



2012 NYSILC Needs Assessment Report

2012 NYSILC Needs Assessment Report

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Acknowledgements

The NYS Independent Living Council (NYSILC) would like to express its appreciation for the dedicated group that formed the Needs Assessment Committee (NAC). The NAC members spent six months wrestling with what questions to ask to identify the critical needs in New York for Independent Living (IL). They reviewed reports, searched for helpful data, and responded to numerous email questions. A full list of NAC members can be found in Appendix I.

NYSILC would also like to thank the California SILC and the NY Association for Independent Living (NYAIL) for their excellent needs assessments. Their respective studies in 2010 and 2008 helped to shape this assessment.

Introduction

The New York State Independent Living Council (NYSILC) is a not-for-profit, non-governmental, consumer controlled state council. It is composed of 24 appointees from around the state, a majority of whom have disabilities. They represent diverse backgrounds and needs across the state. NYSILC is responsible for the development, implementation and monitoring of the three-year Statewide Plan for Independent Living (SPIL). The council is jointly responsible for the SPIL with its state plan partners: New York State Education Department/Office of Adult Continuing and Career Educational Services - Vocational Rehabilitation (ACCES-VR), and the Office of Children and Family Services/Commission for the Blind and Visually Handicapped (CBVH).

Independent Living means controlling and directing your own life, taking risks, and being allowed to succeed and fail on your own terms. Statewide Independent Living Councils (SILCs), established under Title VII of the Rehabilitation Act of 1973, as amended, provide support to the Statewide IL network of 39 centers (plus satellite locations) in addition to their primary SPIL duties. Some specific examples include, but are not limited to: conducting surveys and reports, promoting media awareness about IL and disability related issues, young adult leadership training sponsorships, general support of technical assistance and training, and direction around disability policy issues (voting access, emergency preparedness, outreach to underserved populations).

NYSILC conducts a public input process as part of the development of the three-year State Plan for Independent Living (SPIL). It is guided by a formulation packet with a facilitation outline posing critical questions designed to solicit feedback from the public at various venues.

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To improve the SPIL formulation, NYSILC decided to conduct a needs assessment to help focus on the critical questions. NYSILC hired Alan Krieger, a consultant with Krieger Solutions LLC, to facilitate this process, and established a committee of Council members and stakeholders to lead the process. (See Appendix I for list of the Needs Assessment Committee (NAC) members). Alan Krieger has extensive experience working with non-profit and public sector agencies. He is a former executive director of a statewide organization and is also working with NYSILC to strengthen its evaluation process for the three year state plan. For more information about Alan Krieger, visit his website, www.KriegerSolutions.com.

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Executive Summary of Findings

This needs assessment was designed to collect input on four research questions to help guide the development of the next three-year State Plan for Independent Living (SPIL). The key findings for each question are outlined below. A more complete discussion follows in the main body of this report.

1) Based on what we know (existing data), the following needs were identified:

- There are a high number of veterans with disabilities in New York (232,805) with a high incidence of disability (25.1%) compared to the general population and people with disabilities (11%).
- The poverty rate for New Yorkers with disabilities ages 18-64 is 28.6% - more than twice the rate for persons without disabilities in the State.
- The employment rate for New Yorkers with disabilities ages 18-64 is 31.2% - a 40.8% gap compared to persons without disabilities in the State.
- When types of disabilities among New Yorkers are compared to employment and poverty rates, people with mental health disabilities have low employment (25.3%) and high poverty (35.7%) rates.

2) Utilizing an analysis of penetration rates and inundation indexes, and their relative rankings, the top ten counties with the greatest need for Independent Living (IL) services:

- Livingston
- Bronx
- Queens
- New York
- Suffolk
- Wyoming
- Kings
- Yates
- Orleans
- Ontario.

3) The following information was revealed related to underserved populations:

- In a comparison of center service and ACS/Census data on a percentage basis, the IL network needs to improve its outreach and ability to serve Hispanic/Latinos and Asians with disabilities.
- In addition, the center survey asked what groups were underserved. The top six identified were:
 - Male veterans with disabilities
 - Female veterans with disabilities
 - Rural residents with disabilities
 - Homeless individuals with disabilities
 - Young adults with disabilities
 - Immigrants with disabilities.

It should be mentioned that some of these underserved target populations have been identified going into their second consecutive State Plan. As a result, they should be prioritized. They include: veterans with disabilities, Hispanics and Asians with disabilities, homeless individuals with disabilities, and young adults with disabilities.

The institutionalized population in New York State was extremely difficult to identify. The effort to do so was documented. The following is recommended:

- The IL center network should make an effort to utilize the data to plan local strategies and target impact to transition as many of the 220,277 individuals to the “most integrated setting” per Olmstead.
- Direct system change to make all state agencies post institutionalized data publically like OMH for better planning and tracking of the institutional bias.

4) Based on a survey with almost 600 respondents, consumers identified the following as their most challenging issues:

- Finances/paying bills
- Transportation
- Employment.

When asked what services they need most to live independently, the following were identified:

- Transportation
- Advocacy
- Medical/health issues.

5) Based on a survey of Center directors, with more than two-thirds of the network responding, centers indicated that the following were barriers to expanding or starting new services:

- Lack of financial services
- Lack of transportation to consumers
- Additional space/infrastructure
- Increased awareness about ILC.

Consumers responded when asked what could be done to make it easier for them to access services at their local center:

- Improved transportation
- Increased outreach:
 - Home visits
 - Increase advertising related to center services
 - Closer satellite facilities
 - Increased on-line resources.

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Purpose of the Needs Assessment Study

As part of the formulation of the three-year State Plan for Independent Living (SPIL), NYSILC conducts a public input process for the plan development. This process includes development of a packet with a facilitation outline posing critical questions designed to solicit feedback from the public, at various venues and through written comments.

This needs assessment study was undertaken to improve the SPIL formulation in time for the start of the process toward the development of the 2014-2016 three-year state plan. NYSILC established a committee of Council members to lead this process. (See Appendix I for list of the Needs Assessment Committee (NAC) members).

The committee conducted a review of other statewide needs assessments, including one conducted in 2008 by NY Association for Independent Living (NYAIL) and one conducted by the California SILC entitled: Needs Assessment for People with Disabilities. The committee recommended that NYSILC focus its needs assessment on the four questions that formed the basis of the California SILC's approach (including their analysis of "penetration rates" and "inundation indexes"). The committee also recommended adapting some of the questions from the NYAIL survey to do a four-year comparison on these questions.

The four research questions on which NYSILC decided to focus the needs assessment were:

1. What geographic areas are most in need of IL services?
2. What unserved/underserved ethnic, minority and disability communities are most in need of IL services?
3. What are the most important unmet service needs for New Yorkers with disabilities who live, or wish to live, independently?
4. What are the most important needs that the SILC should address to strengthen New York's independent living network?

Methodology:

The Needs Assessment Committee then reviewed available data to see if some of these questions could be answered. Research questions 1 and 2 were able to be substantially answered by accessing and analyzing existing data, and it was determined that questions 3 and 4 needed to have additional data developed through two surveys – one of consumers and one of Independent Living Center directors. The surveys drew from questions in the 2008 NYAIL survey and while focusing on NYSILC’s research questions 3 and 4 above, it also included a few items relating to the other two research questions.

It should be pointed out that no known public data on the number of people with disabilities who are in institutional settings previously existed within the State. This is the first attempt recognized by the network to capture data about the State’s institutionalized population in any meaningful way. Only the NYS Office of Mental Health maintains their related data publically, online, with the information updated to indicate shifts in the population as people transition in and out of settings. This should be the standard to which all other State agencies are held. Otherwise, NYSILC had to engage in an aggressive effort to FOIA the other State agencies to obtain the necessary data. Specific attempts are mentioned in footnotes of Table 1.5A. NYSILC believes that this information represents a solid start on which to base estimates and planning. However, given the State’s reluctance to release its own information in a public way, there are some issues. The institutionalized population figure could be improved through increased cooperation with State agencies, helping to identify all institutional settings and data sources by county.

The **consumer survey** was an electronic survey for consumers to complete from their home computer via an on-line link, or on a computer in an Independent Living Center. A text based/paper survey was also made available if the on-line survey was not accessible, and many consumers used this option. NYSILC sent information about how to access the survey to all the Independent Living Centers in New York, and to a number of advocacy and service organizations that serve people with disabilities. 578 consumers responded to the survey and their responses are summarized in the report that follows. Many of these consumers are already involved with Independent Living Centers (ILC). Others heard about this from associated stakeholders or advocates and were unfamiliar with ILCs. A demographic breakdown of these consumers is also provided in the report. To increase responses, we provided an incentive – entry in a drawing for a \$50 gift card.

