

**Independent Living in
New York State:
A Needs Assessment**

December, 2008

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

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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.

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The New York Association on Independent Living (NYAIL) understood the need for and value of this needs assessment, and backed it with their financial resources, commitment, leadership and member support.

The commitment, leadership and support were particularly personified by the unfailing cooperation, enthusiasm, energy and insights displayed in numerous ways throughout the project by NYAIL Executive Director Melanie Shaw. She was an effective liaison between CGR and the NYAIL membership, as well as being resourceful in her efforts to help track down needed data on our behalf from various sources and to keep us informed of developments throughout the process. Melanie's tireless efforts during all phases of the study, without ever attempting to taint or bias the findings, were instrumental in helping to shape the final product, and CGR is immensely grateful for her efforts and our partnership throughout the effort.

We are also grateful for the leadership and insights provided by the project's Steering Committee, co-chaired by Maria Dibble and Chris Zachmeyer. In addition to Melanie, Maria and Chris, the Steering Committee also included: Burt Danovitz, Bruce Darling, Susan Dooha, Denise Figueroa, Douglas Hovey, Thomas McKeown, Andrew Pulrang, Lenore Schwager and Melvyn Tanzman. The members expressed strong, and not always consistent, views, but they were united in their focus on the need for a strong, objective needs assessment that could help provide guidance for ILCs in the future.

The Steering Committee helped shape the initial study design and the nature, content and implementation of the three surveys; provided helpful responses to our mid-study presentation of interim findings at the NYAIL conference in September; and provided valuable comments in response to the initial draft of this report. The study's findings, conclusions and recommendations represent the independent, objective perspective of CGR, but we appreciate the helpful insights of Steering Committee members, who helped ensure that we did not inadvertently overlook practical implications of our data.

CGR is also grateful to the ILC Executive Directors and the hundreds of persons with disabilities and community stakeholders who completed surveys and provided valuable perspective as part of the study process. The report would not have been possible without their cooperation.

The NYS Vocational and Educational Services for Individuals with Disabilities (VESID), an agency of the State Education Department, also played an instrumental role in CGR's efforts. Data made available by VESID officials, some in response to a special request by CGR and

NYAIL, were instrumental to some of the important analyses that shaped key findings during the study.

Staff Team

Although the Project Director typically receives much of the credit (or blame) for such a report, many other dedicated staff played key roles in completing this project. Bethany Welch managed the day-to-day aspects of the project and was instrumental in designing the study's surveys, analyzing most of the data, presenting interim findings and drafting most of the final report. Maria Ayoob played a key role in overall methodological design decisions and in facilitating, analyzing and summarizing data from mid-project focus group discussions of interim findings. Meredith Mabe and intern Scott Sobolewski provided important support in analyzing data, and Meredith was also helpful in finalizing the format and structure of the final report. Interns Lara Ericson, Laura Nasr and Matthew Rubenstein also made helpful contributions to the project.

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CHAPTER I: INTRODUCTION

Background

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 State. 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. Independent Living Centers are private, nonprofit corporations which provide a variety of services designed to maximize the independence of people with disabilities. Core services include individual and systems advocacy, information and referral, peer counseling, and independent living skills training. Other services vary from Center to Center but typically include education, assistance with housing, employment, medical needs and personal assistant services. By law, at least 51% of the Board of Directors of each Center must be people with disabilities, and federally-funded Centers have the additional requirement of at least 51% of the staff being people with disabilities.

In this context, NYAIL engaged the Center for Governmental Research Inc. (CGR) to conduct a needs assessment in the realm of independent living. A needs assessment is a systematic way to determine the current reality, the desired reality, and the gap between the two. The findings from this process can be used to inform subsequent planning, policy, service provision, resource allocation, advocacy and action. This needs assessment was designed 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.

NYAIL advocates for increased funding for ILCs, noting that increases in the numbers of people served by the Centers over time have outpaced increases in available dollars to support ILC operations. NYAIL posits that funding for the Centers is cost effective but has been somewhat arbitrary in the past and has not necessarily been allocated on a consistently rational basis. This needs assessment was designed in part to determine if these assumptions are correct; what services currently exist; gaps in needed services in Centers and counties throughout the state; if

additional funding would be needed to adequately meet service needs in the future on a rational and equitable basis, and if so, to begin to identify strategies needed to build the future capacity of ILCs.

A previous needs assessment was conducted in 2006 by the NYS Independent Living Council (NYSILC), a separate quasi-governmental nonprofit entity established to receive federal funds for New York and to implement the State Plan for Independent Living (SPIL) required to guide federal Independent Living funding for people with disabilities within each state. That assessment offered a number of overall findings and some broad helpful implications and recommendations, but it did not include detailed perspectives from representatives of the Centers, and did not attempt to place the data in the context of the overall needs of people with disabilities or to determine gaps in services within various counties and regions across the state. Nor did the scope of the previous study enable a comprehensive assessment of the adequacy of services available to people with disabilities in counties that currently have no ILCs—and what if anything should be done to expand future services to people in such counties.

Purpose of the Study

This project was designed to build on the issues raised in the previous NYSILC needs assessment, but to also use the resources allocated to this assessment by NYAIL to expand on that initial effort by addressing the types of issues noted in the previous paragraph, and by focusing in more detail on the specific more comprehensive research and policy questions raised by NYAIL.

In short, this needs assessment examined services, resources, needs, and priorities. This report provides an analysis of what was found as well as conclusions and recommendations. A Steering Committee established by NYAIL played a significant role in clarifying study objectives and providing technical assistance in developing and adapting the survey instruments to best meet the needs of the intended respondents of each survey. The Committee helped to design survey questions, suggested survey administration options and, for the consumer survey, was involved in the implementation of a survey distribution plan that was best matched to the population being surveyed.

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 and discussed throughout this report—and specifically within the report's

conclusions and recommendations—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.

Working from a set of core issues identified in discussions with the NYAIL Steering Committee a year ago, when this project began, CGR attempted to address the following research and policy questions/issues:

- An assessment of the nature of needs of people with disabilities across various areas of the state;
- An assessment of consumer needs vs. service provision, to determine both those needs that appear to be currently relatively well met and those relatively unmet where there appear to be service gaps;
- An assessment of the levels and adequacy of funding across the state;
- Equity of current distribution of resources across the state;
- Amounts of funding from various sources;
- What resources are necessary to meet demonstrated needs and levels of current and needed services;
- Current and potential future processes for advocating for allocation of funds;
- The geographic distribution of ILCs and of consumers served, including accessibility of services to various areas across the state;
- Extent of services currently provided to people with disabilities in counties with ILCs, without full-fledged ILCs but with satellite offices, and with neither ILCs nor satellites;
- How well the needs of people with disabilities are met in counties without ILCs and/or satellite offices.

It should be emphasized that, even though reference is made at various points in the report to individual ILCs and satellites and to individual county data, this needs assessment is in no way intended as an evaluation of the services provided by individual Centers or satellites. Too many different variables affect the level and quality of services provided in each Center (e.g., level of funding and staffing available to each, differential characteristics of the people with disabilities served by each, location and

accessibility of the Centers, specific services provided, etc.) that could not be controlled for in such an assessment, making evaluation of individual Centers impossible and inappropriate. Rather, the focus of the needs assessment from the beginning, as agreed to in discussions with the NYAIL Board and Steering Committee, was on the overall system and delivery of services across the state. Considerable focus is placed on issues by region and statewide, and on potential actions needed at those levels, but no assessments or evaluations of individual Centers or satellites were undertaken or should in any way be inferred from any of the data or comments presented throughout the report.

Methodology

Components of this needs assessment were developed by CGR with insight and guidance provided by the NYAIL Board and Steering Committee. The primary data sources for the needs assessment were three surveys targeted to three different populations: Independent Living Centers, consumers of independent living services, and public agency stakeholders. Data from the surveys were analyzed and supplemented with data gathered from VESID, the NYS Vocational and Educational Services for Individuals with Disabilities (an agency under the NYS Education Department), and 990s and annual reports from the ILCs. CGR also included in its review data from the NYSILC needs assessment. Additional content for this report was collected on September 8, 2008 in a series of two sessions held during the New York Association on Independent Living's Annual Conference. Copies of the surveys and a more detailed description of the methodology are included in the appendix.

CHAPTER II: KEY FINDINGS

Introduction

According to the U.S. Census Bureau, there are more than 3.5 million New Yorkers age five and older who are disabled. This figure represents 19% of the state's population, a higher proportion than the national disability rate of 16% of the population.¹ Slightly more residents (22%) are included in this figure when the definition for disability is expanded to include any limitation to activities due to a "chronic health problem or condition." Persons with disabilities live in all counties in the state and women are slightly more likely to experience limitations to their day-to-

¹ United States Census Bureau, New York State, 2000.

day activities because of a health issue.² A report released in 2005 demonstrated that the number of persons reporting disabilities in New York is rising across several age groups, including among younger adults, 18-44 years old.³ The greatest increase is among those 75 and older. Not only is the population with disabilities older than the average New Yorker, the average person tends to have less education and earn less than non-disabled state residents.⁴

The age of institutionalized care as the primary service mode for persons with disabilities has ended. Today, independent living strategies have gained increasing popularity with disability advocates who have reframed the discussion as one of civil rights and self-determination. The philosophy of independent living promotes the concept of integration, in which persons with disabilities live, work, worship, play and learn in mainstream environments, often with the support of family and friends, colleagues and supervisors, and through the implementation of assistive devices and technology.

Advocates have used legal, regulatory, and political strategies to advance this movement, resulting in changes to policy and practice. Common themes in independent living include: freedom to choose; ability to live in mainstream communities and to attend schools and work in mainstream settings, as they are able; emphasizing empowerment and expansion of human potential over care; and seeing persons with disabilities as consumers with choices rather than as recipients of social services.

The New York Association on Independent Living promotes this philosophy by advocating for the expansion and strengthening of Independent Living Centers across the state, seeking policy reform, educating the public on disability issues, and offering assistance in implementing the Americans with Disabilities Act and Section 296.2 of the state Human Rights Law, which governs accessibility. Each year NYAIL drafts a legislative agenda with priorities driven by the member organizations. The Association's membership is comprised of individual Independent Living Centers that pay dues.

This chapter highlights a summary of many of the key findings from the needs assessment. Several of the issues addressed in this overview chapter are discussed in more detail in subsequent chapters.

² New York State Department of Health (2003) *Disability in New York State*, Albany, NY.

³ Steele, L. (2005) *Disability among adults in New York State, 2001-2003: Prevalence and risk factors*, New York State Department of Health, Albany, NY., p.2-3.

⁴ *Ibid.*, p.4

The Unique Role of Independent Living Centers

It is important that the unique nature of ILCs be communicated at both the state and local level, in order for ILCs to be recognized for the critical role they play in the system of providers who serve people with disabilities. ILCs have a unique history and philosophy that determines their mission, structure, and menu of services. NYAIL Board members who participated in a focus group felt that bringing this to light will increase the perception of ILCs as adding value to the system of providers and as providing services and a philosophical approach that consumers will not find elsewhere.

A recent national study of Independent Living Centers offered a similar perspective:

Centers for Independent Living continue to demonstrate value in assisting individuals with disabilities of all ages to gain needed skills and obtain needed supports to live independently in integrated community settings. Centers have proven to be effective partners in helping government comply with the Americans with Disabilities Act and save money by supporting individuals with disabilities to live in less-costly community settings. The services provided have evolved from the vital “core” training and support services into more direct services, often funded by Medicaid, such as support coordination, personal assistance, nursing facility transition and home modification....If there is a need in their community for a service for individuals with disabilities, Centers usually find a way to deliver that service, either by doing it themselves or finding reputable service providers.⁵

Empowering Consumers, Offering Choice

Although struggling to engage the resources needed to provide services and to retain staff due to funding constraints, Independent Living Centers offer New York State consumers a range of quality services in rural, suburban and urban communities, across an array of disability types. These Centers not only provide services to persons with disabilities, but also educate and support family members, colleagues, employers, teachers, and the local public on the rights, issues, and needs of people

⁵ Rutgers Center for State Health Policy (June 2008) Independent Living Centers: Experienced Local Partners for Medicaid Home and Community-Based Services, pp. 6,12.

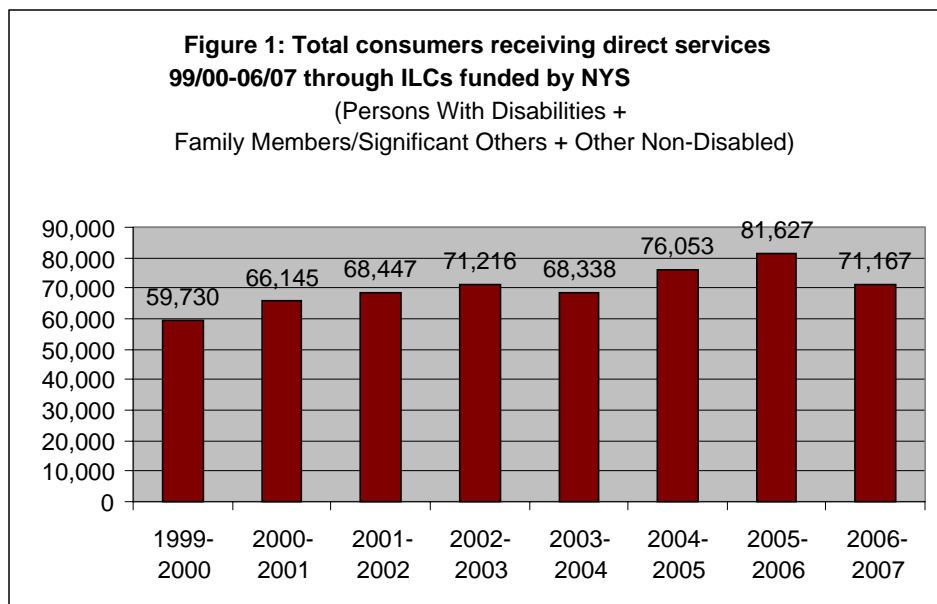
with cognitive, mental, sensory, physical, and co-occurring disabilities. ILCs focus on providing cost-effective services designed to enhance economic self-sufficiency for persons with disabilities.

At the time of this publication, 53 Independent Living Centers (51 if Oswego's three satellites are considered as one) were operating across New York State. Two-thirds of these sites have been in operation for 16 or more years. Last year, well over 71,000 consumers (not counting additional thousands served in ILCs not receiving direct funding from New York State government) chose ILCs for services in the areas of housing, employment, advocacy, benefits assistance, transportation, medical/health, socialization/recreation, education, and much more.⁶ The average ILC provides these services to some 2,000 consumers per year with about 35 full- and part-time staff and an annual budget of \$2.4 million. For most Centers, their largest source of operating revenue is from the Medicaid Consumer Directed Personal Assistant Program. For some sites, Medicaid waivers account for significant amounts of revenues each year. Collectively, more New York State ILCs receive state Independent Living funding than from any other source, although state funding comprises a relatively small proportion of their total revenue. Only 38% of the ILCs report receiving funding from their local municipality. For those that did, the average revenue from this source was less than 1% of their total budget.

Growth in Numbers Served During This Decade

As shown in Figure 1, the number of consumers served by the 36 state-funded Independent Living Centers and satellites (including both persons with disabilities, family members and others assisted without disabilities) grew from 1999 to 2003. The total declined in 2003-2004 and then climbed again through 2005-06. In 2006-07, there was a reported reduction in total served, due in part to several ILCs adjusting data collection and management procedures. (It should be noted that there were 36 Centers and satellites existing in 2006-07; an additional three state-funded facilities were added in 2007-08, bringing the total to 39.)

⁶ Data reported by VESID for 2006-2007, includes Persons with Disabilities + Family Members/Significant Others + Non-Disabled Persons.



Even with the adjustments in methods of recording numbers served in 2006-07, it is significant that even the reduced reported totals in 2006-07 were 19% higher than the numbers served at the beginning of the decade. The actual rate of growth is likely to be even greater, factoring in adjustments in data tracking approaches. And those numbers only include the Centers and satellites funded directly by the state and administered by VESID. The 14 additional non-state-funded sites also serve thousands of additional people with disabilities over and above the 71,000-plus persons shown in the figure.

Independent Living Centers Achieving High Levels of Satisfaction and Cost Savings

ILCs are instrumental in saving the state more than \$110 million a year in costs of institutionalization, according to data provided by VESID. This is consistent with findings at the national level: “Centers for Independent Living provide services that are good investments for the health and well-being of individuals and deliver current and future cost savings for government.”⁷

Persons with disabilities who responded to the consumer survey conducted for this needs assessment reported high levels of satisfaction with the services they receive to help them live more independently. Consumers find the services of such a level of quality and quantity to recommend their local Independent Living Centers to others with disabilities.

⁷ Rutgers Center for State Health Policy, op. cit., p. 7.

