on such services as expanded transportation, strengthened financial support, expanded vocational/employment opportunities, and increased emphasis on integrated housing opportunities for people with disabilities. The degree of need for such services varies across regions and ILCs, so careful assessment and priority-setting processes need to be followed to ensure that resources are allocated where the needs are greatest.

Key Recommendations

Although it is not an ideal time to release a needs assessment report aimed at looking to and preparing for the future, such times of crisis also create opportunities to look at issues from a fresh perspective and to consider new approaches and opportunities for collaborative initiatives that might not have been considered in better times. With the successful track record of Independent Living Centers and their demonstrated ability to successfully impact on the lives of people with disabilities and to save taxpayers significant dollars, NYAIL and ILCs are in a stronger position than many agencies that they can build on in negotiations with state and local officials. The full report contains a number of recommendations designed to provide guidance as ILCs look to their future in an uncertain time. The recommendations include:

- Developing and expanding an advocacy agenda focusing on issues impacting people with disabilities, and the key role that ILCs play in enhancing individual independence and economic self-sufficiency, while at the same time saving taxpayers money.
- Maintaining a united voice as advocates for people with disabilities and their families, and specifically advocating for the creation of a unified NYS Office on Disability to help ensure focused statewide attention on issues affecting people with disabilities.
- Expanding advocacy to ensure inclusion of ILCs as full participants in the development and/or restructuring of systems of services and supports to meet the needs of people with disabilities in the most integrated settings possible.
- Developing new and expanding existing funding streams, even in—especially in—difficult economic times. Specifically, the needs assessment should be used to educate other non-state entities—e.g., county governments, United Ways, foundations, the business community—about the strengths and needs of ILCs.
- Identifying opportunities to leverage existing infrastructure such as staff, board members, and networks of contacts. In particular, such

collaborative opportunities should include overtures to working more closely with such potential partners as county governments, the business community, school districts, health care providers, and various other potential funders and potential service-provision partners.

- Defining new approaches to consistent data collection and management that can drive improved decision-making and agenda-setting; devising regional approaches to critical issue areas such as housing and transportation; and garnering public awareness for what is already available to the community.
- Developing a variety of communications, training and technical assistance approaches to strengthening human capital (staff, board members) within the Centers, building on and expanding existing NYAIL technical assistance and training initiatives.
- Emphasizing the need for such services as expanded transportation, strengthened financial support, expanded vocational/employment opportunities, and increased emphasis on integrated housing opportunities for people with disabilities. The degree of need for such services varies across regions and ILCs, so careful assessment and priority-setting processes need to be followed to ensure that resources are allocated where the needs are greatest.
- Focusing attention on how best to address, in this economic climate, the fact that 17 counties have no ILCs or satellite offices to provide locally-based services to residents with disabilities.
- Addressing what appear to be resource gaps and inequities in the operating costs and resources available to Centers and satellites across regions.
- Developing approaches to improve service access to vulnerable and underserved subsets of the population of persons with disabilities, such as those in rural areas and in various immigrant communities, as well as racial/ethnic minorities in some communities, and as the population ages, seniors with disabilities. Expanded transportation and other service access initiatives, bilingual staff and cultural diversity training may be helpful responses in some cases to help improve service access to such groups.
- Creating an awareness among ILCs, where additional financial resources are not forthcoming to provide needed services, and where even existing resources are threatened, of opportunities to

allocate existing resources in the most equitable and fair ways possible, collaborating with other service providers and seeking ways to use existing resources most efficiently and fairly, given concentration of needs and available resources.

For further information about this study, contact:

Melanie Shaw
Executive Director
New York Association on Independent Living (NYAIL)
One Commerce Plaza
99 Washington Ave., Suite 806A
Albany, NY 12210
518-465-4650
info@ilny.org