The **Center survey** was also an on-line survey with a text based/paper option available if the on-line version was not accessible. More than two-thirds of all Independent Living Centers in the state responded (34 out of 50 locations). Their responses are also summarized in the report that follows.

Appendix V (page 34) contains a full copy of the Consumer and Center survey questions.

Background Data about New Yorkers with a Disability

A large number of statistical documents were reviewed to try to assemble a picture of what it means to be a New Yorker with a disability. According to the 2011 Annual Disability Statistics Compendium¹ compiled by the RRTC on Disability Statistics & Demographics, here is what we found:

- **Total population:** There are over 2 million New Yorkers with disabilities living in the community out of a total of more than 19 million residents (11%). This does not account for institutionalized individuals or active military personnel.
- **Veterans:** There are 928,961 civilian veterans age 18 or older living in the community in New York State, and 232,805 (25.1%) of these individuals have a disability - a high incidence of disability compared to the general population.
- **Poverty rate:** The rate for New Yorkers with disabilities ages 18 to 64 living in the community is 28.6%, which is more than twice that of persons in our state without disabilities (12.3%).
- **Employment:** The employment rate for a New Yorker with a disability (ages 18-64) is 31.2% compared to 72% for a person without a disability resulting in a gap of 40.8 percentage points. Full-time, year-round employment for a New Yorker with a disability (ages 18-64) is 18.7% compared to 52.2% for a person without a disability creating a gap of 33.5 percentage points.
- **Income:** Among civilians age 16 or older during the last 12 months, New Yorkers with disabilities earned \$10,903 less on average compared to a person without a disability (\$21,581 versus \$32,484).
- **Education:** For students with disabilities ages 14-21 during the last 12 months, it was reported that they left New York State schools for the following reasons: 52% (15,937) graduated with diplomas, 21% (6,277) received certificates, 26% (7,788) dropped out, and 1% (390) died or aged out.
- **Health:** 89.7% of New Yorkers with disabilities have health insurance coverage (as a result of 59.4% receiving public health care coverage and 30.3% private health care coverage), resulting in 10.3% New Yorkers with disabilities lacking insurance. For New Yorkers with disabilities age 18 or older, 34.3% are considered obese compared to 21.1% for a person without a disability.

This can be compared with findings from the New York State Disability and Employment Status Report 2009 for the New York Makes Work Pay project. The lead for the report was the

¹ 2011 Annual Disability Statistics Compendium, Rehabilitation Research and Training Center (RRTC) on Disability Statistics and Demographics, www.DisabilityCompendium.org, November 2011. Source is the U.S. Census Bureau, 2010 American Community Survey, and American FactFinder.

Employment and Disability Institute at Cornell University². Here are some highlights from that report:

- Employment rates for people with disabilities by race/ethnicity: African Americans/Blacks have the lowest employment rate at 26.4% followed by Hispanics/Latinos at 28.2% (31.2% overall average employment rate for people with disabilities).
- When types of disability are compared to employment and poverty rates, people with mental health disabilities have low employment (25.3%) and high poverty (35.7%) rates (see Table 2.3 for more information).
- Educational attainment (highest level) for New Yorkers with disabilities: 26% have a less than a high school degree and 16% have a bachelor's degree or higher, compared with people without disabilities where 11% have less than a high school degree and 36% have a bachelor's degree or higher.

This data provides a summary of what we knew statewide. We found additional data that filters some of this by ethnicity and types of disabilities to help identify sub-populations most in need of services (see pages 11-12).

What the figures didn't show was:

- *How* this information varies by county and region
- *What* the greatest needs are for services
- *Where* the greatest needs are for services
- *What* the Council can do to strengthen the Independent Living (IL) network to address these gaps

With this information as a back drop and with our four core questions in mind, we conducted a needs assessment study to find out more about issues related to independent living facing people with disabilities in New York State.

² NYS Disability and Employment Status Report 2009 for NY Makes Work Pay, Employment and Disability Institute, Cornell University, www.edi.cornell.edu, 2009. Source is primarily the three-year estimates (2005-2007) from the U.S. Census Bureau, American Community Survey, and non-institutionalized working-age population between 16-64.

Findings

Question # 1: What geographic areas are most in need of Independent Living services?

Summary:

The data that was reviewed was organized by each county in the state and includes:

- The number of consumers currently served by IL Centers
- The total number of people with disabilities in the civilian population
- The total number of people with disabilities who are in institutional settings

Based on the data analysis explained below, the ten counties with the greatest need for Independent Living services are:

| | | |
|---------------|-------------|--|
| 1. Livingston | 6. Wyoming | These are a mix of rural, urban and suburban counties. The charts below are based on existing data we were able to access. Table 1.1 is a summary of the data, with the remaining tables highlighting key elements of the data. Table 1.7 shows how we reached our conclusion of the ten counties most in need of IL services. |
| 2. Bronx | 7. Kings | |
| 3. Queens | 8. Yates | |
| 4. New York | 9. Orleans | |
| 5. Suffolk | 10. Ontario | |

Comments from both surveys (Independent Living Center directors and consumers) stated that the needs were greatest in rural areas of each county. There were also several comments from urban counties indicating that minority and low income urban areas in those counties were also underserved. The consumer survey didn't have much variation between rural, urban and suburban respondents in terms of what were their most important needs (see question #3).

Table 1.1 below shows the data we used to analyze relative need for services in each of New York's 62 counties. Numbers in bold indicate the 10 greatest needs in each column.

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Table 1.1 Service Needs by County (Top Ten Counties for Each Column Highlighted in Bold)

| NYS County | (A) ³ CSRs Served by IL Network FY 2010-2011 | (B) ⁴ # Incidence of Disability/ County | (A)/(B) Penetration Rate | (C) ⁵ Total # Institutionalized/ County | (C)/(A) Inundation Index |
|-------------|--|---|--------------------------------|---|--------------------------------|
| Albany | 760 | 34,197 | 2.22% | 3,686 | 4.85 |
| Allegany | 165 | 6,855 | 2.41% | 425 | 2.58 |
| Bronx | 308 | 183,928 | 0.17% | 17,250 | 56.01 |
| Broome | 877 | 28,507 | 3.08% | 2,663 | 3.04 |
| Cattaraugus | 649 | 11,518 | 5.63% | 1,046 | 1.61 |
| Cayuga | 543 | 9,486 | 5.72% | 1,317 | 2.43 |
| Chautauqua | 430 | 19,412 | 2.22% | 2,185 | 5.08 |
| Chemung | 264 | 12,714 | 2.08% | 2,347 | 8.89 |
| Chenango | 256 | 8,383 | 3.05% | 730 | 2.85 |
| Clinton | 116 | 11,076 | 1.05% | 1,804 | 15.55 |
| Columbia | 161 | 7,486 | 2.15% | 1,044 | 6.48 |
| Cortland | 198 | 5,399 | 3.67% | 528 | 2.67 |
| Delaware | 231 | 7,525 | 3.07% | 604 | 2.61 |
| Dutchess | 588 | 35,270 | 1.67% | 5,390 | 9.17 |
| Erie | 1,992 | 115,455 | 1.73% | 11,507 | 5.78 |
| Essex | 41 | 5,238 | 0.78% | 718 | 17.51 |
| Franklin | 160 | 6,101 | 2.62% | 1,734 | 10.84 |
| Fulton | 187 | 8,314 | 2.25% | 1,030 | 5.51 |
| Genesee | 291 | 7,844 | 3.71% | 662 | 2.27 |
| Greene | 96 | 5,737 | 1.67% | 1,215 | 12.66 |
| Hamilton | 10 | 701 ⁶ | 1.43% | 76 | 7.60 |
| Herkimer | 608 | 8,859 | 6.86% | 759 | 1.25 |
| Jefferson | 834 | 14,708 | 5.67% | 1,381 | 1.66 |
| Kings | 706 | 244,165 | 0.29% | 19,121 | 27.08 |
| Lewis | 163 | 3,525 | 4.62% | 249 | 1.53 |
| Livingston | 16 | 7,107 | 0.23% | 1,221 | 76.31 |
| Madison | 242 | 7,329 | 3.30% | 579 | 2.39 |
| Monroe | 1,721 | 89,275 | 1.93% | 9,051 | 5.26 |
| Montgomery | 496 | 8,144 | 6.09% | 986 | 1.99 |
| Nassau | 976 | 114,837 | 0.85% | 14,437 | 14.79 |
| New York | 381 | 157,488 | 0.24% | 14,774 | 38.78 |
| Niagara | 578 | 28,810 | 2.01% | 2,286 | 3.96 |
| Oneida | 2,221 | 34,114 | 6.51% | 5,986 | 2.70 |
| Onondaga | 1,253 | 52,720 | 2.38% | 4,765 | 3.80 |
| Ontario | 69 | 12,863 | 0.54% | 1,097 | 15.90 |

³ Based on ACCES VR data, yearend statewide totals, FY 2010-2011, Statistical Report. Plus 704 Report data for CDR and Tri-Lakes centers.