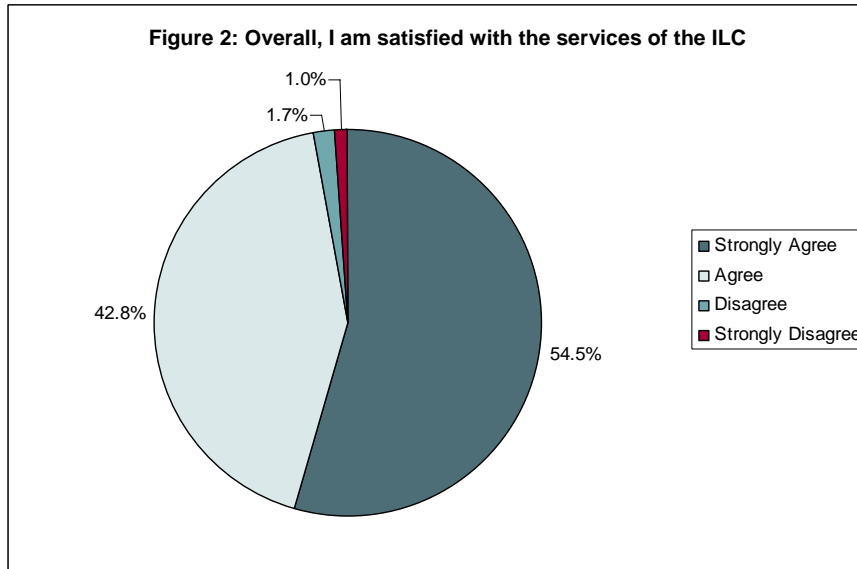
According to ILCs, they frequently receive referrals of consumers from other persons with disabilities. ILCs have also earned the respect of other agencies reaching persons with disabilities. Consumers are more frequently referred to ILCs through other service agencies than through any other source of referrals.

ILCs were considered effective by most of the stakeholders surveyed. More than 70% of the stakeholders agreed that the ILCs were at least adequately meeting the needs of people with disabilities who live in their service area, while 30% felt that the ILCs were not adequately meeting the needs.

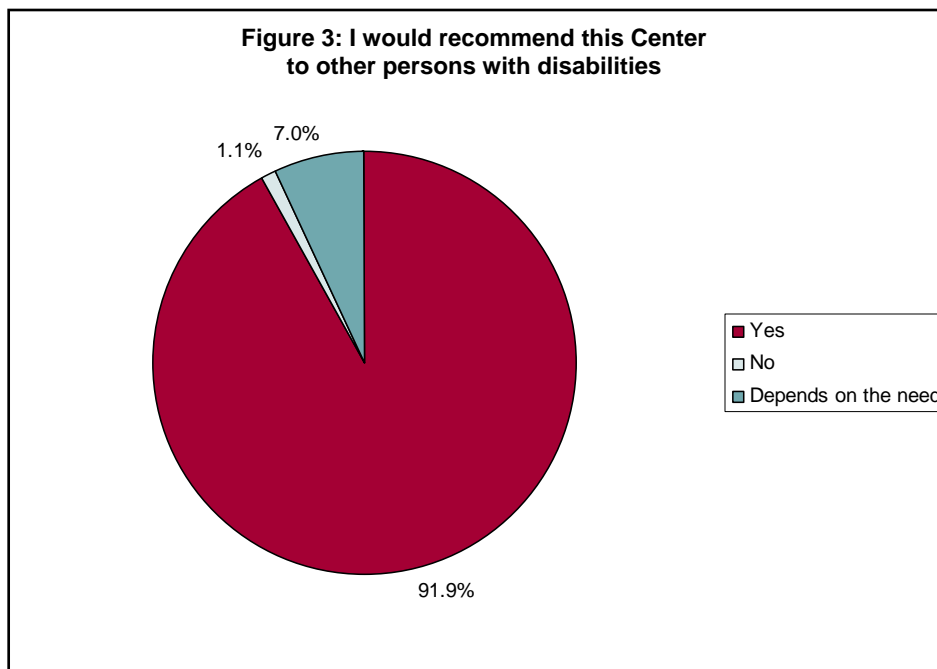
Consumers Highly Satisfied with Independent Living Centers

More specifically, those in the best position to judge the value of the ILCs were even more positive about its impact on them. Consumers had two ways to report their level of satisfaction and regard for the value of the services provided by the Independent Living Center in their area. First, they were asked to report the degree to which they agreed with the statement, “I am satisfied with the services of the Independent Living Center.” Second, they were asked if they would refer another person with a disability to the ILC.

As shown in Figure 2, an overwhelming majority (97%) reported being satisfied with the Independent Living Center with which they were familiar.



When asked about recommending the Center to others, more than 9 in 10 (92%) would recommend the Center where they were surveyed to other persons with disabilities, as shown in Figure 3. A few (7%) qualified their response by selecting the choice, “Depends on the need.”



Consumer Satisfaction as Compared to Other Studies

Both the NYAIL consumer survey and the New York State Independent Living Council (NYSILC) asked similar questions to assess consumer satisfaction with Independent Living Centers. The first measure of satisfaction reported on the NYAIL Consumer survey resulted in slightly higher levels than the satisfaction level reported by the NYSILC Needs Assessment report in 2006 for the first measure. 51% of those consumers strongly agreed that they were satisfied with the center, 40% agreed; 57% of those surveyed by NYILC strongly agreed that they would recommend the center to others, 36% agreed.⁸ In short, there is a high level of consistency over time, indicating strong levels of support among consumers for ILC services and their value.

Significant Economic Impact of Centers

According to VESID, ILCs have reduced the rate of institutionalization with each passing year. The Centers have also reduced the costs associated with services for persons with disabilities by providing local access to alternative options. According to VESID data summarized in Table 1, *each year ILC services result in a net savings of upwards of \$110 million as a result of avoided institutionalized care for people with disabilities.* These totals are based strictly on savings associated with Centers funded by NYS and overseen by VESID, and include only savings reported by an average of 17 “voluntary reporter” Centers each year. It is likely that there are other VESID-administered ILCs that also contributed to additional savings that are not included in these totals because they were not reported to the state.⁹ Thus it is likely that the figures reflected in Table 1 understate the total value of savings resulting from ILC-influenced deinstitutionalization, since they do not include any non-reporting VESID centers, nor do they include those Centers and satellites not affiliated with VESID.

Using very conservative estimates—assuming no savings beyond the \$593.7 million multi-year deinstitutionalization savings reflected in the table below, and attributing full state funds for those years of \$63.6 million spent across all state-funded ILCs, rather than only the “voluntary reporter” share of state funds shown in the table—*CGR conservatively estimates that for every dollar spent by the state to help fund ILCs and*

⁸ New York State Independent Living Council (2006) *Needs Assessment*: Table, Independent Living Center Satisfaction across New York State 2006.

⁹ In the future, all state-funded ILCs overseen by VESID will be required to report on any deinstitutionalization cost-savings, so there should be fewer questions about the total amounts saved in the future.

their satellites across the state, \$9.33 is saved in deinstitutionalization costs. (If a less conservative approach is applied to the calculation and only the state funds for the voluntary reporter ILCs are included, the state saves almost \$25 for every dollar spent on just those ILCs.) Whether conservative or more generous assumptions are made in calculating the savings, either way it is clear that, based on VESID data, the state receives a significant financial return on its investment in Independent Living Centers.

Table 1: NYS ILC Deinstitutionalization Cost-Savings by State Fiscal Year 2001-2007*

ITEM	2001-2003 **	2003-2004	2004-2005	2005-2006	2006-2007	TOTAL
Institutional Preventions	1,216	1,331	1,605	1,361	1,462	6,975
Institutional Terminations	281	288	222	204	231	1,226
Deinstitutionalization Savings	\$119,222,981	\$115,525,533	\$131,116,411	\$110,148,680	\$117,719,426	\$593,733,031
NYS Funds Distributed for Voluntary Reporters	\$8,714,698	\$4,099,991	\$3,452,100	\$3,615,789	\$3,967,122	\$23,849,700
Value Added ***	\$110,508,283	\$111,425,542	\$127,664,311	\$106,532,891	\$113,752,304	\$569,883,331

* Not all voluntary reporting ILCs contributed data for each reporting period.
 ** Project started SFY 02-03 and included cumulative data for SFY 01-02.
 *** Net savings as portion of budgeted NYS funding, after subtracting NYS funds from total dollars saved.

Furthermore, as noted earlier, these statewide findings are consistent with findings at the national level: “These [Center for Independent Living] services are essential for both individual goals and government requirements. CIL services are good investments for the health and well being of individuals and for current and future cost savings for government. Government decision makers should look for additional ways to utilize existing services and seek new ways to support a partnership with these valuable community-based organizations.”¹⁰

ILCs Help Shape Service-Enhancing, Cost-Savings Initiatives

ILCs use a peer model and serve as mentors for tens of thousands of New Yorkers with disabilities, enhancing and fostering independence, and assisting people to live, work, socialize and participate in their communities in the most integrated settings possible. Centers also play a key role in shaping and developing laws, policies and regulations that

¹⁰ Rutgers Center for State Health Policy, op. cit., p. 21.

affect the lives of people with disabilities. According to NYAIL leadership, ILCs have historically been influential either directly or indirectly in the establishment and/or passage of pivotal legislation including:

- The Medicaid Buy-In, which increases employment opportunities by allowing individuals to retain Medicaid while working, and in turn promoting economic self-sufficiency for people with disabilities.
- Adoption of Most Integrated Setting Coordinating Council legislation, responsible for developing an over-arching plan to realize community integration for tens of thousands of individuals with disabilities in NY.
- Passage of legislation to establish the Traumatic Brain Injury Waiver and Resource Development Center model, which has returned thousands of New Yorkers with TBI from extremely expensive out-of-state nursing homes to their communities. This resounding success has in turn led to:
 - The Nursing Home Transition and Diversion Waiver to divert thousands of New Yorkers from nursing homes into their communities. It is acknowledged by both state and federal governmental entities that deinstitutionalization is key to reducing Medicaid costs, but that it requires a reversal of the institutional bias that exists in the long-term care and other systems. ILCs are uniquely qualified to assist policy-makers in this vital restructuring of both systems and attitudes.
 - Passage of significant legislation requiring Consumer Directed Personal Assistance services to be offered in all counties of the state, and later successfully advocating for restoration of cuts to Level I Personal Care services. CDPA has been shown to save the state significant dollars while empowering consumers to hire their own attendants and direct their own care.
 - Adoption of Title III and Reasonable Accommodations provisions of the Americans with Disabilities Act into state law.

There are many more examples of the contributions that ILCs have made to both people with disabilities as well as the systems and laws that serve them. Centers have given people with disabilities more opportunities, increased their independence and self-reliance, and enhanced the quality of their lives, while saving taxpayers millions of Medicaid and other dollars. The distinct ILC perspective on expanding consumer direction and control to encompass other services and programs besides CDPA has the

potential to restructure the service system and meet the needs of even more New Yorkers, while realizing additional savings as the state and local communities struggle with the downward trend in the economy.

Lack of Equity in Service Provision

There are significant differences in the availability of ILCs/satellites by region across the state. In addition, there are wide variations in the proportions of people with disabilities who are served by ILCs across regions, as well as variations in ILC budgets per site and per person served. These issues are addressed in more detail in Chapter III, but are summarized here.

Some Regions with Significant Gaps in ILCs

Not every county in New York State is served equally by Independent Living Centers. While it is true that at least some persons with disabilities in every New York county receive services from some ILC or satellite, *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.* In the Southern Tier region, with 10 counties, only five of the counties have an ILC or satellite. In the Finger Lakes region, only three of the nine counties have an ILC or satellite. In contrast, all seven counties in the Hudson Valley region have ILCs or satellites, including more than one facility in two of the counties.

Variations by Region in Proportions of People with Disabilities Served by ILCs

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. In addition, in four of the nine counties in the underserved Finger Lakes region, only small handfuls of persons with disabilities receive services from any ILC or satellite.

Variations by Region in Dollars Spent per Facility and per Person Served

Although there are limitations with some of the data on persons served and expenditures by Center, as discussed further in Chapter III, the data appear to be accurate and complete enough to justify the conclusion that 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.

Advocacy, Special Education, and Service Coordination Needs Being Adequately Met

Independent Living Center survey findings identified the following as the top five needs that are currently being adequately met in the ILC service areas: access to information and resources; systems advocacy; special education; emergency services; and service coordination. Public agency stakeholders largely agreed. They identified: Information about disability rights; vocational training; service coordination; systems advocacy and special education as the five needs that they perceive are being adequately met in their service areas.

Transportation and Adequate Income are Most Persistent Needs

Transportation and some combination of financial support/adequate income and benefits assistance and advice consistently surfaced at or near the top of lists of persistent needs and service gaps within each of the surveyed groups: ILCs, consumers, and stakeholders. Medical/health issues, employment, and affordable and accessible housing also surfaced as significant issues and unmet needs that need to be addressed by and on behalf of people with disabilities.

Consumer Needs Vary Somewhat by Region

Consumer responses to the question regarding the most challenging issues faced day-to-day varied depending on the region. In New York City, housing (62%) was the most important issue. In the North Country, the major issue was transportation (58%). Similarly, the corresponding service gaps reflected the geographic nature of the region. In New York City, consumers felt they most needed housing (63%), while in the Finger Lakes, the major service need involved transportation (59%).

When asked what service is not received that is needed to live more independently, consumers in the North Country, Central NY, the Southern Tier, and Finger Lakes all cited transportation most frequently. Those in the Upper Hudson Valley (Capital District) reported they needed more benefits assistance and advice, while those in the Hudson Valley reported most needing employment services.

In an effort to more broadly characterize the responses of the roughly 1,300 persons with disabilities who responded to the consumer survey, the responses were split into urban and non-urban areas of the state. A little over a third of the respondents were being served by Independent Living Centers situated in primarily urban areas.¹¹

In terms of services most needed to live independently, transportation and mobility services was the only one to be listed by more than 40% of both urban and non-urban consumers. Benefits assistance and advice, information and referral services, and advocacy were also selected by around 35% of both urban and non-urban respondents. On the other hand, urban consumers were significantly more likely to choose housing and employment services compared with their non-urban counterparts.

Similarly, both urban and non-urban consumers ranked transportation and mobility services as the foremost service that persons with disabilities need, but are not currently receiving. Housing services, employment services, and benefits assistance and advice also emerged near the top of the list of needed services that are presently lacking among urban consumers. Those in non-urban areas, beyond the top-ranked gap in transportation and mobility services, were less likely to report major unmet needs. At a secondary, mid-priority level, they reported recreation and employment services as their next-most-significant service gaps.

Strengths and Opportunities for Independent Living Centers

Consumer and stakeholder satisfaction with service delivery is one of the greatest strengths of New York's network of Independent Living Centers. ILC staff was highlighted as the greatest strength of the Centers themselves. Staff were described as flexible, competent, compassionate, and more. Moreover, management felt that their teams were committed to the philosophy and mission of independent living.

Other frequently mentioned strengths were: Advocacy efforts, connections/networks/relationships in the community, and range/type/quality of services provided by the ILCs and satellites. All of these themes, including staff, provide the statewide network with a strong foundation for service to persons with disabilities. In addition, these strengths represent key tools to overcome the limitations and barriers to

¹¹ Consumer responses were counted as urban if they were served by an ILC submitting surveys from major New York metro areas, including: New York City, Rochester, Syracuse and Yonkers. Consumer surveys were not submitted by all Independent Living Centers in the state.

surviving, growing, and expanding in an uncertain political and economic future.

Stakeholders suggested that Independent Living Centers might add or expand services to persons with disabilities in the following key areas—Transportation, Affordable Housing, and Employment opportunities—in order to enhance the human potential of those being served by the Centers. Believing that consumers are best suited to recommend ways to improve the system, the survey asked them to choose what options might make it easier for persons with disabilities to access Independent Living services. Consumers selected expanded services (31%), expanded transportation to and from the Centers (30%), and advertising about existing services (29%) as the three strongest ways ILCs might make it easier for them to access services.

Challenges and Limitations for Independent Living Centers

As might be expected, ILC survey respondents named funding as the greatest limitation facing their organizations. The nature of this limitation had several dimensions as described by several ILCs. Staff reported frustration with the perceived heavy reliance on New York State funding (albeit a relatively small proportion of actual revenues, as shown in Chapter III); the lack of unrestricted dollars; and the time and resources needed to improve fundraising efforts. While funding is the greatest challenge facing Independent Living Centers organizationally, achieving adequate income, that is, sufficient money to cover expenses, is one of the greatest challenges facing consumers of their services.

Other major challenges for ILCs include: staffing issues (high turnover, recruitment, retention, limitations); inadequate space in the facility; perceived limited involvement, influence, and experience within their Board of Directors; the need for transportation to and from service locations; need for greater awareness among consumers of the ILC services that are needed to live independently; and meeting the needs of unreached or underserved populations with disabilities, including rural residents and immigrants.

Eighty-five percent of Independent Living Centers said that there are particular geographic subareas within their overall service areas that they felt are underserved by their organization. These included areas at the farthest ends of their respective counties, those in rural areas that lack sufficient (or any) public transit, urban areas that have physical barriers that make it difficult for consumers to come in for services, and immigrant communities where there is a language barrier which makes communicating about service availability difficult. Beyond these pockets of underserved communities, 17 entire counties have no Independent

Living Centers or satellites located within their boundaries, as previously noted. When asked how they might reach underserved populations within their target areas, ILC staff suggested that increased funding, better transportation, working collaboratively with other providers, establishing satellites, and use of itinerant staff might be among approaches to consider. Addressing such issues will obviously become even more difficult in light of the economic and budget crisis, and will require creative and collaborative efforts to address (see Chapter VIII).

Many Independent Living Centers reported a desire to expand existing services, offer additional services, and/or to extend their reach beyond their current geographic service areas. However, a large majority stated that there are fiscal and operational barriers to achieving these goals. The resources required to overcome the barriers include more and diversified funding, increased space/physical infrastructure, qualified and well compensated staff, transportation for consumers to access the expanded offering of services, and a strategic, funded public relations plan to alert the public to the services available to advance independent living.

Advocating for Change and Reform

Increased collaboration, local advocacy, and systems-wide policy change emerged as three strong action steps that could be taken to strengthen resources for independent living services, the efficiency and effectiveness of existing service provision, and the range of choices available to consumers.

When asked if and how they collaborate with local human service organizations, 92% of ILCs provided examples of collaboration. ILCs reported collaborating with schools, universities, mental health agencies, employers, health care providers, social service agencies, and many more human service organizations. The most frequently cited example of collaboration involved having staff of the ILCs hold positions on boards, committees, and task forces where groups of providers come together to support persons with disabilities. This overlap of agency stakeholders is perceived as building bonds of trust; increasing communication across disparate agencies, resulting in cooperative pursuit of funding sources; and overall was credited with increasing the quantity and quality of services available to persons with disabilities in New York State.

Although local municipalities provide only a negligible proportion of funding support to most Independent Living Centers, the local community is a logical and strategic location for advocacy efforts to be leveraged. Consumers, public stakeholders, and ILC staff concurred that a greater awareness of the independent living message must be cultivated if services are to be provided most effectively. Education on the civil rights foundation of independent living for persons with disabilities could be a

strong counterpart. Finally, greater activity at the local level could be used to reach elected officials who have the potential to shape policy reform.

CHAPTER III: INDEPENDENT LIVING CENTER OPERATIONS

53 Centers Throughout the State, but None in 17 Counties

Vocational and Educational Services for Individuals with Disabilities (VESID) is a part of the New York State Education Department, and is the state agency which administers Independent Living funding and that provides funding, guidance, and supervision for most ILCs. Not all ILCs receive VESID funding, but those that do must report on specified outcomes and service recipient numbers and characteristics. According to VESID, there are 53 total ILCs and satellites in New York State. (NOTE: For purposes of this study, CGR has used the figure of 51 sites, counting as one entity three separate satellites in Oswego County linked with the ARISE center based in Onondaga County. Accordingly, we used 51 as the total number of Centers and satellites, rather than 53 for the ILC survey and selected analyses.)

As indicated in Table 2, the total includes Centers and satellites funded by New York State, those that are federally funded, some that are jointly funded by both state and federal sources, and those that are funded through other sources. Thirty-nine of the sites in 36 counties (including three counties with two VESID sites each) are funded by the state legislature and administered by VESID. The state helps fund about three-fourths of the total sites. \$13,230,600 in the 2007-2008 budget year was allocated by NYS to those 39 Independent Living Centers and satellites, and an additional \$3.9 million was allocated by federal funds, for a total of \$17.1 million in combined federal and state funding (not counting Medicaid dollars, which are separately counted and shown in more detail later in this chapter).¹² It is largely those that receive direct funding from either New York State or a federal source (or both) that provide the bulk of ILC/satellite services and for whom the most data are available.

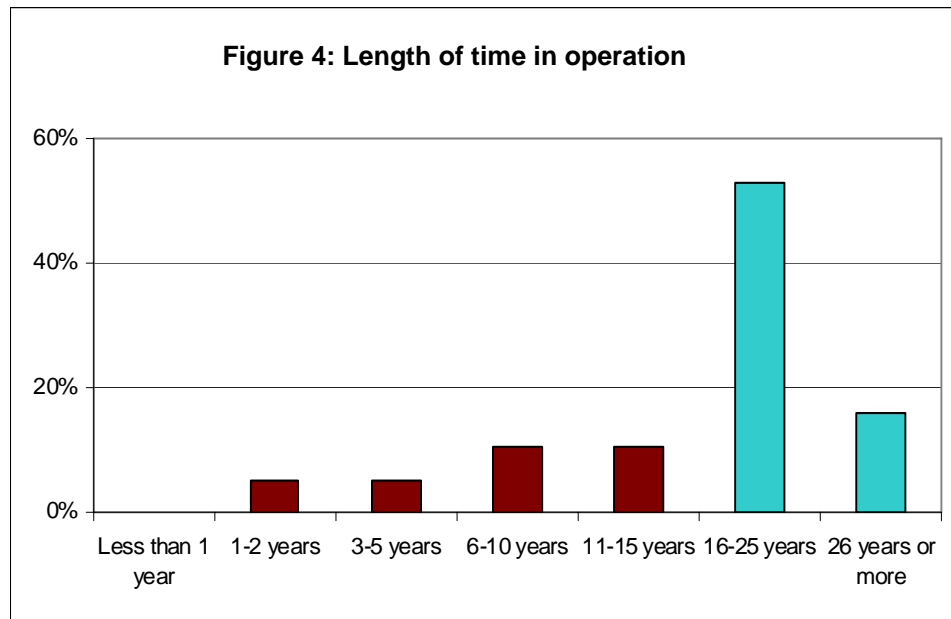
Despite the broad state and federal funding, this arrangement leaves 17 counties throughout the state without formal Independent Living Center services funded by a major government source.

¹² Counties served by state and federal funded ILCs 10/07-9/08, data received 2008 from VESID.

Counties in New York State	62
Total ILCs in NYS (NYS Funded + Federal Funded+*Other Funded)	53
Counties formally served by NYS Funded ILCs	36
Counties formally served by Federal Funded ILCs	6
Total NYS Funded and Federal Funded counties	42
Counties formally served by Other Funded ILCs	3
Total Counties formally served with direct funding	45
Counties not formally served (62 minus 45)	17
*Other Funding: Funding from any source other than NYS and Federal, such as a local municipality or Medicaid.	
Source: VESID, 2008.	

History and Presence of Independent Living Centers in New York State

This needs assessment sought to identify not only the current operations of ILCs, but also to gauge the depth of history and presence of the organizations. Of the Independent Living Centers responding to the ILC survey, 69% had been in operation for 16 or more years. This history and presence suggests that the philosophy of independent living has become a consistent part of local communities.



Awareness of Presence

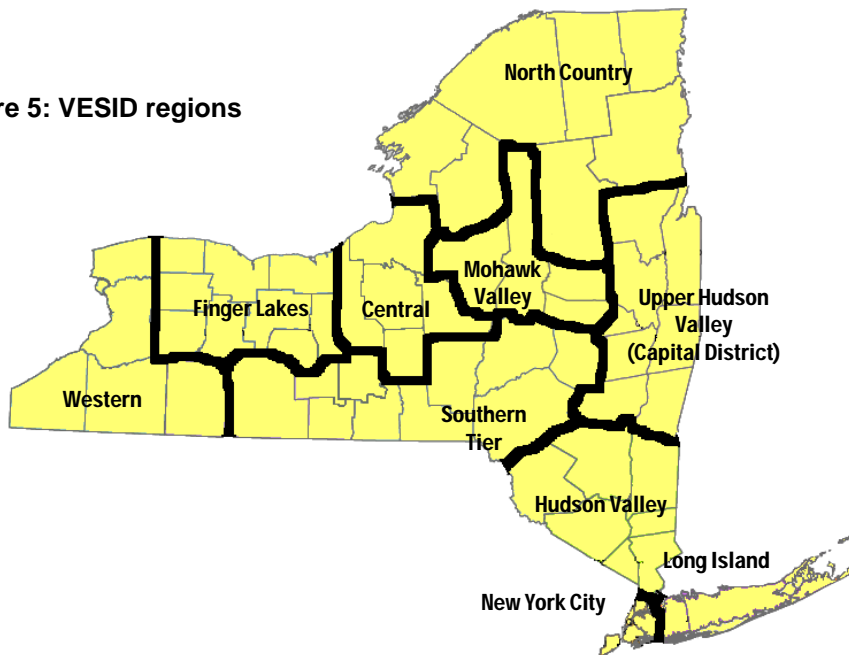
The stakeholders surveyed for the needs assessment reported being largely aware (78%) of Independent Living Centers (or their satellites) operating in the same service area where they worked. More of these public agency staff (96%) were familiar with the types of services Independent Living Centers offer. Most of those stakeholders in counties without centers or satellites indicated that it was somewhat or very important to have an ILC in their county. Awareness of services is a consistent theme that occurs in various contexts throughout this report.

Geographic Locations of Sites

Distribution of ILCs and Satellites by Region

The Vocational and Educational Services for Individuals with Disabilities (VESID) divides the state of New York into ten regions: Central New York, Finger Lakes, Hudson Valley, Long Island, Mohawk Valley, New York City, North Country, Southern Tier, Upper Hudson Valley (Capital District), and Western New York. These regions formed the basis for the regional comparisons used in this analysis. The regions are outlined in the map in Figure 5 below.

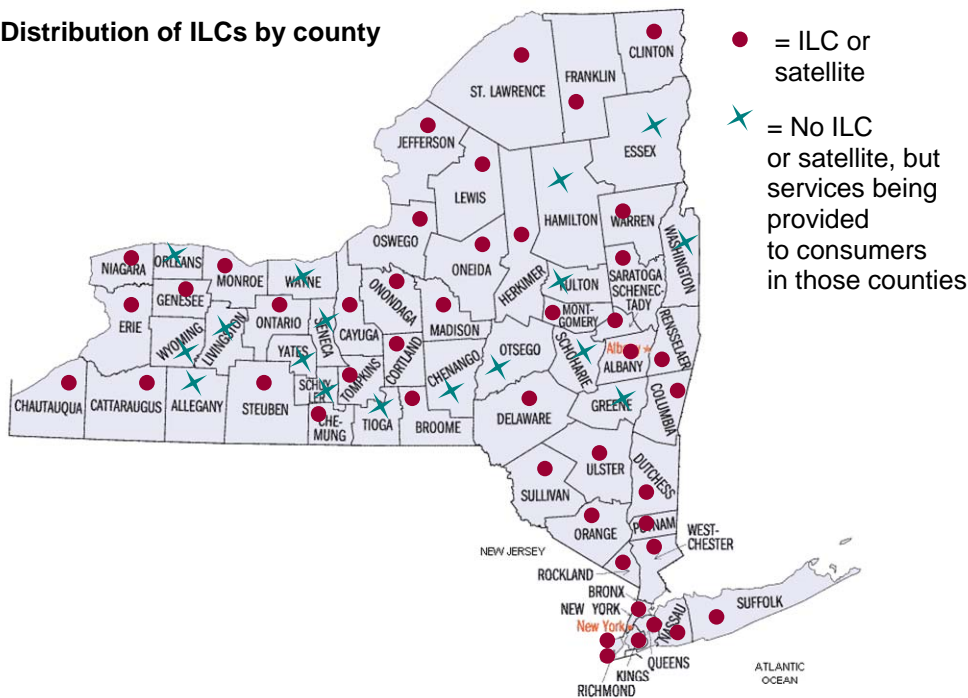
Figure 5: VESID regions



Distribution of ILCs and Satellites by County

Although some residents of all counties throughout the state receive services from ILCs and satellites, centers or satellites are actually physically located in only 45 counties in the state, as indicated in the map in Figure 6. Of the 51 sites in the counties (five counties have more than one ILC or satellite), 35 are ILCs and 18 are labeled as satellites (16 if the three in Oswego are counted as one). It should also be noted that previous satellites in Herkimer, Putnam, and Sullivan counties became state-funded Centers in the 2008-09 fiscal year.

Figure 6: Distribution of ILCs by county



Regional snapshots

This section provides an indication for all ten regions of the numbers of resident persons with disabilities within each county who receive ongoing services from ILCs and satellites. The numbers served refer strictly to unduplicated counts of persons with disabilities receiving sufficient services (typically on a long-term or ongoing basis) that formal Consumer Service Records (CSRs) were opened for them by an ILC or satellite. As such, these totals understate the total numbers served by each ILC/satellite. For example, they do not include persons receiving more casual services, family members or others without disabilities who were included earlier in Figure 1 (showing more than 71,000 total persons served).

The total number of persons with disabilities reflected in the regional tables that follow total 25,883 residents throughout the state. This is a conservative indicator of total numbers of people served by the state's ILCs. Statewide, this represents for 2006-07 only about 36% of the total of 71,000-plus people served by all state-funded ILCs and satellites. As such, the 25,883 total also only reflects those people receiving ongoing services in state-funded sites, so the overall totals served in all ILCs and satellites across the state would actually be significantly larger, if more complete data had been available from the remaining 25% of the sites without state Independent Living funding, and had the thousands of family members and other people without disabilities who are served by the Centers been included.

We have used the VESID CSR data because they are the only data of persons served that exist on a consistent basis enabling county-by-county comparisons to be made. Thus the analyses that follow present a conservative estimate of the numbers of people served by county and by ILC/satellite site. But nonetheless, this statewide total and the county and regional breakouts provided in the subsequent tables provide a best-available, realistic snapshot of persons with disabilities receiving ongoing services across counties, and of how the numbers served vary by county.

It is important in reviewing the subsequent tables in this section to remember that the numbers served are broken down by county of residence of the person being served, and not necessarily by the ILC or satellite where the services are provided. Obviously, in most cases, where a site exists within a county, the numbers served in the county are mostly or exclusively county residents served by that site, but in other cases, residents of a county *without* an ILC or satellite would be counted as being served within the county of residence—though the actual services were

provided by a Center/satellite in a neighboring county. Thus the data in the regional tables that follow provide the best indicator available of how well residents of each county are served, whether or not they live in a county containing a Center or satellite.

The tables reflect not only the numbers of people with disabilities with a CSR who are served within each county by state-funded sites (not including family members or others without disabilities who were also served by ILCs), but in the column labeled “CSRs to total disability rate per 1,000 residents,” they provide a rate of numbers of people served per 1,000 people in the county or region with disabilities, according to the 2000 census. This ratio provides a rough indication of the proportion of persons with disabilities living in each county and region who are served by an ILC or satellite in some location. The proportions are relatively small, indicating the important work done by the Centers/satellites but also emphasizing the untapped potential and need to reach many more people in the future (though of course it should be noted that other people with disabilities are also served in their counties by other service organizations with different service models beyond the ILCs).

Statewide, for comparison purposes, 25,883 residents of NYS received ongoing services (CSRs completed) by state-funded ILCs and satellites in 2006-07—a rate of 7.18 per 1,000 people with disabilities in the state. The regional profiles that follow show the names of the counties in each region, the location by county of the Independent Living Centers or satellites in the region, and the number and rate of resident consumers reported served within each county. Additional county density data noted in the following narratives is reported by the United States Census for 2000. Additional material on a county-by-county and regional basis is available in the appendix—including more details on each county’s total population and numbers of persons with disabilities, as determined by the census.

New York City

Consumers who desire Independent Living Center services in New York City benefit from six locations to choose from, with coverage in all five boroughs/counties. As shown in Table 3, the majority of those consumers receiving services in NYC in 2006-07 were Bronx residents. This region features the largest urban cluster in the state with over 5,000 residents per square mile. *Even though more residents of this region are served by ILCs/satellites than in any of the other regions across the state, the sheer volume of the overall population and numbers of people with disabilities living in the region translates into the lowest regional ratio (2.30) of persons served per 1,000 residents with disabilities.*

Region	Counties in the region	ILC	Satellite	Total # of ILC/Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
New York City	Bronx	1		6	2,158	6.34
	Kings	1			709	1.17
	New York	2			558	1.84
	Queens		1		520	1.06
	Richmond	1			229	2.96
TOTALS	5	5	1		4,174	2.30

Long Island

Long Island consumers have two ILCs available to them, one in each of the region's counties. The ILC operating in Nassau County serves one of the densest areas of the state outside of New York City, with close to 5,000 residents per square mile. Suffolk County is more variable with pockets of high density and some with 250-500 persons per square mile. As the region with the second-largest population and the second-largest number of people with disabilities in the state, *the number of people with disabilities who can realistically be served by the two centers, given funding and resource realities, represents the second-lowest regional rate or proportion of residents with disabilities being served (3.41 per 1,000 residents with disabilities).*

Region	Counties in the region	ILC	Satellite	# of ILC/ Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Long Island	Nassau	1		2	969	4.94
	Suffolk	1			430	2.01
TOTALS	2	2	0		1,399	3.41

Hudson Valley

Ten Independent Living sites exist in the Hudson Valley, and *all seven counties contain at least one Independent Living Center or satellite (and Westchester has three and Orange two)*. This region features both highly rural counties with areas that are difficult to reach such as Sullivan County to more accessible locations such as Orange County with 250-500 residents per square mile. Westchester County offers the greatest choice in locations, two Independent Living Centers and one satellite. The number of consumers served in Westchester in 2006-2007 outpaces all of the other Hudson Valley counties, although as the county in the region with the largest population and number of residents with disabilities, a smaller proportion of those residents are served by ILCs/satellites than in any of the other counties in the region. Overall, however, the rate of residents receiving ongoing services from Center facilities in this region exceeds the overall state proportion. ILCs in this region report serving consumers not only from the region, but also from surrounding states, including New Jersey and Pennsylvania.

Table 5: Hudson Valley Regional Profile

Region	Counties in the region	ILC	Satellite	# of ILC/ Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Hudson Valley	Dutchess	1		10	348	8.45
	Orange	2			530	9.35
	Putnam		1		120	9.33
	Rockland	1			312	7.30
	Sullivan		1		194	12.47
	Ulster	1			784	25.54
	Westchester	2	1		855	5.81
TOTALS	7	7	3		3,143	9.06

Upper Hudson (Capital District)

Independent Living service coverage in the Upper Hudson Valley is somewhat less extensive than in some other regions across the state. Two counties lack any form of ILC, although a number of residents in Washington and a few in Greene counties receive services from Centers in other counties. Both of these counties are highly rural with populations ranging from 50-250 persons per square mile. Schenectady, with a recently-opened satellite, has up to this point had relatively few residents served by a Center or satellite. Taken as a whole, even with the gaps in ILC service, the region's rate of persons served is above the state rate.