⁴ US Census Bureau, American FactFinder, Disability Characteristics (S1810), 2008-2010 American Community Survey 3-Year Estimates, New York State by County. Assistance locating the data was provided by the Employment and Disability Institute at Cornell University.

⁵ Based on last column of Table 1.5A Total # Institutionalized Population by County.

⁶ There were no figures given the ACS-census data for the incidence of disability in Hamilton and Schuyler counties. The figures used above were derived from taking the average rate of disability in the 60 available counties (13.04%), multiplied by the total population of the individual county.

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| NYS County | (A) ³ CSRs Served by IL Network FY 2010-2011 | (B) ⁴ # Incidence of Disability/ County | (A)/(B) Penetration Rate | (C) ⁵ Total # Institutionalized/ County | (C)/(A) Inundation Index |
|--------------|--|---|--------------------------------|---|--------------------------------|
| Orange | 815 | 41,385 | 1.97% | 3,351 | 4.11 |
| Orleans | 33 | 5,402 | 0.61% | 967 | 29.30 |
| Oswego | 790 | 15,843 | 4.99% | 835 | 1.06 |
| Otsego | 261 | 8,719 | 2.99% | 765 | 2.93 |
| Putnam | 238 | 8,637 | 2.76% | 711 | 2.99 |
| Queens | 473 | 209,722 | 0.23% | 20,285 | 42.89 |
| Rensselaer | 354 | 20,251 | 1.75% | 1,968 | 5.56 |
| Richmond | 894 | 45,649 | 1.96% | 5,582 | 6.24 |
| Rockland | 441 | 24,335 | 1.81% | 4,312 | 9.78 |
| Saratoga | 579 | 20,813 | 2.78% | 1,702 | 2.94 |
| Schenectady | 264 | 17,636 | 1.50% | 1,859 | 7.04 |
| Schoharie | 65 | 4,964 | 1.31% | 159 | 2.45 |
| Schuyler | 101 | 2,440 ⁷ | 4.14% | 309 | 3.06 |
| Seneca | 55 | 4,847 | 1.13% | 1,031 | 18.75 |
| St. Lawrence | 272 | 16,629 | 1.64% | 2,372 | 8.72 |
| Steuben | 445 | 14,869 | 2.99% | 1,070 | 2.40 |
| Suffolk | 356 | 129,856 | 0.27% | 15,481 | 43.49 |
| Sullivan | 194 | 11,515 | 1.68% | 1,816 | 9.36 |
| Tioga | 105 | 6,456 | 1.63% | 366 | 3.49 |
| Tompkins | 246 | 9,467 | 2.60% | 811 | 3.30 |
| Ulster | 572 | 23,952 | 2.39% | 3,048 | 5.33 |
| Warren | 524 | 8,025 | 6.53% | 740 | 1.41 |
| Washington | 344 | 7,061 | 4.87% | 1,477 | 4.29 |
| Wayne | 103 | 12,036 | 0.86% | 1,087 | 10.55 |
| Westchester | 821 | 81,330 | 1.01% | 11,650 | 14.19 |
| Wyoming | 25 | 4,768 | 0.52% | 1,531 | 61.24 |
| Yates | 11 | 2,897 | 0.38% | 339 | 30.82 |
| TOTALS | 27,968 | 2,074,594 ⁸ | 1.4% | 220,277 | 7.88 |

The first column of table 1.1 is an alphabetical listing of all 62 counties in New York State. The second column (column “A”) looks at the Independent Living (IL) network service data by county for Fiscal Year 2010-2011. It shows the number of Consumer Service Records (CSR’s) active in each county, which is an indication of the total number of consumers served on an on-going basis by the Independent Living Centers in New York. It does not include consumers who only received information and referral services and for whom a CSR was not started. The ten counties with the lowest number of CSR’s have been identified from this column and highlighted in bold. These ten counties have been ranked according to lowest numbers served in Table 1.2 below.

⁷ There were no figures given the ACS-census data for the incidence of disability in Hamilton and Schuyler counties. The figures used above were derived from taking the average rate of disability in the 60 available counties (13.04%), multiplied by the total population of the individual county.

⁸ Total ACS survey sample was adjusted to accommodate estimates for Hamilton and Schuyler Counties and include the “with a disability” estimates for the other counties.

Table 1.2 Most Underserved Counties in NYS Served by IL Network Based on CSRs

| NYS County | # of CSR's FY 2010-2011 ⁹ |
|------------|---|
| Hamilton | 10 |
| Yates | 11 |
| Livingston | 16 |
| Wyoming | 25 |
| Orleans | 33 |
| Essex | 41 |
| Seneca | 55 |
| Schoharie | 65 |
| Ontario | 69 |
| Greene | 96 |

These counties are generally the smallest counties in the state by population, so it is not surprising that they would serve the fewest consumers. This is presented for general information purposes and was not used to calculate counties with the greatest need.

The third column of table 1.1 (column “B”) indicates the total number of people with disabilities in each county (civilian population). The ten highest are displayed in descending order in the table below.

Table 1.3 Highest Incidence of Disability by County

| NYS County | Incidence of Disability |
|--------------------|-------------------------|
| Kings | 244,165 |
| Queens | 209,722 |
| Bronx | 183,928 |
| New York | 157,488 |
| Suffolk | 129,856 |
| Erie | 115,455 |
| Nassau | 114,837 |
| Monroe | 89,275 |
| Westchester | 81,330 |
| Onondaga | 52,720 |

The ten counties with the highest numbers have been highlighted in bold. In Table 1.3, they are ranked according to the largest populations. Again, it is not surprising that these are among the largest counties in the state by population. This data is also presented for general information purposes and was not included in calculations to identify counties with the greatest need.

In the fourth column of table 1.1, is an attempt at weighting these differences. The number of people served by the network in each county (column A) is divided by the total population of people with disabilities in that county (column B) to obtain a “penetration rate” for each county (A/B). (This is based on the California model.)

The penetration rate represents the percent of the people with disabilities in a county who are currently served, compared to the potential of the full number of people with disabilities in a county. While this is not intended to show the number of people who are not receiving needed services (some people with disabilities are currently able to live independently and don’t need additional services, while others are receiving services from other providers), it is designed to

⁹ Based on ACCES VR data, yearend statewide totals, FY 2010-2011, Statistical Report.

show a relative ranking of which counties seem to be providing Independent Living services to the largest and smallest percentage of their populations of people with disabilities.

The ten counties which have extremely low penetration rates are highlighted in bold and are displayed in table 1.4 below.

Table 1.4 Lowest Penetration Rates by County

| NYS County | Penetration Rates |
|------------|-------------------|
| Bronx | 0.17% |
| Livingston | 0.23% |
| Queens | 0.23% |
| New York | 0.24% |
| Suffolk | 0.27% |
| Kings | 0.29% |
| Yates | 0.38% |
| Wyoming | 0.52% |
| Ontario | 0.54% |
| Orleans | 0.61% |

This analysis helped us sort among a wide range of situations (urban/rural, large/small disability populations). It identifies a relative degree of providing services to a specific population.

The fifth column of table 1.1 (column “C”) shows the total institutionalized population of people with disabilities by county. This is a summary – for more detailed data see Table 1.5A in Appendix II page 25). Table 1.5A shows the institutionalized population broken down by the type of institutions. This data did not previously exist in one place and while this is a good summary, it is not fully complete. Some individuals may return to other counties upon release from the institution. It is also likely that the data does not identify all institutionalized people with disabilities in New York State. However, we believe the chart captures most individuals and is enough to provide a general relative ranking among the counties. This data is taken from the last column of Table 1.5A Total Institutionalized Population by County (page 25).

Table 1.5 Highest Institutionalized Populations by County of People with Disabilities in NYS

| NYS County | Highest Institutionalized Population PWD |
|-------------|--|
| Queens | 20,285 |
| Kings | 19,121 |
| Bronx | 17,250 |
| Suffolk | 15,481 |
| New York | 14,774 |
| Nassau | 14,437 |
| Westchester | 11,650 |
| Erie | 11,507 |
| Monroe | 9,051 |
| Oneida | 5,986 |

This data was organized to show the potential for needed services if de-institutionalization efforts had full success. The ten counties with highest institutionalized populations have been highlighted in bold and are shown in rank order in Table 1.5 starting with the highest population. Again, these are among the largest counties in the state by population. This data is for general information and was not included in calculations to identify counties with the greatest need.

This institutionalization data was further analyzed to try to determine which counties had the greatest relative need. In the sixth column of Table 1.1 (C/A), the institutionalized population from column C is divided by the number of people currently served by the network in each county (column A). The result is considered the potential “inundation index” for each county should there be a large de-institutionalization effort. (This is also based on the California model.) The ten counties with the highest Inundation Indices are shown in Table 1.6 below.

Table 1.6 Highest Inundation Indices in NYS by County

| NYS County | Inundation Indices |
|------------|--------------------|
| Livingston | 76.31 |
| Wyoming | 61.24 |
| Bronx | 56.01 |
| Suffolk | 43.49 |
| Queens | 42.89 |
| New York | 38.78 |
| Yates | 30.82 |
| Orleans | 29.30 |
| Kings | 27.08 |
| Seneca | 18.75 |

This shows the proportion of people in a county who are institutionalized in relation to the number of people with CSRs in that county. Counties with extremely high inundation indices are most at risk for having their local independent living services overwhelmed if there was a large exodus from local institutions. The ten highest inundation indices are marked in bold and are ranked starting with the highest number in Table 1.6.

Finally, Table 1.7 identifies the ten counties with the greatest need for additional services based on an analysis combining their proportional relative rankings of penetration and inundation rates. The data with the full details is shown in Table 1.7 A (see Appendix II, page 28).

Table 1.7 – What geographic areas are most in need of additional IL services?

| Rating is combination of ranking for (penetration rate + inundation rate) | |
|---|-----------------|
| NYS County | Combined Rating |
| Livingston | 87.1% |
| Bronx | 86.7% |
| Queens | 65.2% |
| New York | 60.0% |
| Suffolk | 59.0% |
| Wyoming | 56.1% |
| Kings | 46.7% |
| Yates | 42.2% |
| Orleans | 32.9% |
| Ontario | 26.0% |

A relative ranking analysis was utilized for each of the 62 counties based on their penetration and inundation rates. Their relative ranking was based on the ratio of each county’s rates compared to the rate of the county with the highest rated need (lowest penetration rate and highest inundation index). These two proportions (percentages) were averaged, and the highest average equaled the highest rate of need for services.

From this assessment, the ten counties with the greatest need for additional services (starting with the highest need) were: Livingston, Bronx, Queens, New York, Suffolk, Wyoming, Kings, Yates, Orleans, and Ontario.

Question # 2: What unserved / underserved ethnic, minority and disability communities are most in need of IL services?

Center directors were asked to indicate which of 21 different target populations they thought were underserved or hard to reach. The two most underserved disability communities were male and female veterans. The third was rural residents. (See Table 2.4 below for details.)

Tables 2.1 and 2.2 below compare how ethnic and disability groups are served by IL centers in proportion to their representation in the overall disabled population. Table 2.3 shows employment and poverty rates in New York State by type of disability. It was difficult to find data that is organized consistently by category, so the comparisons are not precise. The data shows that the groups that are underrepresented in consumers served by IL centers include Hispanics, Asians, and people with sensory disabilities. Persons with visual disabilities may more often seek services from other providers, or it could represent an increased need by deaf and or deaf/blind community. This data on its own does not necessarily mean that any one category is being underserved. It just raises the question.

Table 2.1 compares how various ethnic groups are served by IL centers in proportion to their representation in the overall disabled population. Most groups are served close to their representation overall, except for Asians, Hispanics and people with disabilities reporting two or more races, who are significantly underrepresented.

Table 2.1 Ethnic Groups served in the IL network compared to overall disability population in NYS

| Column A Race/Ethnicity Category | Column B IL Network Service Data By Race/Ethnicity FY 2010-2011 ¹⁰ | Column C NYS Disability Characteristics: Rates By Race/Ethnicity ¹¹ | Column D Variance (-/+) | Column E Relative comparison of percentages in Columns B & C |
|--|---|---|-------------------------------|--|
| American Indian/ Alaska Native | 429 (2%) | 11,596 (<1%) | +2% | 200% |
| Asian (Includes Pacific Islander) | 314 (1%) | 80,921(3%) | -2% | 33% |
| Black or African American | 4,529 (16%) | 352,277 (15%) | +1% | 106% |
| Hispanic/Latino | 2,131 (8%) | 337,289 (14%) | -6% | 57% |
| White | 18,626 (66%) | 1,437,908 (60%) | +6% | 110% |
| Two or more races | 364 (1%) | 47,845 (2%) | -1% | 50% |
| Other/Unknown | 1,667 (6%) | 143,372 (6%) | 0% | 100% |
| Total | 28,060 (100%) | 2,411,208 (100%) | | |

¹⁰ Based on ACCES VR data, yearend statewide totals, FY 2010-2011, Statistical Report; contains some duplicate counts.

¹¹ Based on US Census Bureau, American FactFinder, Disability Characteristics (S1810), 2008-2010 American Community Survey 3-Year Estimates, New York State by County. Assistance locating the data was provided by the Employment and Disability Institute at Cornell University.

Table 2.2 Types of disability served in the IL network compared to overall disability population in New York State

| Type of Disability | IL Network Service Data By Type of Disability FY 2010-2011 ¹² | Adjusted data to exclude mental health disability and multiple disabilities** | NYS Statewide Disability Type ¹³ | Percentage Variance Adjusted Data (-/+) |
|-----------------------|--|---|---|---|
| Physical | 27,938 (34%) | 27,938 (58%) | 1,161,163 (42%) | 16% |
| Sensory | 5,897 (7%) | 5,897 (12%) | 881,399 (32%) ¹⁴ | -20% |
| Mental | 19,335 (24%) | 0** | ** | - |
| Cognitive | 14,723 (18%) | 14,723 (30%) | 753,734 (27%) | 3% |
| Multiple Disabilities | 13,358 (17%) | 0** | ** | - |
| Total | 81,251 (100%) | 48,558 (100%) | 2,796,296 (100%) | |

** The data set the general statewide data did not include mental health disabilities or multiple disabilities, so the comparisons are not accurate. However, when those categories are excluded from the first set of data, there is more of an “apples to apples” comparison.

Note: numbers in table 2.3 include duplicate counts.

Table 2.3¹⁵ Statewide Employment and Poverty Rates by Type of Disability

| Type of Disability | Employment Rate | Poverty Rate |
|--------------------|-----------------|--------------|
| Physical | 28.9% | 28.9% |
| Sensory | 43.2% | 25.5% |
| Mental | 25.3% | 35.7% |

This table shows that the employment rate is highest for those with sensory disabilities and lowest for people with mental health disabilities. Likewise, poverty rates are highest for those with mental health disabilities and lowest for those with sensory disabilities. Data for people with cognitive or multiple disabilities was not available.

¹² Based on ACCES VR data, yearend statewide totals, FY 2010-2011, Statistical Report.

¹³ Based on US Census Bureau, American FactFinder, Disability Characteristics (S1810), 2008-2010 American Community Survey 3-Year Estimates, New York State by County.

¹⁴ Combination of hearing and visual disability types.

¹⁵ NYS Disability and Employment Status Report 2009, Employment and Disability Institute, Cornell University, 2009.

On the Center directors’ survey respondents were asked to rate a list of population groups that are most underserved or most difficult to reach. Table 2.4 shows the number of respondents who selected each of the population groups.