Table 6: Upper Hudson (Capital District) Regional Profile

Region	Counties in the region	ILC	Satellite	# of ILC/Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Upper Hudson	Albany	1		6	573	11.73
	Columbia		1		85	7.86
	Greene				27	2.76
	Rensselaer	1			205	8.00
	Saratoga		1		206	7.58
	Schenectady		1		47	1.82
	Warren	1			457	41.57
	Washington				233	21.67
TOTALS	8	3	3		1833	10.79

North Country

The North Country, comprised of seven counties, includes much of the state's most rural areas with population densities ranging from one to 50 persons per square mile. *Essex and Hamilton are both without ILC sites, and each has a relatively small handful of residents receiving services.* These counties are home to the state's Adirondack Park, the largest publicly-protected green space in New York and the largest protected by any one state. Only 1% of the park includes residential areas. *Although this region has one of the smallest averages of number of residents served per county, it also has the smallest number of residents with disabilities. Thus its overall rate of persons served per persons with disabilities is one of the highest in the state.*

Region	Counties in the region	ILC	Satellite	# of ILC/ Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
North Country	Clinton	1		5	214	15.44
	Essex				57	7.62
	Franklin	1			141	13.69
	Hamilton				16	13.85
	Jefferson	1			717	41.55
	Lewis		1		138	28.04
	St. Lawrence	1			303	14.79
TOTALS	7	4	1		1586	21.02

Mohawk Valley

The Mohawk Valley region has a wide variation in population density ranging from locations that are quite rural (Herkimer) to moderately urban (Oneida). It includes the Utica-Rome metropolitan statistical area with a population of 299,896 residents. This large area accounts for the largest number of consumers being served in the region through Independent Living Centers. However, most of the residents of this region live in villages and towns with populations under 5,000. Fulton County does not have an ILC site, and relatively few of its residents receive ILC services. However, largely because of the concentration of residents served from Oneida County, and relatively large proportions served in Herkimer and Montgomery, *the numbers of residents with disabilities served in this region is second only to NYC, and the overall rate per 1,000 people with disabilities is the highest of all regions in the state.*

Region	Counties in the region	ILC	Satellite	# of ILC/ Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Mohawk Valley	Fulton			3	94	8.87
	Herkimer		1		549	46.97
	Montgomery		1		461	48.75
	Oneida	1			2,651	60.11
TOTALS	4	1	2		3,755	49.50

Central New York

Consumers in the five counties in the Central New York region have access to five Independent Living Centers and satellites, with coverage in each county in the region. Residents served in Onondaga County outnumber those served in all the four other counties combined. This county is home to the region's largest city, Syracuse. The Syracuse metropolitan statistical area does include the surrounding counties of Madison and Oswego and includes a population of 650,154. The region has one of the highest proportions of persons receiving ongoing services (i.e., with CSRs) of any of the regions in the state, and each county's rate per 1,000 persons with disabilities receiving services is at least double the statewide rate.

Table 9: Central New York Regional Profile

Region	Counties in the region	ILC	Satellite	# of ILC/ Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Central NY	Cayuga	1		5	270	18.83
	Cortland	1			208	25.75
	Madison		1		268	23.74
	Onondaga	1			1,631	21.83
	Oswego		1		698	32.46
TOTALS	5	3	2		3,075	23.67

Southern Tier

Residents of the Southern Tier have among the fewest ILC/satellite options available to them, with only five sites available within the region's ten counties. Five counties lack an ILC or satellite site. Populations across the region range from 10-250 persons per square mile. The Binghamton-Tioga metropolitan statistical area has 252,320 residents and is situated just on the border of Pennsylvania. Despite the significant gaps in service options within the region, the rate of persons receiving ongoing services per 1,000 people with disabilities is above the state rate in all but one county, suggesting that the existing Centers and satellite are reaching out beyond their immediate county borders to serve residents of other counties. However, these data suggest that significant travel time (potentially for both staff and consumers) may be involved in serving many of these residents of non-Center counties.

Table 10: Southern Tier Regional Profile

Region	Counties in the region	ILC	Satellite	# of ILC/Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Southern Tier	Broome	1		5	752	21.32
	Chemung		1		266	15.50
	Chenango				132	12.56
	Delaware	1			197	19.65
	Otsego				165	14.77
	Schoharie				105	18.75
	Schuyler				10	2.73
	Steuben	1			571	29.99
	Tioga				87	10.56
	Tompkins	1			225	18.82
TOTALS	10	4	1		2510	18.93

Finger Lakes

The Finger Lakes region is home to the state's third largest urban cluster, the Rochester metropolitan area, with a population just over one million. The city itself has over 200,000 residents. And yet, *the region has the smallest number of Independent Living Centers or satellites per county—six of the region's nine counties lack ILC sites.* The ILCs in the surrounding areas have managed to provide the region's consumers with some services in those counties, but *in four of the counties, only 15 or fewer people were served in 2006-07—all with rates per 1,000 of 1.5 or less.* The average number of residents served per county (178.5) is the lowest of any region in the state.

Region	Counties in the region	ILC	Satellite	# of ILC/ Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Finger Lakes	Genesee	1		4	328	34.80
	Livingston				15	1.51
	Monroe	2			707	5.91
	Ontario		1		13	0.84
	Orleans				86	11.41
	Seneca				305	52.32
	Wayne				9	0.63
	Wyoming				139	21.05
	Yates				5	1.13
TOTALS	9	3	1		1607	8.32

Western New York

Consumers who receive services in the Western New York region are served by five locations. The city of Buffalo and its surrounding metropolitan area (including the cities of Cheektowaga, Tonawanda and Niagara Falls) is home to 1,170,111 residents. This is the second largest metropolitan statistical area in the state. Consumers have been largely served in Erie County by an Independent Living Center and a satellite site. Allegany County is the only county in the region to lack a site of its own. The overall rate of persons served per 1,000 persons with disabilities is above the statewide rate.

Region	Counties in the region	ILC	Satellite	# of ILC/ Satellite	Consumers Served in 2006-2007	CSRs to total disability rate per 1,000 residents
Western NY	Allegany			5	80	8.87
	Cattaraugus	1			416	27.24
	Chautauqua	1			398	15.29
	Erie	1	1		1,651	9.80
	Niagara		1		256	6.66
TOTALS	5	3	2		2801	10.88

Summary

There is a wide variation across regions and counties in the extent to which persons with disabilities have access to Independent Living Center or satellite services—presenting significant opportunities and needs for expansion of services even in this difficult economic environment. Some regions appear to be doing relatively well, given available resources, at serving significant numbers of people with disabilities. On the other hand, *given the sheer volume of persons in need in the NYC and Long Island regions, very small proportions of residents with disabilities are being reached through ongoing services by the Centers in those regions. Moreover, in the Southern Tier and Finger Lakes regions, there are no Centers or satellites in half or more of the counties, and in four of the Finger Lakes counties, only miniscule numbers of persons with disabilities are being reached by any of the regional facilities. In the interests of equity of service provision, even in difficult financial circumstances at all levels of government, these data suggest that a strong case can and should be made for expanding services to more adequately cover these underserved regions.*

Specific Service Gaps Within Regions and Counties

In addition to the gaps reflected in the data presented above and the accompanying regional narratives, ILC staff also commented in their surveys on their perceptions of service gaps. Their perceptions are generally consistent with the data shown above, and also provide supplemental perspectives within regions of subsets of counties where the geography, service locations and/or staffing resources make it difficult and costly for many residents to access services. The areas reported as most difficult to reach were:

- Rural areas beyond the City of Cortland
- Lower Orange County
- Most of Sullivan County
- Extremely rural areas of Delaware County
- Rural parts of Tompkins County
- Wyoming and Orleans Counties
- Rural areas of Rensselaer County
- Rural parts of Niagara County
- Essex County
- Fair Haven and Moravia
- Ellenville
- Western Part of Montgomery County and Fulton County
- Northern Herkimer County
- Rural areas within counties of Oneida, Lewis, Herkimer, Hamilton, Fulton, and Montgomery
- Rural areas of Saratoga, Warren and Washington Counties
- Areas outside of Broome County, especially rural areas and the far reaches of Chenango and Tioga
- Rural areas of Long Island
- Selected neighborhoods within New York City

- Communities surrounding Tupper Lake, Saranac Lake and Lake Placid

Financial Profile of Independent Living Centers

Based on data from ILC surveys as well as from 990 forms and annual reports, CGR's analyses indicate that the average Independent Living Center and satellite has an annual budget of \$2,439,600, with a median budget of more than \$800,000 (half above and half below that budget amount). The difference between the largest reported annual budget and the smallest was over \$19 million, demonstrating the full range of the size of ILC operations across the state. For the 48 ILCs/satellites represented, the combined annual budgets total more than \$117 million.¹³

Financial Profile for Independent Living Centers and Satellites	Annual Budget n=48
Mean	\$2,439,600
Median	\$834,967
Minimum	\$173,356
Maximum	\$19,391,926

Breakdowns by expense categories were only available for 27 of the ILC/satellite sites. Thus the totals shown below in Table 14 are not reflective of the totals of all sites across the state. They represent about two-thirds of all ILC/satellite annual expenditures. Our analyses suggest that the proportions of expenditures by category shown in the table are similar to what the statewide proportions would be had the comprehensive data been available for all locations. The largest expenditures for ILCs are staff salaries and staff benefits, representing 78% of the overall expenses for the reporting Centers. The next largest category is administrative expenses, including utility costs and supplies, at 14%.

¹³ As discussed in the methodology section, not all ILCs in New York State responded to the survey and of those that did, not all included their fiscal data. Additional research was conducted to populate a larger portion of the population of ILCs. These data points included location, staff size, annual budget, and numbers of consumers served to reach a total of 48 sites.

Line Item	Totals across sites (N=27)	Average spent by each site*	Proportion of expenses reported by source**	% of total sites reporting this category***
Staff salaries	\$48,081,989	\$1,780,814	61%	100%
Staff benefits (healthcare, retirement, vacation, etc.)	\$13,348,387	\$494,385	17%	100%
Rent/Mortgage for your facility	\$1,441,691	\$55,450	2%	96%
Staff travel	\$900,334	\$34,628	1%	96%
Administrative expenses (utilities, postage, supplies, etc.)	\$11,194,858	\$414,624	14%	100%
Direct consumer supports (e.g rent subsidies)	\$1,476,095	\$164,011	2%	33%
Other	\$1,940,377	\$138,598	2%	52%
TOTAL EXPENSES	\$78,383,731	\$3,082,510	100%	100%

*The average is calculated based on the total across the sites reporting. **Reports on the proportion of the overall totals in each category. ***Of the 38 sites reporting on the ILC survey, 11 did not provide expense breakdowns. 27 sites had the majority of these categories reported.

As shown below in Table 15, the revenue side of the Independent Living Centers' budgets demonstrates the heavy reliance on Medicaid funding and reimbursements. No ILCs reported receiving revenue from private insurance or Medicare.

	Totals Across Sites	Average revenue by each site*	Proportion of revenue reported by source**	% of total sites reporting this category***
State IL funding	\$8,561,604	\$356,734	10%	83%
Services under contract with NYS OMRDD	\$1,542,432	\$110,174	2%	48%
Medicaid Consumer Directed Personal Assistant Program	\$34,769,181	\$2,897,432	40%	41%
Other services under contract with NYS DOH	\$1,568,954	\$196,119	2%	28%
Federal IL funding	\$1,838,083	\$153,174	2%	41%
Other federal funding	\$1,714,718	\$171,472	2%	34%
County funding	\$1,426,101	\$129,646	2%	38%
City or Municipality funding	\$122,965	\$20,494	0.1%	21%
Other reimbursements – Medicaid waivers	\$12,393,540	\$1,770,506	14%	24%
Other reimbursements – Medicare	\$0	\$0	0%	0%
Other reimbursements – Private insurance	\$0	\$0	0%	0%
Other reimbursements – Fees	\$17,228,274	\$1,722,827	20%	34%
United Way	\$263,981	\$23,998	0.3%	38%
Other grants	\$1,547,729	\$103,182	2%	52%
Private or business contributions	\$263,255	\$23,932	0.3%	38%
Fundraising	\$711,959	\$50,854	1%	48%
Other	\$2,618,891	\$174,593	3%	52%
Total revenue	\$86,571,667			

*The average is calculated based on the total across the sites reporting to the survey. **Reports on the proportion of the overall revenue totals in each category. ***Of the 38 sites reporting on the ILC survey, 11 did not provide revenue breakdowns. 27 sites completed the survey, but the proportions reflect the percentage of those that reported revenues in each category.

The expense and revenue tables depict one facet of the information known about the ILC budgets. Another way of looking at the budget data is to examine how many of the participating sites reported the figures for each of the possible categories. For example, Table 15 indicates that 83% of the sites reported receiving state Independent Living funding even though on average state funds represent only about 10% of the cumulative ILC annual revenues. This might be interpreted as state funding being the most commonly-shared source of income for Independent Living Centers, but only accounting for a fraction of the total revenues needed to operate the Centers. Clearly, this represents the most common single reported source

of income, though not the largest in total dollars by a long shot. The largest single source of funds, with 40% of reported revenues, is the Medicaid Consumer Directed Personal Assistant Program—plus an additional 14% from Medicaid waivers. Various other fees account for 20% of all revenues.

By contrast, while 52% of the Centers reported bringing in revenues from grants, and 48% reported revenues from fundraising activities, the money raised only constituted 2% and 1%, respectively, of ILC/satellite cumulative annual support. Similarly, 38% reported receiving County funds, but they only accounted for 2% of all revenues; and the United Way and private contributions each helped fund 38% of the sites, while each contributed less than 1% of total revenues. *These figures suggest several opportunities for expanded sources of funding support in the future, and may help direct advocates and policymakers to consider where to place their energy to increase or sustain subsequent ILC funding.*

Staffing Profile of Independent Living Centers

The average Independent Living Center and satellite operates with an administrative staff of 8 employees (7 full-time) and a direct service staff of 26 employees (14 full-time and 12 part-time), for an average of 35 total personnel (rounded). The size of the Centers varies, depending on factors such as location, numbers served and range of services provided. The smallest site operates with one staff person, presumably a director, while the largest site has 388 full- and part-time staff. The median total staff size for an Independent Living Center is 11.

Staff profile by position	Admin Full Time	Admin Part Time	Direct Service Full Time	Direct Service Part Time	Total By Site
TOTAL staff by position	281	55	526	455	1317
Mean/Avg staff by position	7	1	14	12	35
Median staff by position	3	1	5	2	11

Table 17: Staffing breakdowns n=37	
Staff size	
Least number of staff	1
Greatest number of staff	388
Staff size distribution	
1 to 8	11
9 to 18	14
19 to 70	9
71 to 388	3

Additional human resources are available from two sources: volunteers and persons assigned through the Consumer Directed Personal Assistance Program. These are personal care positions supported by the Department of Health, but directed and managed by consumers themselves.

Table 18: Other staffing support n=37		
	Volunteers	CDPAs
Total by position across sites	718	2601
Mean/Avg by position by site	19	68
Median by position by site	4	(only 12 sites have CDPA)

Regional Summary of ILC Operations

The size of the operating budget and the average numbers of staff and consumers differ across the regions. Because there was a 25% gap between those that responded to the ILC survey (38) and the remainder of the ILCs in operation in New York State (53 officially per VESID, although the survey was sent to a list of 51), additional data were collected to round out the missing information. These data were gathered from annual reports, 990 forms, organization websites, and VESID consumer statistics. When aggregated by region, the data present a snapshot of the size and operation of Independent Living Center services in each area.

Staff, CSRs, and Budgets

The following overview in Table 19 presents the variation across the regions in terms of staff, consumers served, and the annual operating budgets for Independent Living Centers across the state.

Region	Number of independent living sites	# of ILC/Satellite	Average consumers per county	# of counties in the region	Average staff size per site	Average annual budget per site
Central NY	3 ILC, 2 satellite	5	615	5	166	\$3,070,350
Finger Lakes	3 ILC, 1 satellite	4	179	9	24	\$8,709,994
Hudson Valley	7 ILC, 3 satellite	10	449	7	24	\$2,766,180
Long Island	2 ILC	2	700	2	25	\$1,668,852
Mohawk Valley	1 ILC, 2 satellite	3	939	4**	388**	\$10,332,769**
New York City	5 ILC, 1 satellite	6	835	5	18	\$581,335
North Country	4 ILC, 1 satellite	5	227	7	12	\$332,378
Southern Tier	4 ILC, 1 satellite	5	251	10	23	\$454,693
Upper Hudson Valley (Capital District)	3 ILC, 3 satellite	6	229	8	22	\$1,548,982
Western NY	3 ILC, 2 satellite	5	560	5	45	\$634,234

*Presents data for 51 sites. **One family of sites (1 ILC, 2 satellites) reporting for the Mohawk Valley, the figures are reported as totals not averages, except for consumers by county, which is an average.

Care should be taken in interpreting the average staff size and average annual budgets per ILC/satellite. Average staff size can vary considerably depending on the ratio of full-time to part-time staff in each site. This is likely to account for much of the major differences in reported average staff sizes in the Central and Mohawk Valley regions, compared to averages in the other regions. Differences in sources of budget information needed to supplement the ILC survey data may help account for the wide variations in average budgets across the regions. For example, it makes little intuitive sense for the average ILC/satellite budget in the Finger Lakes region, which serves the smallest number of consumers per county of all the regions, to be as high as is shown in the table. Similarly, the Mohawk Valley budget figure is unrealistically high, as referenced in the table footnote. At the other end of the spectrum, the NYC ILC/satellite operations appear to have among the smallest budgets per location, despite the added differential costs of operating in NYC, and the larger numbers of people served in those facilities. *Thus there appear to be significant inequities in the operating costs and resources available across regions, but before drawing any conclusions, a further attempt should be made by NYAIL to obtain more consistent budget data from*

each ILC/satellite, so that more definitive comparisons can be made about equity of resources allocated across sites and regions.