Table 2.4 Groups of people with disabilities that are most underserved or hard to reach. (Sorted by highest response first) (From Center Directors Survey - 30 out of 34 survey individuals responded to this question.)

| Answer Options | Response Percent | Response Count |
|---|------------------|----------------|
| Male Veterans | 60.0% | 18 |
| Female Veterans | 56.7% | 17 |
| Rural Residents | 40.0% | 12 |
| Homeless | 33.3% | 10 |
| Children / Young adults | 30.0% | 9 |
| Immigrant groups / Non-native English speakers | 30.0% | 9 |
| Seniors | 23.3% | 7 |
| Hispanic | 23.3% | 7 |
| Deaf | 23.3% | 7 |
| Deaf / Blind | 23.3% | 7 |
| Blind | 20.0% | 6 |
| Multi-ethnic | 16.7% | 5 |
| LGBT | 16.7% | 5 |
| Mental / emotional disabilities | 16.7% | 5 |
| Dual diagnosis - intellectual / mental health | 16.7% | 5 |
| Dual diagnosis - mental health / chemical abuse | 16.7% | 5 |
| Black non-Hispanic | 13.3% | 4 |
| American Indian | 10.0% | 3 |
| Asian/Pacific Islander | 10.0% | 3 |
| Physical disabilities | 10.0% | 3 |
| Cognitive disabilities | 10.0% | 3 |

Those selecting “immigrant groups/non-native English speakers” were asked to specify which groups in a comment box. The only two immigrant populations that were noted were West African and Middle Eastern. One comment mentioned the need for resources for the homeless, and another for minority populations. One comment identified the middle class as hard to reach thinking they don’t need services and are surprised to find out the IL system can be helpful.

Question #3: *What are the most important unmet service needs for New Yorkers with disabilities who live, or wish to live, independently?*

This issue was examined through several questions on both the center director and consumer surveys. Consumers were asked about the greatest challenges they face and about which services are most important to help them live independently. Center directors were asked directly to rate which consumer needs were met well, met adequately, or not well met.

Consumers indicated that their greatest challenges were:

1. finances (paying bills)
2. transportation
3. employment.

None of these received more than 47% of the responses, so no single challenge was universally felt. Approximately 20% of respondents added a comment to this question. Many related to the three highest rated challenges and a sizable number also referenced the challenge of finding appropriate helpers in the home, such as “*Securing reliable and friendly people to come into my home and provide support as needed.*” Other comments related to greater acceptance of people with disabilities. “*...More education to become familiar with all disabilities both physical and mental.*”

When this data was filtered by whether consumers lived in rural, urban or suburban settings, the responses were very similar. The top three issues for each were:

| Rural | Urban | Suburban |
|--|-------------------------|-------------------------|
| Finances (paying bills) | Employment | Transportation |
| Transportation | Finances (paying bills) | Finances (paying bills) |
| Social (needing support from family and friends) | Transportation | Employment |

Social (needing support from family and friends) was number four for suburban respondents and number five for urban. Employment was number seven for rural respondents. (For a full display of the responses, for each item in this question, sorted by rural, urban and suburban, see Table 3.1 page 32.)

Center directors were asked to rate how well specific needs for people with disabilities were being met in their community overall. The two needs ranking lowest in being well met in their community echoed the consumers’ highest rated challenges: employment opportunities and adequate income. Tied for third at the bottom in the center survey were affordable housing and integrated housing (these were combined into one category and rated sixth lowest on the consumer survey).

Consumers were asked which services were most important to help them live independently. Again, no single issue received more than 50% of the consumer responses. Transportation was

the highest rated, followed by advocacy and medical / health services. Transportation scored highly as both a challenge and a critical service, so this seems to be an important area to focus on. The results were again fairly consistent when this data was filtered by whether consumers lived in rural, urban or suburban settings.

| Rural | Urban | Suburban |
|---------------------------|--------------------------------|---------------------------|
| Transportation | Advocacy | Transportation |
| Medical / health services | Transportation | Advocacy |
| Advocacy | Benefits assistance and advice | Medical / health services |

Medical / health services were number four for consumers who were urban respondents, and benefits assistance was five for both rural and suburban consumers. For a full display of the responses for each item in this question sorted by rural, urban and suburban, see Table 3.2 page 33.

Consumers were also asked what services were most readily available and which were not available in their area. The most readily available services were: advocacy, medical / health services and information and referral to other services. Advocacy and medical / health services were also cited as among the top three most important services, so it is especially good that a large number of consumers feel these are readily available.

Consumers were also asked to rate those services that were not available in their area and these all had much lower responses, indicating that overall, services are more available than not. The three least available services were: recreation services, housing services, and peer counseling. However, approximately the same number of consumers said these services *were* readily available, so the data doesn't point strongly to any one service that needs to be expanded. Also, none of the low rated services were ranked as the most important services or the most challenging issues, so while they are important issues, only a small minority finds them unavailable *and* important.

Interestingly, transportation, which was one of the choices, was not rated strongly as unavailable. However, one-third of consumers' comments related to the inadequacy or absence of transportation services. In cases where transportation is severely lacking, consumers feel it strongly. One consumer indicated that there are lots of services available, but transportation is needed to get to them: *"There is a DESPERATE NEED for paratransit. There are services but NO WAY to get to them."* Another spoke of the unreliability of transportation services: *"Though transportation is somewhat available, the bus system is horrible and it is very hard to attend events, college/vocational training, and especially hold a job while being considered reliable."* Another comment focused on the need for more long distance transportation: *"Transportation is available within the community. I have many appointments outside my local community and it is very difficult to find transportation to these appointments."*

Consumers were asked if they have any other comments about the services that help them live independently. There were 135 comments and the largest number (23, or 17%) were positive statements about the services they currently receive:

- *Access VR and Search for Change are helping me*
- *So far, I have been exceptionally fortunate in finding services and support*
- *My local Independent Living Center and case manager are excellent*
- *The staff is well trained and concerned about creating barriers inadvertently*
- *I just appreciate the help.*

There were a few negative comments as well:

- *In the 25 years I've lived here, all the existing services have been a great disappointment. Most the time, I do better by going it alone & not counting on anyone's help (which always falls short of the need)!*
- *There should be independent oversight of agencies, and real consequences when administrators misbehave.*

In addition, there were 10 comments for each of the following needs: transportation, housing and expanded services.

Several consumers commented on their appreciation for NYSILC conducting this survey:

"Thank you for this survey."

Question #4: What are the most important needs that the SILC should address to strengthen New York's independent living network?

The Center survey addressed this question by asking center directors about barriers they faced in delivering existing services and in expanding or starting new services.

Not surprisingly, the major barriers to current, expanded or new services were lack of financial resources and the restrictions that were part of current funding. The other high ranking barrier was lack of transportation for consumers. This lined up with a major need identified by consumers.

When Center directors were asked which services they wanted to initiate or expand to better address needs in their area, the top rated ones were: architectural barrier services, benefits advisement, advocacy/legal services and vocational services. This lines up well with many of the consumers' highest rated needs. (This summary reflects the data for new and expanded services in combination. Overall, there was less interest in starting new services than in expanding existing services.)

When asked to respond to a list of resources that would be needed to overcome these barriers, center directors reported that additional funding was number one for existing services, expansion and starting new services. Additional space/infrastructure was also cited as a needed resource for all three. Transportation for consumers was ranked high as an important resource for overcoming barriers to existing services; but for expanding or starting new services, more assistance from local and state providers was the third highest rated. This might reflect the need for advice, technical assistance or new networks that are needed to start or expand services.

Center directors were also asked what services are no longer needed. None of the services listed received more than 3 votes out of 34.

Another question looked at how to strengthen the services network to better reach unserved/underserved groups. Nearly two-thirds of center directors cited the need for more outreach. This lines up well with consumer feedback on the need for increased outreach. A few center directors cited more funding for staff and programs, and several cited opening satellite offices. One expressed the need for advice and training.

In the consumer survey, consumers were also asked questions related to strengthening the services network. One question asked consumers: What would make it easiest for you to access services at your local Independent Living Center (ILC)?

Transportation was the highest rated selection which lines up with findings from both consumers and center directors as to this being a critical barrier to service. The next two highest rated suggestions both related to increasing outreach, which again parallels the findings from the Center survey. These two selections were home visits and for centers to advertise existing

services. There were a large number of consumer comments (217) on this question and many of the comments also reflected these top choices. Comments related to outreach were the most common (45 comments) and transportation was second (31 comments).

The majority of the outreach related comments asked for increased home visits, closer satellite facilities, increased on-line information, and advertising to inform them about the availability of services and events. They include recommendations as to how to get the word out: *“Mail out information packets for new services as they become available.” “Tell what services they offer; create email updates; put articles in journal news services; have seminars and advertise.”* Outreach comments also meant literally getting out of the center to reach out: *“Be ready and willing and able to go out in the field.” “Come to my house.”*

Many of the comments asked if there was a center in their area and/or indicated they didn't know enough about ILC's to comment. *“I don't even know where there is one in my area.”*

There were a number of comments indicating satisfaction with current services and access: *“I'm satisfied with the services I receive at this time.” “The help we DO get is TERRIFIC.”* Other comments indicated a need for increased staff and services and faster response times: *“The current services they offer are limited and not individualized.” “More one on one and more added timed with your counselors.” “More immediate response to request for services.”*

To broaden the focus, consumers were also asked where else they go to receive services or support that helps them live independently. Counseling or therapy was the highest rated response, at 43%. Half of those who selected this reported having a mental health disability and the other half reported a range of other disabilities. The second highest other services was internet resources and social services was third. Internet resources reflect the comments from the prior question regarding a desire for more on-line information and access.

And finally, consumers were asked how often they were able to resolve problems they might have with service agencies. Nearly two-thirds said they always, or most of the time, are able to resolve problems or that this was not applicable, meaning they did not generally have problems with service agencies. Only 8% said they could never resolve problems, and 30% said they were only sometimes able to resolve problems.

Comparison with results from NYAIL needs assessment 2008.

NYAIL results and comments are in bold italic font.

Overall, the results from the NYSILC and NYAIL surveys were fairly consistent.

Table 2.4 From Center Directors Survey: Groups of people with disabilities that are underserved or hard to reach. (Sorted by highest response first on NYSILC survey)

| Answer Options | Response Percent | NYAIL |
|---|-------------------------|--------------|
| Male Veterans | 60.0% | <i>n/a</i> |
| Female Veterans | 56.7% | <i>n/a</i> |
| Rural Residents | 40.0% | 24% |
| Homeless | 33.3% | <i>n/a</i> |
| Children / Young adults | 30.0% | 13% |
| Immigrant groups / Non-native English speakers | 30.0% | 24% |
| Seniors | 23.3% | 13% |
| Hispanic | 23.3% | * |
| Deaf | 23.3% | <i>n/a</i> |
| Deaf / Blind | 23.3% | <i>n/a</i> |
| Blind | 20.0% | <i>n/a</i> |
| Multi-ethnic | 16.7% | <i>n/a</i> |
| LGBT | 16.7% | <i>n/a</i> |
| Mental / emotional disabilities | 16.7% | <i>n/a</i> |
| Dual diagnosis - intellectual / mental health | 16.7% | <i>n/a</i> |
| Dual diagnosis - mental health / chemical abuse | 16.7% | <i>n/a</i> |
| Black non-Hispanic | 13.3% | * |
| American Indian | 10.0% | * |
| Asian/Pacific Islander | 10.0% | * |
| Physical disabilities | 10.0% | <i>n/a</i> |
| Cognitive disabilities | 10.0% | <i>n/a</i> |

* ***Combined Into one category: racial/ethnic minorities – 18%***

n/a: Note: the NYAIL survey had fewer categories and those marked “n/a” were not listed on the NYAIL survey. The deaf population was most frequently cited in the “other” category on the NYAIL survey

Consumers were asked what their greatest challenges were:

1. finances (paying bills) (*NYAIL: same*)
2. transportation (*NYAIL: same*)
3. employment (*NYAIL: was fourth behind medical/health coverage*)

Center directors were asked to rate how specific needs for people with disabilities were being met in their community overall. The two needs that were least well met were: employment opportunities (*NYAIL: 2*) and adequate income (*NYAIL: 1*). Tied for third at the bottom were affordable housing (*NYAIL: 3*) and integrated housing.

Consumers were asked to rate which services were most important to help them live independently. Transportation was the highest rated (*NYAIL: transportation and mobility services*), followed by advocacy (*NYAIL: 3rd*) and medical / health services (*NYAIL: 6th*) (*NYAIL: Benefits assistance and advice was second.*)

Consumers were also asked to rate services that were not available in their area. The three most unavailable services were: recreation services (*NYAIL: 6*), housing services (*NYAIL: 4*), and peer counseling (*NYAIL: 8*), (*NYAIL: Transportation was number one, medical services 2, and employment services 3.*)

Center directors were asked what barriers they faced in delivering existing services and in expanding or starting new services. The major barriers to current, expanded or new services were lack of financial resources (*NYAIL: 1*) and the restrictions that were part of current funding (*NYAIL: 2*). The other high ranking barrier was lack of transportation for consumers (*NYAIL: 2 – tied*).

When asked to respond to a list of resources that would be needed to overcome these barriers, center directors reported that additional funding was number one for existing services, expansion and starting new services (*NYAIL was the same for all three*). Additional space/infrastructure was also cited as a needed resource (*NYAIL: 3, 4, 3 respectively for existing, expanding, starting new*). Transportation for consumers was ranked highly as an important resource for overcoming barriers to existing services (*NYAIL: 2*); but for expanding or starting new services, more assistance from local and state providers was the third highest rated (*NYAIL: 6, 5 respectively*). *In second place on the NYAIL survey for expanding new services was a public relations plan and for starting new services was training/technical assistance.*

When asked how to strengthen the services network to better reach unserved/underserved groups, nearly two-thirds of center directors cited the need for more outreach (*NYAIL: similar*)

In the consumer survey, consumers were asked what would make it easiest for them to access services at their local Independent Living Center (ILC). Transportation was the highest rated selection (*NYAIL: 2*). The next two highest rated suggestions were home visits (*NYAIL: 5*) and for centers to advertise existing services (*NYAIL: 3*). *On the NYAIL survey, expanding services was number 1.*

Consumers were also asked how often they were able to resolve problems they might have with service agencies. Sixty-two percent (**56%**) said they always, or most of the time, are able to resolve problems, or that this was not applicable, meaning they did not generally have problems with service agencies. Only 8% (**6%**) said they could never resolve problems, and 30% (**37%**) said they were only sometimes able to resolve problems.

Conclusions and Recommendations

Based on the data collected and analyzed, NYSILC has identified a number of priority areas for resources and services. These findings will be combined with other input collected through the SPIL planning process to guide the emphasis for the next three year plan.

The following are the recommendations that come from this needs assessment:

1) Increase resources for the following geographic areas most in need of IL services:

- Livingston
- Bronx
- Queens
- New York
- Suffolk
- Wyoming
- Kings
- Yates
- Orleans
- Ontario.

2) Increase resources for the following most underserved populations most in need of IL services:

- Male veterans with disabilities
- Female veterans with disabilities
- Rural residents with disabilities
- Homeless individuals with disabilities
- Young adults with disabilities
- Immigrants with disabilities
- Hispanic/Latinos and Asians with disabilities
- Institutionalized individuals with disabilities.

For a few of these underserved groups, this is the second consecutive SPIL cycle that they have been identified. As a result, their persistent need has to be recognized:

- Veterans with disabilities
- Homeless individuals with disabilities
- Young adults with disabilities
- Hispanic/Latinos and Asians with disabilities.

- 3) Direct increased resources to the following most important service needs of New Yorkers with disabilities:
- Finances/paying bills
 - Transportation
 - Employment
 - Advocacy
 - Medical/health issues
 - Poverty.
- 4) The most important resources to strengthen the IL center network:
- Additional financial resources
 - Transportation for consumers
 - Additional space/infrastructure
 - Increased awareness about ILCs.
- 5) An effort should be made to better identify and help more of the disabled institutionalized population in New York State transition to Independent Living. The following is recommended:
- The IL center network should plan local strategies to transition as many of the 220,277 individuals to the “most integrated setting” per Olmstead.
 - Undertake efforts to direct system change to make all state agencies post institutionalized data publically as NYS OMH currently does for better planning and for tracking of institutional bias.

Appendices

The following pages include:

- Appendix I: a list of the Needs Assessment Committee members.
- Appendix II: tables and charts with additional statistical data that relates to the tables for questions 1 and 2 above.
- Appendix III: tables and charts from the Consumer survey that provides a respondent profile.
- Appendix IV: tables and charts from the Center and Consumer surveys that provide additional data for some of the questions.
- Appendix V: copies of the two surveys used in the study.

Appendix I: List of the NYSILC Needs Assessment Committee (NAC) members

Council Members:

- Chair, Denise Figueroa, NYSILC, ILCHV, dfigueroa@ilchv.org.
- Melanie Shaw, NYSILC, NYAIL, mshaw@ilny.org.
- Chad Underwood, NYSILC, ATI Cortland, cwunderwood@aticortland.org.
- Carla Lewis-Irizarry, NYSILC, Carlalewis34@gmail.com.
- Susan Ruff, NYSILC, STIC, advocate@stic-cil.org.
- Julie Cardone, NYSILC, CBVH, Julie.cardone@ocfs.state.ny.us.