Ratio of CSRs to ILC/Satellite Budgets

Table 20 indicates the ratio of costs/budgets per numbers of CSRs, i.e., unduplicated persons with disabilities receiving ongoing services from the ILCs/satellites in each region. In this analysis, Table 20 presents comparison data only for the 36 sites for which VESID collects CSR data. Thus the budget data used in this and previous Table 19 are not necessarily the same within each region. In this scenario, the average cost per CSR consumer to operate those 36 ILCs/satellites in New York State (counting only consumers with disabilities, and not including other family members and others served without disabilities) is \$2,985.

Region	Total CSRs by ILC	Total of Budgets for Sites in the Region	Ratio of \$ to CSR by site
Central NY	6,637	\$12,281,400	\$1,850
Finger Lakes**	1,306	\$16,282,411	\$12,467
Hudson Valley	3,148	\$20,235,574	\$6,428
Long Island	1,431	\$3,337,704	\$2,332
Mohawk Valley	733	\$603,725	\$824
New York City	4,142	\$3,879,097	\$937
North Country	1,456	\$1,329,511	\$913
Southern Tier	2,319	\$8,021,212	\$3,459
Upper Hudson	2,011	\$5,480,168	\$2,725
Western NY	2,735	\$5,903,692	\$2,159
ALL REGIONS TOTAL SERVED	25,918	\$77,354,494	\$2,985
*Data from 36 sites that VESID reports on for CSR data by site by county. **The figures for the Finger Lakes seem inconsistent with the overall picture, additional analysis may be needed to address this aberration.			

As with the data in Table 19, these data should be treated with caution, as the budget information comes from different sources in some cases. For example, budget data appear significantly different between the two tables for the Mohawk Valley, Southern Tier and Western NY regions, and the Fingers Lakes data seem to be an anomaly in both tables. Also, ILCs/satellites vary considerably in the numbers of persons served over and above just the persons with disabilities reflected in Table 20 (i.e., additional family members and various others who receive advocacy and other types of services). Thus these ratios presented in Table 20 are not likely to reflect actual “apples-to-apples” comparisons of costs per total persons served. More direct comparisons, not possible the way data are currently maintained and presented to VESID or in our survey, are needed

to make the most appropriate comparisons in the future. On the other hand, subject to the budget limitations, the data do present the opportunity to make tentative direct comparisons across regions involving persons meeting the criteria established by ILCs/satellites for completing a CSR as evidence of ongoing service provision.

The Table 20 data do suggest that there are significant differences in the ways in which resources are allocated across ILCs/satellites and across regions that need further investigation to help ensure appropriate allocation of resources in the future. The data in Tables 19 and 20 appear to suggest that there are significant inequities in the operating costs and resources per person served between Centers and satellites across regions. There is consistency in the two tables suggesting that 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.

To ensure that resources are equitably allocated in the future, consistent budget data for each location needs to be compared against the full range of services provided at each facility, and compared against not only the numbers of persons with CSRs by site, but also persons served for whom CSRs are not completed, family members served, and the numbers of other persons without disabilities who are also served (and the types of services provided for such persons). *Data are not currently maintained in a consistent fashion across ILCs/satellites and across those dimensions. Unless and until they are, it will be difficult to determine if resources are allocated across ILCs/satellites and regions in a fair and equitable manner.* NYAIL's potential role in addressing these gaps in data collection, management, and application is discussed in greater detail in the recommendations section of the document.

CHAPTER IV: INDEPENDENT LIVING SERVICES AND CONSUMERS WHO USE THEM

Staff at Independent Living Centers believe that the range of services they provide, both in terms of the quantity of what is available and the degree of quality, is one of their three greatest strengths. The data collected for the needs assessment attests to the array of services available to promote and advance independent living in New York State, from rural areas to urban, for those with one disability to those with many, for persons of all racial and ethnic backgrounds, for those across the income scale. Consumer choice is an integral element of the philosophy guiding the operation of Independent Living Centers. For the most part, consumers are

provided with that range of options across New York. However, the availability of some services differs across regions, counties, and ILCs. This distribution may be attributed to the demand, the availability of resources to fund the service delivery, the expertise of staff trained to offer the service, or the feasibility of providing the service in the geographic location where consumers reside.

Target Population and Consumer Eligibility

According to the Independent Living Centers surveyed for this study, nearly 60% define their target population simply as persons with disabilities. Some expanded this statement to include family members and local communities, while a small number identified the density of their population: rural or urban or the county in which they are located.

When asked what makes a person eligible for their services, the ILCs also were brief, with most reporting that the person must have a disability or be a family member of a person with a disability. Some argued with the term eligibility, saying that the only requirement was that the person needed, requested, or wanted the service.

Service Categories and Volume

According to the survey of Independent Living Centers, in 2006-07, information and referral services were the most frequently-provided service to persons with disabilities (30% of all the documented services provided). Advocacy and legal services were the next-most-frequently-provided services (12%). The remaining 58% of services were distributed across a wide range of service offerings, as reflected in Table 21.

Units of service (CSRs X service provided; consumers may have received more than one service) n=38	Totals	Average per site reporting each category	% of Total Service Units
Information and referral	31,329	824	30.3%
Advocacy/legal services	12,723	335	12.3%
Other	9,523	733	9.2%
Business/Industry/Agency services	7,132	193	6.9%
Benefits advisement	6,038	159	5.8%
Independent living skills development and life skills services	4,984	131	4.8%
Peer counseling	4,295	113	4.2%
Assistive devices/equipment	4,113	108	4.0%
Housing and shelter services	3,833	101	3.7%
Vocational services	2,505	66	2.4%
Counseling services	2,327	61	2.3%
Voter registration	2,023	53	2.0%
Personal assistance services	2,021	53	2.0%
Communication services	1,898	50	1.8%
Transportation services	1,789	47	1.7%
Recreational services	1,733	46	1.7%
Youth services	1,669	44	1.6%
Architectural barrier services	1,463	39	1.4%
Family services	1,265	33	1.2%
Children's services	329	9	0.3%
Plan for achievement for self support	200	5	0.2%
Mobility training	152	4	0.1%
TOTAL units of service	103,344		

In light of information presented elsewhere in this report, indicating perceived service gaps for people with disabilities in areas such as transportation services, housing and employment, it is instructive to note for future reference that actual provision of such services currently reflects relatively low proportions of the total of all services currently provided by ILCs/satellites: i.e., housing and shelter services represent just under 4% of all reported services annually, vocational services just over 2%, and transportation services just under 2% of all services (an average of 47 per site on an annual basis). Centers and satellites may

need to consider ways of expanding the provision of such services in the future, in order to more effectively target needs of their consumers.

Consumers Accessing Services

Transportation and Finances Most Important to Live Independently

Out of a list of 15 service categories, consumers were asked to identify the services they needed most to live independently. They could select all that they felt applied to them. Of these, transportation and mobility services ranked most important (43%), with benefits assistance and advice (40%), advocacy (39%) and information and referral (37%) closely behind, followed by housing services (34%), medical services (33%) and employment services (31%).

Consumers identified transportation, finances, employment, and medical/health coverage as the most challenging issues they encounter every day. Finances/income/help in applying for benefits and transportation were among the most frequently reported issues, as reported both in the consumer survey, and also as reflected in the survey of public agency stakeholders. These two issues appeared consistently across consumer disability, race, age and region categories, albeit to differing degrees of need. For example, in rural communities, transportation ranked toward the top of the need categories, less so in more urban settings where it tended to be surpassed by housing as the foremost need.

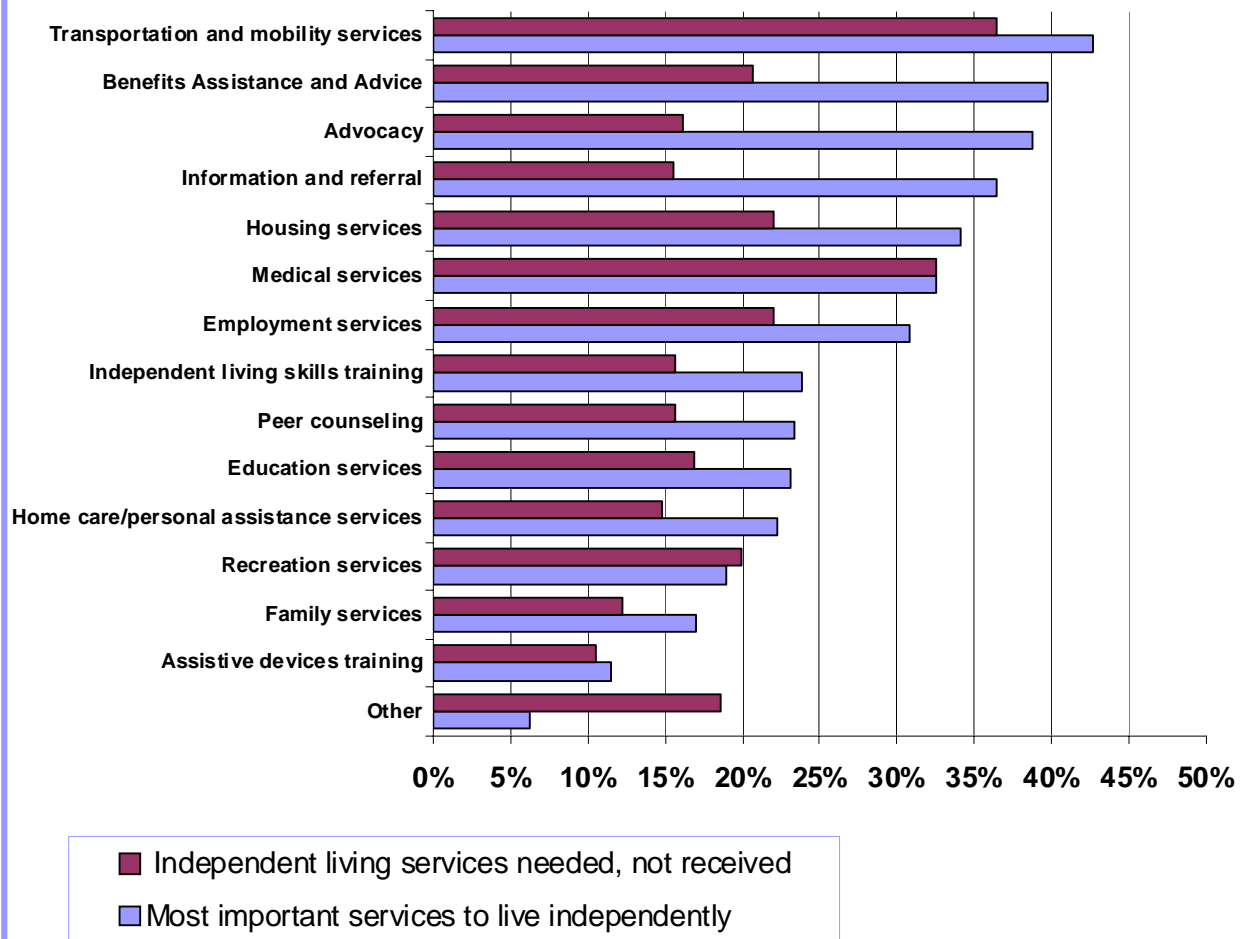
As indicated in Table 22, consumers and public agency stakeholders were in general agreement that transportation and some grouping of either finances or applying for benefits were among the most challenging issues facing consumers. Consumers felt that applying for benefits was not as challenging an issue for them as the stakeholders perceived, and stakeholders also perceived housing to be more of an overall issue than did the consumers. However, there was general agreement among both groups that some combination of the following were in the top four or five most challenging issues: finances and/or applying for benefits, transportation, employment and housing.

Issue	Consumers*	Stakeholders*
Applying for benefits	6.8%	20.6%
Housing	8.7%	20.6%
Transportation	12.0%	16.8%
Finances (paying bills)	13.2%	12.1%
Employment	9.6%	10.3%
Personal care	5.5%	3.7%
Education	5.6%	3.7%
Mobility	5.7%	2.8%
Social	8.0%	2.8%
Medical/health coverage	10.3%	2.8%
Other	3.3%	1.9%
Discrimination	5.3%	1.9%
Recreation	6.1%	0.0%
*Consumers could check all that applied, stakeholders could check three. The % reflect the ranking within the survey question		

Key Perceived Service Gaps: Transportation, Medical, Housing and Employment

Figure 7 contrasts the services that consumers identified as needed to live independently with those that they reported they need, but are not receiving. It is clear from the data that there are some gaps.

Figure 7: Services needed by consumers to live independently compared to services needed, but not receiving



For example, *there is an expressed need (43%) for transportation and mobility services and also recognition from 37% that these services are not readily available to meet that demand.* In contrast, consumers desire assistance with applying for benefits, citing it as a major service needed to live more independently, yet they seem to be receiving much of the support they need, as only about half of those with the need say they are not receiving the needed service. This appears to be true to an even greater degree with advocacy and information and referral services. These latter two service areas are in fact among the services that Independent Living Center staff feels are the strongest aspects of their service provision. In Figure 7, the consumer feedback seems to concur. On the other hand, *consumers indicate that in the following important service*

categories, high proportions of those expressing a need for the service are not receiving it: medical, housing and employment services. Attention may need to be paid by various Centers to strengthening provision of such services. Several other services with lower levels of expressed needs also have relatively high proportions of consumers saying they are not receiving the services.

Differences in Service Needs by Demographics

There are some demonstrated differences in the choices made by consumers regarding the services they need to live independently. Some of these differed by race/ethnicity, gender, age, and disability.

Differences in Needed Services by Race/Ethnicity

Consumer choices regarding the most important services to live independently had some consensus across race/ethnicity categories. For example, transportation was selected the most often in the American Indian, Multi-ethnic, and White categories (ranging from 43% to 59%). Black non-Hispanic consumers most often selected housing services (51%). Employment services, housing services, and information and referral services shared the most important place (50% each) for Hispanic consumers.

Differences in Needed Services by Age

Here, the numbers demonstrate a logical breakdown by one's position in life. Education was identified as the most important service (47%) needed by young people 17 and under to live independent lives. Benefits assistance and advice ranked the highest (42%) for adults ages 18-54. Elderly consumers selected transportation as the service that most enables them to achieve independence (50%).

Differences in Needed Services by Disability

When services were examined across types of disabilities, transportation was consistently one of the top priorities (ranging from 43% to 52%). However, those self-identifying with a mental health disability chose benefits assistance and advice more often than transportation (52%). In addition, those with sensory disabilities also selected advocacy (50%) along with transportation as most important.

Differences in Needed Services by Region

Consumer views on the services they needed were fairly consistent. Consumers in all but two regions reported that transportation was the service they most needed, but did not receive. The only two regions that

did not have transportation as their top priority need were more urban regions, New York City and the Hudson Valley, an area that extends up from the city and includes Westchester, Dutchess, Putnam and Rockland counties.

Service Needs as Perceived by ILCs

Independent Living Centers ordered the issues somewhat differently from the consumer or even stakeholder perspectives, but the themes of transportation, finances, and health care also appeared in their top five issue areas. ILC staff was given a list of 25 issues to rate from “not a major need” to “major need”:

- Access to assistive technology
- Access to information and resources
- Accessible health care
- Accessible housing
- Adequate income
- Affordable health care
- Affordable housing
- Affordable, accessible exercise opportunities
- Affordable, accessible opportunities to socialize
- Assistance with disability benefits
- Community based long term care services and supports
- Consumer directed personal assistance
- Culturally sensitive services
- Disability awareness among service providers
- Emergency services
- Employment opportunities
- Health insurance
- Information about disability rights
- Integrated housing
- Service coordination
- Special education
- Systems advocacy
- Transition services
- Transportation
- Vocational training

From this list, the top five ranked needs were, in order from first to fifth: Accessible housing, transportation, adequate income, affordable housing, and affordable health care. The appearance of these two dimensions of housing—affordability and accessibility—points to the nuanced nature of

many of the issues addressed by Independent Living Centers. Moreover, it speaks to the need to communicate these considerations to external stakeholders, such as funders and policymakers, who may not see beyond housing to consider the full range of issues associated with this one need.

Referrals to Independent Living Centers

ILC consumers make contact with the Centers in a number of ways. As shown in Table 23, ILC staff report that other service providers are the most frequent sources of referrals for consumers to their sites. Peer to peer referrals, i.e., other persons with disabilities, are the second most common source by which consumers learn about the services of ILCs. Because satisfaction levels are so high with current consumers, peers could become an even greater source of referrals in the future. *In addition, if the peer to peer network is this strong, it could be an ideal way for NYAIL and ILCs to leverage increased public awareness in local communities.*

At the other end of the referral spectrum, relatively few referrals come from businesses, even though presumably many workers would be aware of family members or friends who might profit from the services of ILCs. *There would appear to be opportunities for the Centers to do more education and outreach with the business sector in many communities, as well as with health-care providers and with schools, as potential sources of increased referrals to Centers in the future.*

Table 23: Sources of referrals and frequency n=35	
Frequency persons with disabilities are referred to the ILC from the following sources	
State and local government agencies	
Rarely	3%
Occasionally	49%
Frequently	49%
Other service providers	
Rarely	0%
Occasionally	11%
Frequently	89%
Other persons with disabilities	
Rarely	0%
Occasionally	17%
Frequently	83%
Family members	
Rarely	0%
Occasionally	40%
Frequently	60%
Self-referrals	
Rarely	0%
Occasionally	31%
Frequently	69%
Referrals from health-care providers	
Rarely	20%
Occasionally	40%
Frequently	40%
Referrals from schools	
Rarely	17%
Occasionally	54%
Frequently	29%
Businesses	
Rarely	46%
Occasionally	49%
Frequently	6%
Other	
Rarely	3%
Occasionally	11%
Frequently	6%

Demographics of ILC Consumers

The Independent Living Center survey asked the respondents to identify the numbers of persons with Consumer Service Reports (CSRs) who were served from October 2006 to September 2007. The data solicited corresponded to Part 2, Section II of the annual VESID report.