Non-Council Members:

- Joe Bravo, jbravo@wilc.org.
- Doug Usiak, Former NYSILC Chair, WNYIL, djusiak@buffalo.edu.
- Fred Ayers, ACCES-VR, fayers@mail.nysed.gov.
- Brad Williams, NYSILC Executive Director, bradw@nysilc.org.
- Alan Krieger, Krieger Solutions, Consultant, alan@kriegersolutions.com.

Appendix II: Tables and charts with additional statistical data that relates to the tables for questions 1 and 2 above

Table 1.5A: State Institutionalized Population by County

| NYS County | DOH Nursing Home ¹⁶ | DOH Assisted Living ¹⁷ | OPWDD Developmental Center ¹⁸ | OPWDD All Other Group Home Care ¹⁹ | OMH Psychiatric Or RTF ²⁰ | OMH All Other Community Care ²¹ | Correctional Facilities ²² <i>(Represents 31% of the total number)²³</i> | Total Institutionalized Population²⁴ <i>(Top Ten Counties Highlighted in Bold)</i> |
|-------------|--------------------------------|-----------------------------------|--|---|--------------------------------------|--|---|---|
| Albany | 1,789 | 73 | | 733 | 261 | 830 | | 3,686 |
| Allegany | 304 | 2 | | 75 | 3 | 41 | | 425 |
| Bronx | 11,217 | 542 ²⁵ | | 1,779 | 976 | 2,736 | | 17,250 |
| Broome | 1,439 | 77 | 183 | 374 | 173 | 417 | | 2,663 |
| Cattaraugus | 527 | 27 | | 348 | 32 | 112 | | 1,046 |
| Cayuga | 558 | 71 | | 158 | 63 | 142 | 325 | 1,317 |
| Chautauqua | 1,006 | 212 | | 431 | 46 | 222 | 268 | 2,185 |
| Chemung | 708 | 14 | | 239 | 149 | 405 | 832 | 2,347 |
| Chenango | 520 | 2 | 47 | 102 | 22 | 37 | | 730 |
| Clinton | 440 | 21 | | 161 | 54 | 126 | 1,002 | 1,804 |
| Columbia | 630 | 17 | | 218 | 24 | 37 | 118 | 1,044 |
| Cortland | 364 | 1 | | 122 | 8 | 33 | | 528 |
| Delaware | 324 | 6 | 116 | 130 | 2 | 26 | | 604 |

¹⁶ This data was not available to the public. It was requested from the state agency and refused. Data obtained by formal FOIA request to NYS DOH. "Number of residents in Nursing Homes by County and Ownership." It includes columns for State/County/Municipal nursing homes and Private nursing homes.

¹⁷ This data was not available to the public. It was requested from the state agency and refused. Data obtained by formal FOIA request to NYS DOH. "NYS Medicaid Recipients in Assistant Living Programs By County of Fiscal Responsibility, Calendar Year, 2011" (Claims as of April 2012).

¹⁸ This data was not available to the public. It was requested from the state agency that has the primary authority NYS OPWDD and refused. It was further explained that such data would have to be obtained through a FOIA request to NYS DOH. The request was made and the data was obtained for only developmental centers, "Number of Clients by County in NYS Development Center as of 1/1/2012."

¹⁹ This data was not available to the public. Several requests were made by NYSILC by staff, a council member, and a consultant to the NYS OPWDD Commissioner's Office for the information. Eventually the request was honored by early July 2012, providing the breakdown of individuals living in all other OPWDD residential group home care settings by county (excluding developmental centers) as of March 2012.

²⁰ This data was obtained via NYS OMH website at the following link, <http://bi.omh.ny.gov/pcs/Summary%20Reports?pageeval=prog-re>. It consists of the following categories: Psychiatric Centers and Residential Treatment Facilities (RTF's).

²¹ This data was obtained via NYS OMH website at the following link, <http://bi.omh.ny.gov/pcs/Summary%20Reports?pageeval=prog-re>. It consists of the following categories: Private Residences (which includes unlicensed supported housing, independent living and living with family), Licensed MH Housing, Adult Care, Foster Care, Youth-Community Based, Homeless, Youth Institution-Residential Treatment Center, Youth Institution-Juvenile Justice Facility, Nursing Home, Incarcerated, Inpatient or Residential Treatment Facility, and Other.

²² This data was not available to the public. It was requested from the state agency and refused. It was explained that a FOIA request needed to be sent to the State Commission of Correction. The Office of Counsel responded back to the FOIA request that they had "no such documents responsive to the request." Outraged, NYSILC staff looked up state legislators with corrections committee assignments and found a local Assembly member. They were informed of the situation and provided with the documentation. The Assembly member's office investigated the situation and came up with the data that previously "didn't exist," NYS Department of Corrections and Community Supervision Daily Population Capacity Report (6/7/12)" for all levels of correctional and treatment facilities in the State.

²³ The figures in this column have been prorated to 31% of the total amounts based on the following report. Research Brief: A Review of Disability Data for the Institutionalized Population. Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics, <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1205&context=edicollect>. "Disability in the Incarcerated Population: Based on data from three Department of Justice (DOJ) surveys ...31 percent of state prison inmates...report a disability of some sort. Mental and learning disabilities are particularly prevalent in the jail and state prison populations."

²⁴ The Total Institutionalized Population figures will be transferred over to the fourth column of Table 1.1 for the number of individuals institutionalized per county.

²⁵ Figure based on total number given for New York City prorated for each county/borough based on a percentage scale according to ACS disability statistics.

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| NYS County | DOH Nursing Home ¹⁶ | DOH Assisted Living ¹⁷ | OPWDD Developmental Center ¹⁸ | OPWDD All Other Group Home Care ¹⁹ | OMH Psychiatric Or RTF ²⁰ | OMH All Other Community Care ²¹ | Correctional Facilities ²² <i>(Represents 31% of the total number)²³</i> | Total Institutionalized Population²⁴ <i>(Top Ten Counties Highlighted in Bold)</i> |
|-----------------------|--------------------------------|-----------------------------------|--|---|--------------------------------------|--|---|---|
| Dutchess | 1,795 | 197 | | 928 | 152 | 710 | 1,608 | 5,390 |
| Erie | 5,675 | 260 | | 2,303 | 552 | 1,638 | 1,079 | 11,507 |
| Essex | 291 | 12 | | 236 | 5 | 8 | 166 | 718 |
| Franklin | 197 | | 183 | 271 | 6 | 58 | 1,019 | 1,734 |
| Fulton | 321 | 43 | | 395 | 9 | 99 | 163 | 1,030 |
| Genesee | 465 | | | 121 | 5 | 71 | | 662 |
| Greene | 248 | 34 | | 87 | 4 | 30 | 812 | 1,215 |
| Hamilton | | 1 | | 75 | 0 | 0 | | 76 |
| Herkimer | 490 | 5 | | 212 | 5 | 47 | | 759 |
| Jefferson | 517 | 2 | | 205 | 56 | 157 | 444 | 1,381 |
| Kings | 9,965 | 715 ²⁶ | 265 | 2,935 | 1,370 | 3,871 | | 19,121 |
| Lewis | 153 | 0 | | 88 | 1 | 7 | | 249 |
| Livingston | 338 | 1 | | 284 | 5 | 14 | 579 | 1,221 |
| Madison | 377 | 7 | | 166 | 2 | 27 | | 579 |
| Monroe | 4,995 | 159 | 122 | 1,735 | 471 | 1,545 | 24 | 9,051 |
| Montgomery | 526 | 44 | | 219 | 30 | 167 | | 986 |
| Nassau | 6,831 | 198 | | 1,770 | 1,469 | 4,169 | | 14,437 |
| New York ¹ | 6,410 | 468 ²⁷ | | 1,022 | 1,695 | 4,619 | 560 | 14,774 |
| Niagara | 1,344 | 167 | | 420 | 74 | 281 | | 2,286 |
| Oneida | 2,465 | 186 | | 944 | 355 | 647 | 1,389 | 5,986 |
| Onondaga | 2,828 | 338 | | 641 | 265 | 693 | | 4,765 |
| Ontario | 559 | 28 | | 368 | 20 | 122 | | 1,097 |
| Orange | 1,331 | 70 | | 866 | 266 | 641 | 177 | 3,351 |
| Orleans | 281 | 6 | | 73 | 7 | 23 | 577 | 967 |
| Oswego | 585 | 14 | | 119 | 32 | 85 | | 835 |
| Otsego | 375 | 31 | | 245 | 45 | 69 | | 765 |
| Putnam | 285 | 13 | | 246 | 3 | 164 | | 711 |
| Queens | 11,477 | 616 ²⁸ | 79 | 1,963 | 1,342 | 4,725 | 83 | 20,285 |
| Rensselaer | 1,194 | 75 | 40 | 309 | 83 | 267 | | 1,968 |
| Richmond | 2,896 | 123 ²⁹ | 40 | 1,006 | 457 | 1,060 | | 5,582 |
| Rockland | 1,551 | 148 | | 1,095 | 451 | 1,067 | | 4,312 |
| Saratoga | 758 | 8 | | 419 | 167 | 220 | 130 | 1,702 |
| Schenectady | 1,014 | 18 | 46 | 431 | 100 | 250 | | 1,859 |
| Schoharie | | 34 | | 102 | 1 | 22 | | 159 |
| Schuyler | 119 | 30 | | 64 | 3 | 30 | 63 | 309 |
| Seneca | 271 | 7 | | 132 | 4 | 373 | 244 | 1,031 |
| St. Lawrence | 650 | 41 | | 355 | 239 | 397 | 690 | 2,372 |
| Steuben | 639 | 12 | | 213 | 51 | 155 | | 1,070 |
| Suffolk | 8,115 | 444 | | 2,949 | 1,059 | 2,914 | | 15,481 |