Age, Gender, Race/Ethnicity

As shown in Table 24, adults, those 18 and older, comprise the majority of ILC consumers receiving ongoing services (i.e., those with CSRs)—82%. Of those, 18-54 year olds are the largest proportion of those utilizing services. Unlike the statewide population proportion, men are slightly more likely to be consumers of ILC services. The distribution of race/ethnic categories across ILC consumers has somewhat different characteristics than the state population, with fewer black, fewer Hispanic, and fewer Asian or Pacific Islander consumers.

Table 24: Consumer demographics as reported by ILCs			
Unduplicated CSRs by age	Total	Avg/Mean	% of total
Under 6	408	11	2%
6-17	2,050	54	12%
18-22	1,332	35	8%
23-54	8,518	224	51%
55 and over	3,851	101	23%
Unknown	651	17	4%
Unduplicated CSRs by gender	Total	Avg/Mean	% of total
Male	8,420	222	50%
Female	8,253	217	49%
Unknown	127	3	1%
Unduplicated CSRs by race/ethnicity	Total	Avg/Mean	% of total
White	11,293	297	67%
Black (Non-Hispanic)	2,583	68	15%
American Indian or Alaska Native (Includes Native Hawaiian)	205	5	1%
Asian or Pacific Islander	115	3	1%
Hispanic	1,028	27	6%
Unknown	1,651	43	10%

Education and Employment

As shown below in Table 25, the ILC survey showed that the majority of consumers (63%) were not employed, with the largest percentage being

unemployed and not looking for employment.¹⁴ The second largest percentage of non working consumers were reported as looking for a job, while others were listed as students or program participants. In addition to the 63%, an additional 9% were listed as retired. Only 13% were listed as full- or part-time employees, plus another 6% participating in a day program or segregated work setting or other unspecified employment category.

Table 25: Consumer education and employment as reported by ILCs			
Unduplicated CSRs by Employment	Total	Avg/Mean	% of total
Full Time	947	25	6%
Part Time	1058	28	7%
Looking for a Job	2925	77	18%
Unemployed (not looking)	4496	118	28%
Student or in a program	2688	71	17%
Retired	1504	40	9%
Participating in segregated work or day program setting	195	5	1%
Other employment category not specified above	729	19	5%
Unknown	1496	39	9%
Unduplicated CSRs by Education level	Total	Avg/Mean	% of total
Pre-K program	587	15	4%
K-8	1913	50	13%
Some high school	2334	61	16%
Completed high school	3784	100	26%
Some college	1648	43	11%
Business trade, vocational school	589	16	4%
Completed two year undergraduate degree program	603	16	4%
Completed four year undergraduate degree program	647	17	5%
Completed post graduate degree program	234	6	2%
Unknown or not yet enrolled in school	2021	53	14%

When looking at education, it is important to note that 14% of consumers with CSRs were under the age of 18 (see Table 24), while 33% were reported as not having completed high school (Table 25). About a fourth

¹⁴ Figure represents those unemployed and looking for a job, those unemployed and not looking for a job, and those currently enrolled in school or a work training program.

did complete high school and went no farther, and a similar proportion were reported as having completed some form of post-secondary education.

Disability Category

In order to document the establishment of a CSR, a disability category must be recorded. The disability data in Table 26 reflect duplicated numbers because consumers may be counted in more than one disability category. If this is the case, the consumer would also be included in the multiple disability category. For example, a consumer who selects both epilepsy and blindness would be reported under physical, sensory, and multiple disabilities. Physical disabilities were reported most prevalent, with cognitive and mental disabilities also being frequently reported.

	Total	% of total categories
Cognitive	7,413	23%
Physical	9,401	29%
Mental	7,092	22%
Sensory	2,144	7%
Multiple	6,349	20%
Total across all sites	32,399	100%

Learning disabilities make up the greatest proportion of the cognitive disabilities category of those reported by the Independent Living Centers surveyed. TBI or traumatic brain injury is also a common disability in this category. Often affecting the most consumers in any given region, physical disabilities sometimes defy categorization. In the case of Independent Living Center consumers, most were reported as “other” physical disabilities beyond those requested by the VESID report. Mental disabilities were most often associated with mental illness (55%) and then with emotional or behavioral conditions (21%). The most commonly reported sensory disability was deafness (22%). Over 6,000 of the Independent Living Centers’ consumers were categorized as having multiple disabilities.

CHAPTER V: SERVICE GAPS

Gaps in services were assessed directly through questions to the Independent Living Center staff, by analyzing the existing service offerings in contrast to suggested demand, and through the feedback provided by public agency stakeholders.

Needs Not Being Met

Independent Living Centers were asked to identify the top five needs that are not currently being met in their service area (the previous chapter identified ILC perceptions of consumer needs; this takes the question to the next step and asks to what extent the needs are being met). *ILC staff reported that provision of adequate income, employment opportunities, affordable housing, transportation, and affordable, accessible opportunities to socialize were the five foremost issues in their service area that were not well met at present.* Interestingly enough, socialization opportunities do not appear often in the top need categories for consumers and stakeholders, except among consumers age 17 and under. Stakeholders were in general agreement with ILC staff in identifying transportation, accessible housing, affordable housing, adequate income, and employment opportunities as those needs not being well met in their service areas.

Underserved Populations and Steps to Reach Them

One of the major considerations of this needs assessment was the potential for gaps in service to exist among particular subgroups of persons with disabilities. These gaps might exist because of geography, finances, or complexity of outreach efforts. Nearly all (92%) of respondents to the ILC survey said yes, there are particular groups of people within their service area that they feel are underserved or hard to reach by their Independent Living Center or satellite. Similarly, 86% of stakeholders said that there are particular groups of people with disabilities within their service area that they feel are underserved by local agencies. Each set of respondents was asked to choose from a list of possible groups that might be underserved locally: immigrant groups, children, seniors, rural residents, racial/ethnic minorities, and other.

Underserved Populations: Immigrants and Rural Populations

The data in Table 27 indicate that ILCs struggle to reach particular groups, including, most frequently, both documented and undocumented immigrants, and rural residents. Public agency stakeholders also saw these subsets of persons with disabilities as underserved in their own local communities.

	ILC	Stakeholders
Immigrant groups	24%	17%
Children	13%	14%
Seniors	13%	15%
Rural Residents	24%	30%
Racial/Ethnic Minorities	18%	9%
Other (please specify)	8%	16%

Of the ILCs who selected “other,” most said that the deaf population in their area is underserved.

Considerations on Reaching Immigrant Groups

Solutions to extend services to immigrant populations include using outreach methods such as bilingual outreach workers and outreach through faith-based organizations; finding partners to help with translation services; and for NYAIL to take a lead role in creating tools and trainings for working with this population. The survey responses show that ILCs are willing to take innovative steps to reaching the unserved and under-served. When asked to describe how they might strengthen their services to reach these groups, the responses included:

- “Collaboration with local refugee resettlement center.”
- “Hiring and training bilingual/cultural staff to reach these populations.”

Urban centers specifically mentioned:

- “Funding to hire bilingual staff to better meet the needs of the community. Outreach and development of materials. Training for staff on outreach and cultural diversity.”
- “Hiring staff that is conversant in Haitian Creole, Mandarin, Cantonese, Spanish, Russian, Sign Language.”
- “Resources to hire qualified bilingual staff.”

The NYAIL Board/focus group participants convened in September noted that New York State’s primary support system for ILCs lacks cultural competency. According to those assembled, this absence or gap in VESID’s operation affects the system of services as a whole. It is of note that even with potential solutions to language/cultural issues, a major barrier to reaching undocumented immigrants is their fear of being identified; this issue is difficult to address and the focus group had few

comments on how to mitigate such fears. This is clearly an issue that needs further discussion and solution-seeking.

Considerations on Reaching Rural Residents, Children with Disabilities, and Seniors

When asked how they might extend their services to persons with disabilities in rural areas and to more children, some articulated specific goals and explained how they might achieve them. For example, one site said, “We would like to start a peer support group for youths as well as working with the local schools on transition plans and services for children with disabilities. . . . To serve rural residents we need more funding for satellites or at least mileage reimbursement to travel to these areas.”

Others described how they have already begun to address the unmet needs of specific groups of persons who desire independent living services: “We have offered programming specific to seniors, and done extensive outreach to them. We also work jointly with the Area Agency on Aging. Services for children are being addressed through one of our staff becoming credentialed as a Family Development professional.” Often they suggested collaboration: “Network with other agencies to provide new services to individuals with disabilities who are part of these groups,” noted one ILC.

Waiting lists

Of the 26 ILCs that responded to the question regarding waiting lists, 65% said no, they do not have waiting lists for their services, and 34% said yes, and listed the following services as those that do: computer training, special education advocacy, Medicaid service provision (OMRDD), residential habilitation, modular ramp loan program, supportive housing, and Work Incentives Planning and Assistance (WIPA) services.

CHAPTER VI: BARRIERS TO EXPANSION AND GROWTH

Financial Challenges Foremost Barrier

Independent Living Centers noted the lack of unrestricted dollars as a limitation facing their respective organizations. Their feedback also suggested that they might close the funding gap by increasing fundraising income, but that the time and resources needed to improve fundraising efforts was also in short supply. When asked about barriers to providing

existing services, expanding existing services, providing additional services, and extending services to new geographic areas, almost every corresponding resource to overcome the barriers had fiscal implications. Staffing solutions require additional funding for salaries and benefits. Expansion of physical locations requires capital funding. Transportation for consumers to and from services requires program funding, although this dimension might be the most likely component that could be reimbursed from a state or federal source.

Some Steps to Grow and Diversify Funding

Not only did ILC staff report that they faced an ongoing shortage of funding for operations, they also expressed frustration with reliance on certain types of funding sources. *Diversification of funding was cited repeatedly as a target goal for ILC organizations.* In a memo released to ILCs in February of 2008, VESID reported that the annual reports submitted to the agency had begun to reflect a trend toward less reliance on state-funded contract funding in recent years. In addition, some ILCs have grown their organizations with larger annual budgets. According to VESID, 14 ILCs in 2004-2005 had total funding over \$1,000,000 and the same number surpassed the \$1 million mark again in 2005-2006. It was also reported that the ILCs with the most significant funding resources serve as intermediaries for the Consumer Directed Personal Assistance (CDPA) Program operated by the Department of Health.

Barriers to Providing Existing Services

Ninety-seven percent of staff at ILCs perceived that there are barriers to providing their existing services. Staff was asked to choose from a list of 16 possible barriers to identify the most difficult. As indicated in Table 28, two of the three most-frequently-reported barriers deal with funding—the lack of sufficient resources, and limitations or restrictions on those that do exist. Beyond funding issues, the most-frequently-cited barriers have to do with transportation, lack of sufficient awareness of ILC services, staffing concerns (especially perceived insufficient wages and benefits), and space/infrastructure limitations. These issues are cited as barriers consistently across regions, across all types of opportunities to strengthen ILC services, and across ILC staff, consumers and community stakeholders.

Lack of financial or other resources	19%
Funding limitations or restrictions	13%
Lack of adequate transportation for consumers	13%
Lack of public awareness of ILC services	11%
Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits	10%
Lack of space or other infrastructure	9%
Size of service areas	5%
Lack of cooperation from providers (e.g. schools, agencies, etc)	4%
Staffing issues – difficulty retaining staff	4%
Staffing issues – inability to recruit due to shortage of qualified staff	3%
Staffing issues – lack of resources to train staff	3%
Lack of interpretation services	2%
Lack of board support	2%
Low demand or interest from target population	1%
Other	1%
Lack of support from key agencies or other groups in the community	0%
(Choice of up to five)	

Ninety-three percent of stakeholders believe that there are barriers to providing existing services to persons with disabilities in their service areas. They were then asked to choose the five most significant barriers from a list of 16 potential barriers. The five most commonly-identified barriers were similar to those selected by the ILCs:

- Lack of adequate transportation for consumers;
- Funding limitations or restrictions;
- Lack of financial or other resources;
- Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits;
- Staffing issues – inability to recruit due to shortage of qualified staff.

Barriers to Expanding Existing Services

Independent Living Center staff were also asked if there were barriers to expanding existing services. Staff again reported that the main barrier was the lack of financial or other resources, followed by funding limitations and restrictions. The restrictions refer to the ongoing concern many non-

profits face of not having enough unrestricted dollars. Insufficient space is a significant barrier to expanding ILC services. Lack of public awareness continues to be a persistent threat to the ability of Centers to expand and grow their services to additional persons with disabilities.

Lack of financial or other resources	23%
Funding limitations or restrictions	13%
Lack of space or other infrastructure	12%
Lack of adequate transportation for consumers	11%
Lack of public awareness of ILC services	10%
Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits	10%
Size of service areas	6%
Staffing issues – inability to recruit due to shortage of qualified staff	4%
Lack of support from key agencies or other groups in the community	3%
Lack of cooperation from providers (e.g. schools, agencies, etc)	3%
Staffing issues – difficulty retaining staff	2%
Lack of board support	1%
Other	1%
Lack of interpretation services	1%
Staffing issues – lack of resources to train staff	0%
Low demand or interest from target population	0%
(Choice of up to five)	

Barriers to Providing Additional Services in the Same Location

The five leading barriers cited by ILC staff as roadblocks to providing new services beyond their existing range of services focus on the same themes of funding restrictions, transportation, infrastructure, and insufficient wages and benefits. ILC management suggest that the ability to increase the range of services their sites can offer is constrained by the inability to recruit qualified staff in an environment where their organization cannot compete with other employment opportunities, whether these be non-profit, for-profit, or public sector positions.

Lack of financial or other resources	23%
Funding limitations or restrictions	14%
Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits	11%
Lack of adequate transportation for consumers	10%
Lack of space or other infrastructure	8%
Lack of public awareness of ILC services	6%
Size of service areas	6%
Lack of support from key agencies or other groups in the community	6%
Lack of cooperation from providers (e.g. schools, agencies, etc)	5%
Staffing issues – inability to recruit due to shortage of qualified staff	3%
Other	3%
Staffing issues – difficulty retaining staff	1%
Staffing issues – lack of resources to train staff	1%
Lack of interpretation services	1%
Lack of board support	1%
Low demand or interest from target population	0%
(Choice of up to five)	

Barriers to Expanding Services Beyond the Current Service Area

When asked about possible barriers to providing services to consumers beyond their service area, ILC staff reported that they lacked sufficient financial or other resources, and for the funding they did have, it had limited application or was restricted in some way that did not permit them to use it for expanding service offerings beyond their target geographic location. Staff also noted that the size of their service areas is a barrier to expansion. This is particularly true for those already facing low-density, geographically large service territories, for which expanding would mean the need for even more resources than they currently depend upon.

Table 31: Barriers to providing services to consumers outside the current service area n=38	
Lack of financial or other resources	24%
Funding limitations or restrictions	17%
Lack of adequate transportation for consumers	15%
Lack of space or other infrastructure	10%
Size of service areas	9%
Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits	8%
Lack of public awareness of ILC services	6%
Staffing issues – inability to recruit due to shortage of qualified staff	4%
Other	3%
Lack of cooperation from providers (e.g. schools, agencies, etc)	1%
Staffing issues – lack of resources to train staff	1%
Lack of support from key agencies or other groups in the community	1%
Staffing issues – difficulty retaining staff	0%
Lack of interpretation services	0%
Low demand or interest from target population	0%
Lack of board support	0%
(Choice of up to five)	

CHAPTER VII: STRATEGIES AND SOLUTIONS TO REMEDY GAPS

Not surprisingly, given the stated barriers to service enhancement, additional funding was considered the greatest resource that could break down barriers to better provision of existing services, to expand new services, and to extend into new geographic areas. As one ILC staff member said, echoing comments provided in numerous other ILC survey responses: “It would enable us to hire additional staff to provide services to more people and retain the staff we have as they leave to take other jobs that pay better. It would allow us to rent space that better meets our needs...The space we currently occupy is overcrowded and does not provide adequate space to meet the needs of the people with disabilities we serve in our county. We would be able to hire additional staff for programs that are currently on hold where we are collaborating with other agencies because we do not have the funding to hire qualified staff members to provide those services.”

Resources Needed to Better Provide Existing Services

ILC staff could choose up to three resources from a list to suggest how the previously-cited barriers to providing existing services might be surmounted. As shown in Table 32, additional funding was the leading resource mentioned, followed by enhanced transportation and space. A well-designed and funded public relations plan and more assistance from local and state providers were also cited as important needed resources.

Additional Funding	31%
Transportation for consumers	16%
Additional space/Infrastructure	15%
A well-designed and funded public relations plan	12%
More assistance from local and state providers	9%
Training/Technical Assistance	6%
Political support	5%
Examples of model programs	3%
Grassroots support	3%
Other	1%
(Choice up to 3)	

Community stakeholders identified similar resources to be used to overcome the barriers to existing services: additional funding; transportation for consumers; and training/technical assistance. The emergence of training/technical assistance in the stakeholders list speaks to the potential for NYAIL to have an expanded convening role, based on what they are already doing, in providing support for on-site, remote, or peer training with staff on a wide range of topics including everything from billing to fundraising (see Chapter VIII for more detailed recommendations along this line).

Resources Needed to Expand Existing Services

The resources suggested to overcome the barriers to expanding existing services again include funding and transportation, but also include as the second-most-needed resource, the need for Centers to have a well-designed and funded public relations plan.

Additional Funding	33%
A well-designed and funded public relations plan	14%
Transportation for consumers	13%
Additional space/Infrastructure	11%
Examples of model programs	9%
More assistance from local and state providers	9%
Political support	6%
Training/Technical Assistance	3%
Grassroots support	3%
Other	0%
(Choice of up to three)	

One ILC, among many, desired to reach new populations not currently served, and to use innovative practices to do so, but that requires resources not currently available:

We would be able to greatly expand the transitional services we offer to students with disabilities. We have developed a Round T-Able program that provides transitioning students with self determination, self advocacy skills, information about their rights as a person with a disability, benefits advisement and other disability-related information. Unfortunately we have no funding stream to support this program and can offer it in only a limited number of schools. We would also be able to expand our efforts to assist individuals living in institutions who want to re-integrate into the community to do so. We have helped a handful of people with this but again, we have no funding stream supporting this effort.

– ILC Director in the eastern part of the state.

This same ILC suggested that it would like to go a step further and open a new office. According to their staff, they serve hundreds of persons in an adjacent county, but have no physical presence there. Finding ways to grow physical infrastructure was also a theme in the discussion on barriers.

Resources Needed to Provide Additional Services in the Same Location

Organizational infrastructure and physical space persists as a barrier to adding services. Accordingly, additional space and infrastructure are

among the top three resources needed to accommodate growth. Training and technical assistance also appears for the first time in the ILC ranking of the top three resources needed to support the addition of new services. Consistent with the expressed need for such technical assistance, several ILC staff also noted that examples of model programs would be helpful in the process of adding services.

Additional Funding	30%
Training/Technical Assistance	14%
Additional space/Infrastructure	12%
A well-designed and funded public relations plan	9%
More assistance from local and state providers	9%
Examples of model programs	8%
Transportation for consumers	8%
Political support	5%
Grassroots support	4%
Other	0%
(Choice of up to three)	

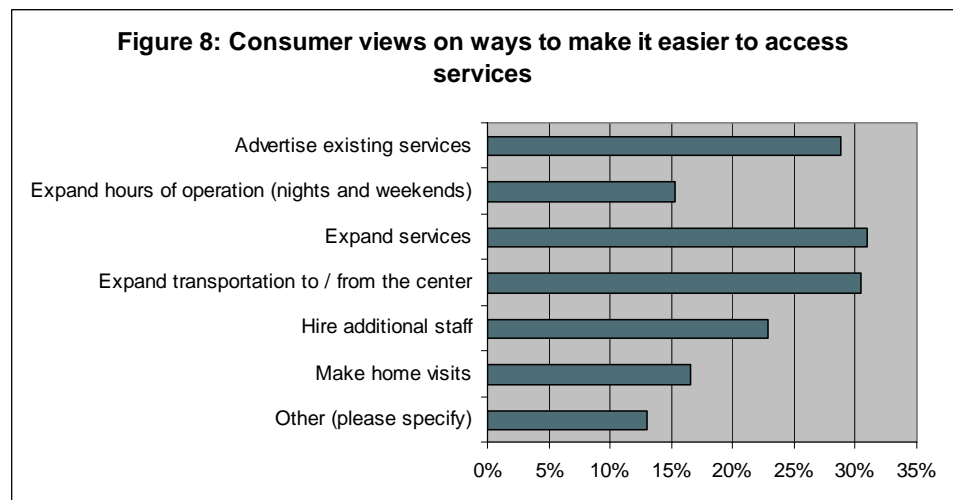
Resources Needed to Provide Services Outside the Current Service Area

Reaching persons with disabilities off-site by using staff travel is already an issue for many ILCs. “Our ILC has significant travel expenses. Additional revenue would allow our staff to travel to the far reaches of our county,” stated one ILC director. If this is true for many ILC current operations, it would be expected that the most common proposed resources to surmount the barriers to providing services to new areas would include additional transportation, as well as enhanced funding and space.

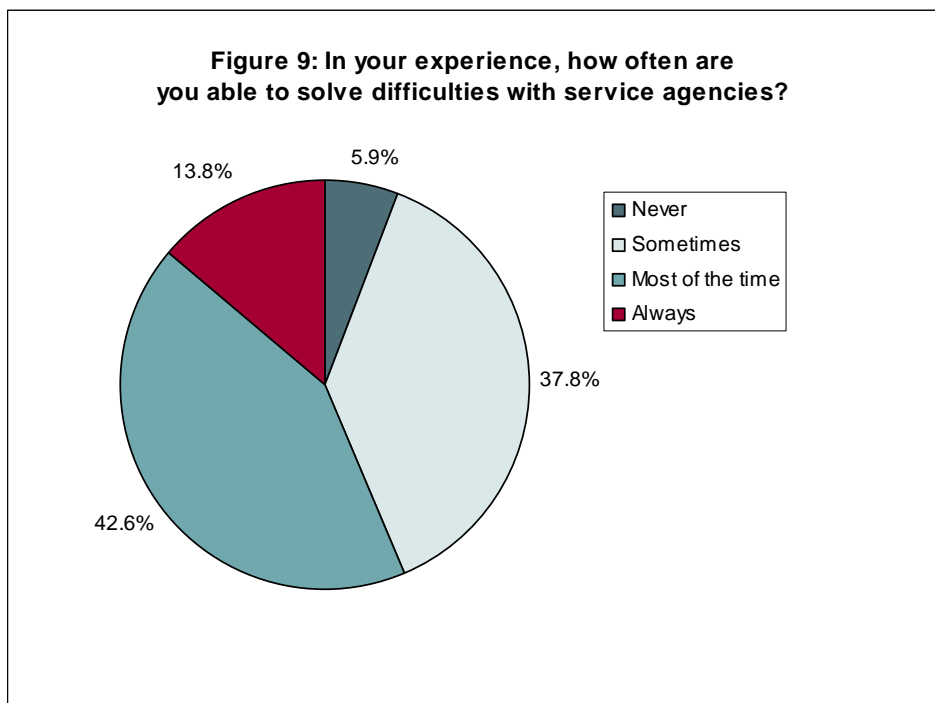
Additional Funding	36%
Additional space/Infrastructure	14%
Transportation for consumers	12%
A well-designed and funded public relations plan	9%
More assistance from local and state providers	9%
Grassroots support	7%
Political support	5%
Training/Technical Assistance	3%
Other	3%
Examples of model programs	2%
(Choice of up to three)	

Consumer Solutions to Unmet Needs

Consumers were asked about a range of ways they might address needs that are not being met and how they would solve difficulties they might encounter with agencies from which they receive services. As indicated in Figure 8, consumer respondents reported that the ILCs themselves could do more to increase access to services: 31% of the persons with disabilities who responded to the survey selected expanding services as a way to increase access; 30% suggested expanding transportation to/from the Center; and 29% thought advertising the existing services would increase access for persons with disabilities.

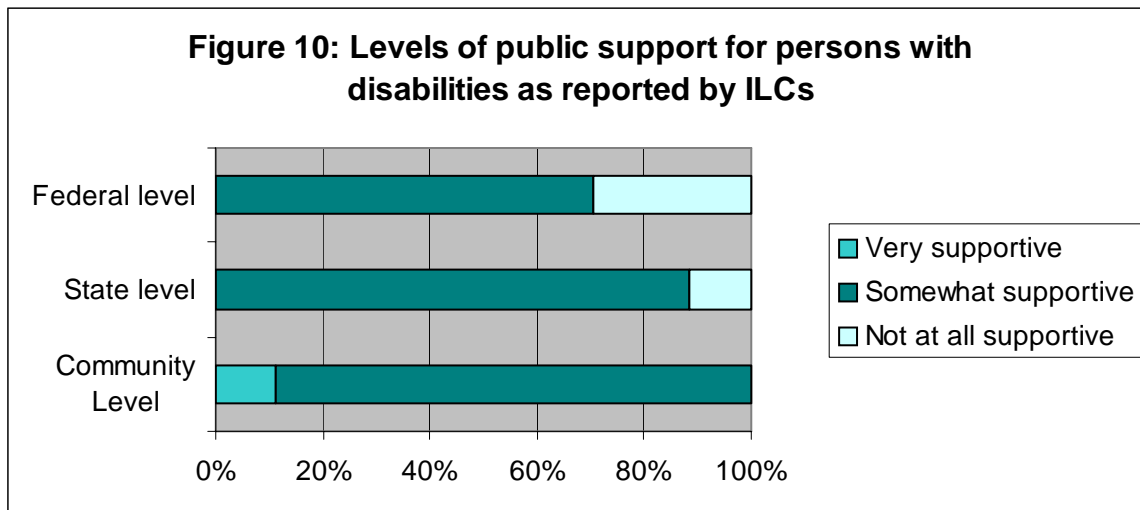


As indicated in Figure 9, more than half of the consumer respondents reported that they can solve difficulties with service agencies all or most of the time (total of 56%). Over a third said that they could do so sometimes. Nearly 6% said that they are never able to solve difficulties with service agencies. *This suggests that some level of consumer empowerment exists, but that there is potential to increase consumers' self-advocacy through training or other supports.*

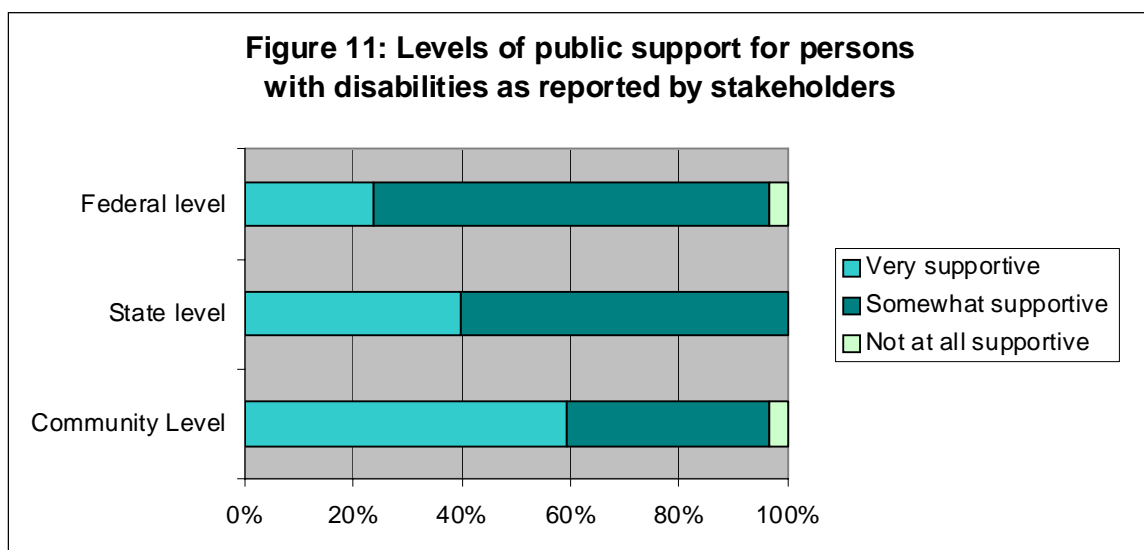


Public Support and Suggestions for Change

Collectively, staff at Independent Living Centers were much less optimistic than their public agency counterparts about the public levels of support for persons with disabilities. As indicated in Figure 10, only 12% of the responding ILCs perceive their local community to be very supportive, with the rest saying their communities are “somewhat supportive.” While relatively low, this was the only level of civic participation in which the ILCs felt there was any strong support, as they ranked both the state and federal levels as overwhelmingly moderate in their support, with some ILC suggestions that state and federal levels were “not at all supportive.”



As indicated in Figure 11, community stakeholders reported stronger degrees of confidence in the levels of perceived support from the local community, as well as from the state and federal governments. Together, *the ILC and stakeholder findings suggest the need for increased emphasis between Centers and community stakeholders on strengthened communications and dialogue concerning service availability and opportunities to work together.* Increased local/regional emphasis is needed on changing the systems that affect persons with disabilities, and creating more effective partnerships between Centers and local, state and federal stakeholders as ways of obtaining increased levels of ongoing financial support, referrals to ILCs, volunteer support, and additional resources needed to strengthen and expand services to persons with disabilities throughout the state.



Opportunity for Change at the Community Level

ILC staff reported that public awareness was the key to unlocking the changes needed at the local level. One person spoke of developing a “Disability Awareness Plan designed for all community levels (schools to employment).” Another suggested that the “Attitudes of people need to change to fully integrate people with disabilities into the community.”

Stakeholders surveyed for this study reported that local human service organizations were very supportive (59%) or somewhat supportive (37%) of persons with disabilities in their service areas. Their feedback was insightful. Their comments presented an outside perspective to the ILC philosophy and movement. For example, one stakeholder suggested that more should be done to build “awareness to mobilize support,” and suggested that “more resources and infrastructure” be allocated for “educational, vocational support, and transportation.”

Regional Variation in Community Change Recommendations

Another stakeholder described how in their region the needs differ based on density of the population. This person reported that the cities in the region were “well-served,” but that the “rural areas have no Independent Living support and the only adaptive technology is in some One-Stops.” Independent Living Centers in urban areas emphasized the need for collaboration. “More collaboration to tackle poverty issues (a new group has been formed to address this issue),” stated one ILC staff member. Another suggested that stakeholders could “build more collaboration between human service agencies and businesses to create more and better job opportunities and with it, create exposure of persons with disabilities to the larger community.” “Increased accessibility to public facilities” as well as “more funding for housing” and “housing set asides and priorities,” were also considered critical points of change by urban ILC staff.

Transportation Considered a Key Community Issue

Transportation was the most frequently mentioned community level change that should be pursued.

One stakeholder described the current landscape for ILCs:

Our Independence Center advocates successfully for persons with disabilities but is met with roadblocks. The lack of transportation

services evenings and 7 days/week, and the lack of dependable caregivers to provide the ADL supports through personal care and/or consumer directed home care programs prevents many disabled persons from leading a "normal" life, i.e., getting up and going to bed at the times they would if they had full control; going wherever they want whenever they want within reason. Financing is a big part of the problem but not all.

Other Considerations

For both the ILC staff and stakeholders, the next major category of comments focused on systems issues. For instance, stakeholders suggested that better coordination amongst advocates and those providing supportive services could improve the lives of persons with disabilities. As one ILC staff person remarked, “Create more connections between many disparate groups who have their own agendas assisting varying segments of the disabled populations. There needs to be more emphasis on joint efforts that can maximize potential to assist all disabled persons, not just those in specified categories.”

Like their ILC counterparts, community stakeholders also felt that community awareness of the needs of consumers was lacking. Several suggested that formal dialogue about these needs could be conducted at the community level and should include elected officials as well as the staff of human service organizations and public systems—ultimately leading to increased collaborative partnerships in their respective communities.

Finally, the other expressed systems area of concern was with regard to perceived liability issues associated with providing services to persons with disabilities. Whether this is a real or merely a perceived threat, the theme was consistent in the feedback received. Perhaps the awareness discussion could be coupled with an education session for providers on the risk management issues, or lack thereof, associated with providing services to persons with disabilities.

Opportunity for Change at the State Level

The relationship between agencies serving persons with disabilities and the New York State government is at the same time tenuous and dependent. ILCs rely on state agencies for funding and are often regulated by the corresponding source. Other oversight agencies also extend from the state to consumers.

In this study, most public agency stakeholders, some of whom represent state agencies, reported that they believe that New York State government is at least somewhat supportive of persons with disabilities (60%), and

40% said that the state was very supportive. None reported that the state was not all supportive. By contrast, as shown above in Figure 11, ILCs portrayed the state as only moderately supportive of persons with disabilities, with about 10% saying they were not at all supportive.

The narrative feedback revealed a focus on the need for additional funding for services from the state, but also an emphasis on many stages in the system that supports persons with disabilities, from the process of designating a person as disabled to the resource allocation to agencies to provide services. *ILC staff suggested the creation of a statewide “Office of Disabilities under which all disability-related services would be located.”* Funding for systems change and to provide more cost-effective services for persons to live more independently was the strongest consistent theme emanating from the narrative comments supplied by ILC staff.

Many stakeholders and ILC staff applauded the practice of using person-centered plans that promote self-determination. This practice, in which funds and resources are allocated to the individual, has gained traction across New York State, but stakeholders would like to see it implemented formally in a way that streamlines not only the allocation of resources, but also the regulatory oversight of service provision for persons with disabilities.

Regional Variation in State Change Recommendations

There was little regional variation in recommendations made regarding opportunities for change at the state level to improve the lives of persons with disabilities. More funding for affordable, accessible housing was mentioned more often by urban ILCs as was enforcement of accessibility regulations. In terms of transportation change at the state level, one ILC staff person suggested that a bill be passed to “force taxi companies to provide accessible taxis.”

Opportunity for Change at the Federal Level

Of the three levels discussed in the stakeholder survey, respondents had the least favorable view of the federal government’s role in supporting persons with disabilities. Only 24% of the stakeholders said the federal government was very supportive, with the largest grouping, 73%, saying they felt the federal government was somewhat supportive.

ILC staff were even more pessimistic about the lack of public support coming from the federal government. None said the federal government was very supportive, most said it was somewhat supportive, but about a third said it was not at all supportive. Some suggested that this was due to

partisan politics, while others felt that it was the implementation and regulation of existing legislation that needed improvement. For example, one ILC staffer stated, “The federal government has passed a plethora of laws aimed at improving conditions for people with disabilities (Rehab Act, ADA, HAVA, etc.)” The need for enforcing and strengthening the ADA was a clear focus of the ILC staff comments. Pursuing federal support for greater community integration of persons with disabilities was the strongest secondary theme that emerged.

ILC staff suggested the following policy measures be considered:

- “Continued push for community based living, support given to local housing authorities for housing subsidies.”
- “Better enforcement of laws that would prevent employers from discriminating against persons with disabilities. Funding programs that would enable employers to make their businesses more accessible.”
- “Funding for purchase and modification of accessible personal vehicles, based on disability and income. Provide entitlement, based on disability and income, to nonmedical personal assistance services.”
- “Funding for affordable accessible housing, ADA enforcement, universal health care.”
- “Ensuring compliance with human and civil rights, as well as ensuring the ADA is enforced.”

Regional Variation in Federal Change Recommendations

As in the state change recommendations, the only major variation between urban and non-urban ILC respondents to the change question was in the area of housing. Urban ILC staff specifically argued for “Support given to local housing authorities for housing subsidies,” and to “reinvigorate housing subsidies.”

NYAIL Network Perspective on Change and Action

Following the presentation of interim study findings in September 2008, CGR held a focus group of NYAIL Board members to elicit ideas in response to three of the most salient issues that emerged in the study. The focus group concluded with a discussion of how best to use the results of

the needs assessment to encourage solutions, move forward, and promote action.

Change Issue 1: Awareness of Services

The first issue brought to the group was how low levels of public awareness might affect their operation. This issue affects some ILCs more than others; some report having a strong presence, and significant leverage, in their counties. Others note that in the context of a system of services for persons with disabilities, ILCs may not be at the forefront; many feel that they are competing with other service providers or are not recognized as a critical part of the service system.

Branding

Focus group participants noted that something as fundamental as naming of ILCs may undermine the community's view and awareness of what an ILC is and what an ILC offers. On the one hand, the term "Independent Living" represents a unique philosophy representing an historic change in the way people with disabilities have been perceived and the focus of services available to them. However, for those not familiar with that history and philosophy, the meaning of "Independent Living Center" may not be immediately obvious.

One question that emerged in the focus group was related to the potential consequences of renaming Centers. Changing a Center's name could allow an ILC to capture its role in such a way that would clarify its purpose and mission for the general community. However, given the history and significance of the concept of independent living, this could also weaken the message that an ILC would wish to convey. The group did not reach consensus on the issue. It is recommended that the discussion be continued in the months to come, particularly as Centers consider where their core operations fit in the current fiscal climate.

Community and Consumer Education

Ideas for increasing awareness at the local level included using local media to communicate the message of ILC services and philosophy, and partnering with other organizations. One ILC whose administrator participated in the focus group has used public service announcements (PSAs) to increase awareness of available services in the community. *One suggestion that emerged was to create one PSA that could be customized and used by individual ILCs across the state. This would reduce cost and simplify media access.*

Another means of increasing awareness that emerged in the focus group was to *increase collaboration between ILCs and other service providers.* Focus group participants noted that many service providers are neither aware of ILCs nor familiar with the services they provide, though this

perception varied among ILCs represented in the group. Since ILCs do have a unique set of services, increasing awareness of these services can increase opportunities for collaboration and ultimately create a stronger system of services. Focus group participants mentioned connecting with regional and local agencies to communicate what ILCs do, and *demonstrate the potential value added to, for example, county agencies by the local presence of an ILC.*

Along with the unique philosophy and services offered by ILCs across the board, individual ILCs have characteristics that increase their leverage and their ability to add value to a local system of services. For example, one NYAIL Board member noted that the ILC she runs is the largest provider of Medicaid coordination services in the region served by the ILC. Bringing such information to light can further drive home the message that *ILCs are critical components of the system of services for people with disabilities, and key to the coordination of such services.*

Maximizing Awareness to Promote Policy

Participants noted that next steps for ILCs should include addressing how increased awareness may help ILCs promote favorable policies and increase their ability to advocate for themselves at local, state and federal levels. Their hope is that *increased awareness at the county level can translate to increased support for the ILC mission and ultimately strengthen their ability to advocate for additional funding and resources.*

Potential Downside to Increased Awareness

As focus group participants noted, increased awareness can have unexpected consequences, namely an increase in demand that ILCs may not be able to adequately meet with existing resources. Potential implications include greater numbers of persons requesting services, increased burden on staff to accommodate the requests, the utilization of waiting lists for those who do not currently use them, and the limitations of funding to meet the new demand. This is an issue that may not affect all sites, but it is one that will need to stay at the forefront as ILCs take collective action to increase the public's awareness of what is available.

Change Issue 2: Staffing Challenges

Staffing emerged as both a major strength and a weakness in the study. ILC staff were described as competent, compassionate, and reliable. However, certain staffing issues are major challenges for many ILCs. Turnover can be high, providing adequate compensation is a struggle, and recruitment can be difficult both due to a shortage of qualified individuals and due to the inability to offer competitive wage and benefits packages.

Funding

Funding is a clear obstacle to addressing staffing challenges and, as funding streams are limited, it is difficult to envision major changes in relation to these challenges. Some focus group participants noted that benefits packages are often strong, while wages tend to be less-than-competitive. At least one participant noted that their staff receives a wage boost if they opt out of insurance coverage. While participants emphasized that ILCs and NYAIL clearly need to focus on increasing funding streams, there may be other means through which they can address both recruitment and retention, specifically through emphasizing existing benefits of working for an ILC, as well as the community impact and the intrinsic fulfillment of working for a mission-based organization.

Increase Recruitment and Retention

Focus group participants noted that low wages, few opportunities for training and minimal career ladders can lead to a low level of employee engagement. ILCs should continue to seek low- or no-cost means to engage employees in their work and increase their sense of themselves as valuable to the organization and the community. Innovating around promotion opportunities internally, and also seeking opportunities externally, such as workforce development programs and trainings available through other agencies (e.g. OMRDD), may be ways to increase both recruitment and retention. Other options might be to advertise the benefits package as competitive and generous, thereby highlighting an existing perk.

CHAPTER VIII: CONCLUSIONS AND RECOMMENDATIONS

Independent Living Centers 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 over the years have indicated that ILCs have conservatively saved New York taxpayers at least \$9 in deinstitutionalization costs for every state dollar invested in ILCs and satellites throughout the state. A recent national study has confirmed similar cost savings for ILCs beyond NYS. And the numbers of people served by the Centers have increased substantially during this decade.

And yet, despite the demonstrated successes and accomplishments over the years of ILCs and their statewide association, the New York Association on Independent Living, these accomplishments and future

opportunities to build on these successes are currently threatened by the economic and budget crisis facing New York as this report is written. Even with the previous successes of the ILCs, there are currently significant gaps in services and underserved geographic areas which need to be addressed. These gaps existed and had not been fully addressed under more favorable circumstances. The ability to close those gaps and address apparent inequities in the allocation of resources across the system obviously becomes even more difficult under the growing fiscal crisis that will shape service-provision and funding decisions for years to come.

It is not an ideal time in which to release a needs assessment report aimed at looking to and preparing for the future. But 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 recommendations that follow are designed to provide guidance as ILCs look to their future.

Using the Needs Assessment for Action and Improvement

The final portion of the focus group session with NYAIL Board members on September 8, 2008 was devoted to addressing the ways that the needs assessment findings can help NYAIL and individual ILCs meet their goals and objectives and continue to fulfill their important mission throughout the state. Focus group participants felt that it is critical to create an overarching policy agenda that represents the needs of ILCs throughout the state and that an infrastructure is needed to capture ongoing needs, policy issues and advocacy agendas. NYAIL is a natural “home” for these issues and can use the findings of this study to further develop its policy agenda and both short-term and long-term advocacy priorities. Participants noted that such an advocacy agenda should focus 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.

Developing new and expanding existing funding streams, even in—especially in—difficult economic times, is a critical priority as well. *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.*

An issue that emerged throughout the discussion is the potential for ILCs to share knowledge, solutions, and innovations with each other. Promoting clear channels of communication across ILCs, potentially through NYAIL, will increase the possibility that one Center's successful approach can also be applicable to another. This "peer-to-peer" learning can benefit individual ILCs as well as alert NYAIL to issues that may be well suited for systemized procedures, policies or tools that NYAIL can create, advocate for, and distribute.

NYAIL Positioned to Advance Change

The New York Association on Independent Living offers consumers and stakeholders many opportunities to become involved with the independent living movement. Since its inception, the Association has hosted meetings, set policy agendas, advocated for change, and organized persons with disabilities to convene the skills, services, and supports needed to promote independent living across the state and in local communities. The findings from this 2008 needs assessment suggest that the Association has a strong grasp of the issues and needs facing its constituents.

Unfortunately, in today's tough economic times, the issue is not likely to be how much new money can be identified for additional or expanded programming, but what priorities must stay in next year's budget, and how they can be provided most efficiently and cost effectively. *To advance the goals of equality of opportunity, empowerment, self-determination, self-sufficiency and a client choice model, NYAIL and its partners must, first, identify those services that are most critical to daily living and, second, consider innovative solutions to retaining those services.*

The statewide network of Independent Living Centers has an opportunity in these challenging times to identify 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.*

In addition, *the ILCs should work together under the auspices of NYAIL to define new approaches to consistent data collection and management that can drive improved decision making and agenda setting; devise regional approaches to critical issue areas such as housing and transportation; and garner much needed public awareness for what is already available to the community.*

Develop Human Capital

Staff were cited as both one of the top three strengths of Independent Living Centers and also as one of the top three limitations. Staff received accolades for their compassion, investment in the independent living philosophy, their flexibility and energy, and their expertise in specific service areas. However, hiring, retaining, and promoting these staff can be especially challenging in tight fiscal times. This may be the time in which promoting the mission, ideology and cost-savings role of independent living has the greatest impact. Existing potential employees should be made fully aware of the history of ILCs, their successes and goals in order to understand where they fit in the mission. Internal recognition and celebration of successes can be a tangible way to improve employee morale and strengthen office rapport. Expanded training, professional development, and providing opportunities for ownership over projects are other ways that non-profits have successfully motivated employees.

Independent Living Center board members should be seen as another source of human capital that can be leveraged for the organization's mission. According to the survey, not all ILC board members are fully engaged or active in the operation of the agencies, nor are many of them consistently considered to be strong sources of fundraising income. This could be due in some part to the difference in preparation amongst members to take on the fiduciary and programmatic responsibilities expected of them. Basic governance training, development targets, advocacy opportunities and clear strategic planning activities can take the board of an organization from being passive attendants at monthly or quarterly meetings to actively participating voices for change. Board members should be educated on what is expected of them in the role, how much money they might be expected to contribute or raise, how often and how they should volunteer their time, where they might best invest their own unique talents (public relations, fundraising, media skills, facilities and maintenance, programming, etc.), and how their role in the organization advances the mission of independent living.

NYAIL is ideally situated to assist Independent Living Centers with staff and board development opportunities. The Association website could be host to various webinars, short seminars that are presented entirely online. This format could also make the material accessible to a wide range of constituencies who use assistive technology or who live in the far reaches of New York State. Topics such as grant writing, strategic planning, the policymaking process, budgeting and fiscal oversight, human resource policies, and national best practices in regional planning for transportation, housing, etc. could be valuable additions to the resources NYAIL currently offers, while yielding stronger organizational outcomes for the members.

A loaned executive program concept might even be the means to produce several of these trainings without a cost to NYAIL. The wide range of talented board members on Independent Living Centers across the state could likely provide trainers on any number of these specific topic areas. Peer training has demonstrated secondary impacts as well, such as increased trust amongst colleagues and new networks. This approach could be particularly valuable for the most rural Centers whose boards may have proportionately lower concentrations of highly trained professionals or access to regular training opportunities more likely to be available in larger urban areas. Universities and colleges are other sources of free or low-cost trainers who specialize in non-profit management and public policy topics.

NYAIL has a history of providing technical assistance and training to Independent Living Centers through in-person and web-based training events for staff and board members, and through on-going individual Center technical assistance via telephone and email. These efforts have been directed primarily at smaller ILCs with budgets of under \$1 million and have focused on strategic planning, impact evaluation, board development, and diversification of funding sources. Technical assistance has been directly available through NYAIL staff and via the nationally-known consulting firm of Richard Male & Associates, as well as through peer mentoring by ILC executive directors. NYAIL has indicated that it expects to continue these efforts in the coming two years, including continued collaboration with Richard Male & Associates. NYAIL anticipates building on previous technical assistance activities to help smaller ILCs respond to challenging times by developing strategic partnerships and positioning their organizations to take advantage of new opportunities, while adjusting to potential state budget cuts resulting from the fiscal downturn.

Leverage Networks and Community Relationships

Many Independent Living Centers referenced their agencies' local presence in the community and relationships to decision makers as a source of strength to the organization. These networks and community connections should be strategically leveraged to promote not only the concept of independent living, but also to address operational issues, achieve desired policy reform, and to garner additional funding for services.

Over 92% of Independent Living Centers said they collaborate in some way with other human service agencies in their area. These networks offer a potential foundation for grant applications, access to a broader range of

talent, and the opportunity to creatively address some of ILC consumers' most pressing needs. For example:

- The need for increased transportation and other approaches to expand access to services was a consistent theme across the needs assessment. What if local agencies collectively determined a more comprehensive regional approach to providing improved transportation in outlying areas?
- What if various stakeholders collectively determined the foremost gaps in services to persons with disabilities (e.g., rural, immigrants, seniors, racial/ethnic minorities), and collectively decided to use their resources and human capital to target such populations? A bilingual outreach worker, for example, could be shared by several agencies that provide different services, but all trying to reach the same population.
- Or, one site with available space/infrastructure, yet limited human resources, might host a satellite location for an Independent Living Center with a grant for a program staff member who had been located on the other side of the county.

NYAIL and its member ILCs and satellites should follow the leveraging and partnership suggestions offered in a recent national evaluation of Independent Living Centers throughout the country. The summary report from that evaluation emphasizes the strong investment and payback to the community represented by such Centers, and the strong value of partnerships between Centers and all levels of government:

Centers for Independent Living have developed services to support individuals with disabilities to remain independent and live in integrated community settings. These services are essential for both individual goals and government requirements. CIL services are good investments for the health and well being of individuals and for current and future cost savings for government. Government decision makers should look for additional ways to utilize existing services and seek new ways to support a partnership with these valuable community-based organizations.¹⁵

Utilize the Power of Coalition Advocacy

NYAIL has achieved what many other advocacy groups could only hope to achieve, a strong base of support driven by years of corresponding

¹⁵ Rutgers Center for State Health Policy, op. cit., p. 21

results. This base will need to be cultivated even more as the resources that flow through the Association may be constricted by funding cutbacks. It is clear from Governor Paterson's September 8th address to the NYAIL conference that it was the united front that impressed him most about the groups' desire to maintain and strengthen funding for persons with disabilities in the state budget. *This united voice comprised of persons with a range of disabilities as well as family members, friends and other stakeholders, can continue to garner the attention of state leaders if the voice stays unified in its message that Independent Living Centers reduce rates of institutionalization, save money, represent a more equitable approach to disability services, and represent a non-partisan policy position.*

The concept of a unified NYS Office on Disability has been broached with the Governor, and is an example of a targeted initiative that NYAIL and its members should pursue to help ensure focused statewide attention on issues affecting people with disabilities.

Service Gaps and Inequities Needing Attention

As emphasized in this report, there are clearly significant gaps in services affecting people with disabilities. Among those needing attention:

- 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. Clearly, across-the-board, "one approach fits all" approaches are not appropriate in determining what each area needs the most.
- State and local officials must give focused attention to the fact that 17 counties have no ILCs or satellite offices to provide locally-based services to residents with disabilities. People with disabilities in some counties clearly have fewer opportunities for access to services than is true in the majority of counties in the state. The Finger Lakes and Southern Tier regions are particularly underserved.
- Given the sheer volume of numbers of residents with disabilities living in the New York City and Long Island regions, very small proportions of people with disabilities are able to be served by the ILC facilities in those regions.

- 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 expenditures per facility and 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. 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 vulnerable and underserved subsets of the population of persons with disabilities. In addition, as the population ages, seniors with disabilities will be increasingly in need of expanded services.

ILCs need to consider how they can seek new sources of funds from various local resources, to supplement state and national funding sources, to expand services where possible to best address these needs. And, where additional resources are not forthcoming, and where even existing resources are threatened, they must be aware 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.

The Power of Collaboration and Sharing of Resources

Consumers, ILC staff, and stakeholders have reached several points of consensus across the needs assessment. They agree that transportation and/or other forms of increasing accessibility to Center services must be addressed if consumers are to receive the services they need to live more independently. Expanding employment opportunities and securing adequate sources of income for consumers is also critical. An effective way to address both policy objectives would be to situate them in the context of the larger shift toward deinstitutionalized and increased community-based care. Rather than emphasizing what has not yet been achieved, the Association might lead with the message that transportation to and from services is more cost effective than providing comprehensive on-site care. Moreover, research suggests that employment has a strong rehabilitative and social component that benefits consumers. Transportation is also needed to get consumers to and from jobs, workshops, and training services.

Emphasizing collaborative measures to addressing the dual needs of employment and transportation (and/or other combinations of issues) could demonstrate to policy makers and elected officials that the organizations that comprise NYAIL are not merely voicing their opinions to advance their own personal, individual or agency agendas. Rather, the ILCs are prepared to work together and with other organizations, even if that means sharing resources or leveraging networks, to achieve the best possible result for their target population. Strategically situating the annual NYAIL policy agenda with the self-interest of the policymakers in mind, in this case to balance the budget, may go a long way to achieving the objectives desired.