²⁶ Ibid.

²⁷ Ibid.

²⁸ Ibid.

²⁹ Ibid.

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| NYS County | DOH Nursing Home ¹⁶ | DOH Assisted Living ¹⁷ | OPWDD Developmental Center ¹⁸ | OPWDD All Other Group Home Care ¹⁹ | OMH Psychiatric Or RTF ²⁰ | OMH All Other Community Care ²¹ | Correctional Facilities ²² <i>(Represents 31% of the total number)²³</i> | Total Institutionalized Population²⁴ <i>(Top Ten Counties Highlighted in Bold)</i> |
|---------------|--------------------------------|-----------------------------------|--|---|--------------------------------------|--|---|---|
| Sullivan | 416 | 9 | | 793 | 22 | 226 | 350 | 1,816 |
| Tioga | 251 | 21 | | 74 | 0 | 20 | | 366 |
| Tompkins | 428 | 2 | | 201 | 32 | 148 | | 811 |
| Ulster | 1,180 | 82 | | 601 | 54 | 226 | 905 | 3,048 |
| Warren | 378 | 6 | | 193 | 49 | 114 | | 740 |
| Washington | 502 | 3 | | 175 | 8 | 52 | 737 | 1,477 |
| Wayne | 512 | 26 | | 376 | 7 | 77 | 89 | 1,087 |
| Westchester | 6,079 | 83 | | 1,580 | 1,140 | 1,925 | 843 | 11,650 |
| Wyoming | 188 | 1 | | 96 | 21 | 48 | 1,177 | 1,531 |
| Yates | 191 | 2 | | 84 | 4 | 58 | | 339 |
| TOTALS | 108,282 | 5,855 | 1,121 | 35,055 | 14,011 | 39,500 | 16,453 | 220,277 |

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Table 1.7A Ranking by penetration rate; inundation index, and overall combined ranking.

| NYS County | CSRs Served by IL Network | # Incidence of Disability | Penetration Rate | # Institutionalized | Inundation Index | Proportional ranking by penetration rate | Proportional ranking by inundation rate | Average percent |
|-------------|---------------------------|---------------------------|------------------|---------------------|------------------|--|---|-----------------|
| Albany | 760 | 34,197 | 2.22% | 3,686 | 4.85 | 7.53% | 6.36% | 6.95% |
| Allegany | 165 | 6,855 | 2.41% | 425 | 2.58 | 6.96% | 3.38% | 5.17% |
| Bronx | 308 | 183,928 | 0.17% | 17,250 | 56.01 | 100% | 73.39% | 86.70% |
| Broome | 877 | 28,507 | 3.08% | 2,663 | 3.04 | 5.44% | 3.98% | 4.71% |
| Cattaraugus | 649 | 11,518 | 5.63% | 1,046 | 1.61 | 2.97% | 2.11% | 2.54% |
| Cayuga | 543 | 9,486 | 5.72% | 1,317 | 2.43 | 2.93% | 3.18% | 3.05% |
| Chautauqua | 430 | 19,412 | 2.22% | 2,185 | 5.08 | 7.56% | 6.66% | 7.11% |
| Chemung | 264 | 12,714 | 2.08% | 2,347 | 8.89 | 8.06% | 11.65% | 9.86% |
| Chenango | 256 | 8,383 | 3.05% | 730 | 2.85 | 5.48% | 3.74% | 4.61% |
| Clinton | 116 | 11,076 | 1.05% | 1,804 | 15.55 | 15.99% | 20.38% | 18.18% |
| Columbia | 161 | 7,486 | 2.15% | 1,044 | 6.48 | 7.79% | 8.50% | 8.14% |
| Cortland | 198 | 5,399 | 3.67% | 528 | 2.67 | 4.57% | 3.49% | 4.03% |
| Delaware | 231 | 7,525 | 3.07% | 604 | 2.61 | 5.46% | 3.43% | 4.44% |
| Dutchess | 588 | 35,270 | 1.67% | 5,390 | 9.17 | 10.04% | 12.01% | 11.03% |
| Erie | 1,992 | 115,455 | 1.73% | 11,507 | 5.78 | 9.71% | 7.57% | 8.64% |
| Essex | 41 | 5,238 | 0.78% | 718 | 17.51 | 21.39% | 22.95% | 22.17% |
| Franklin | 160 | 6,101 | 2.62% | 1,734 | 10.84 | 6.39% | 14.20% | 10.29% |
| Fulton | 187 | 8,314 | 2.25% | 1,030 | 5.51 | 7.45% | 7.22% | 7.33% |
| Genesee | 291 | 7,844 | 3.71% | 662 | 2.27 | 4.51% | 2.98% | 3.75% |
| Greene | 96 | 5,737 | 1.67% | 1,215 | 12.66 | 10.01% | 16.58% | 13.30% |
| Hamilton | 10 | 701 ³⁰ | 1.43% | 76 | 7.60 | 11.74% | 9.96% | 10.85% |
| Herkimer | 608 | 8,859 | 6.86% | 759 | 1.25 | 2.44% | 1.64% | 2.04% |
| Jefferson | 834 | 14,708 | 5.67% | 1,381 | 1.66 | 2.95% | 2.17% | 2.56% |
| Kings | 706 | 244,165 | 0.29% | 19,121 | 27.08 | 57.91% | 35.49% | 46.70% |
| Lewis | 163 | 3,525 | 4.62% | 249 | 1.53 | 3.62% | 2.00% | 2.81% |
| Livingston | 16 | 7,107 | 0.23% | 1,221 | 76.31 | 74.38% | 100.00% | 87.19% |
| Madison | 242 | 7,329 | 3.30% | 579 | 2.39 | 5.07% | 3.14% | 4.10% |
| Monroe | 1,721 | 89,275 | 1.93% | 9,051 | 5.26 | 8.69% | 6.89% | 7.79% |
| Montgomery | 496 | 8,144 | 6.09% | 986 | 1.99 | 2.75% | 2.60% | 2.68% |
| Nassau | 976 | 114,837 | 0.85% | 14,437 | 14.79 | 19.70% | 19.38% | 19.54% |

³⁰ There were no figures given the ACS-census data for the incidence of disability in Hamilton and Schuyler counties. The figures used above were derived from taking the average rate of disability in the 60 available counties (13.04%), multiplied by the total population of the individual county.

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| | | | | | | | | |
|--------------|-----------|---------------------|--------------|---------------|--------------|--------|--------|--------|
| New York | 381 | 157,488 | 0.24% | 14,774 | 38.78 | 69.22% | 50.81% | 60.02% |
| Niagara | 578 | 28,810 | 2.01% | 2,286 | 3.96 | 8.35% | 5.18% | 6.76% |
| Oneida | 2,221 | 34,114 | 6.51% | 5,986 | 2.70 | 2.57% | 3.53% | 3.05% |
| Onondaga | 1,253 | 52,720 | 2.38% | 4,765 | 3.80 | 7.05% | 4.98% | 6.01% |
| Ontario | 69 | 12,863 | 0.54% | 1,097 | 15.90 | 31.22% | 20.83% | 26.03% |
| Orange | 815 | 41,385 | 1.97% | 3,351 | 4.11 | 8.50% | 5.39% | 6.95% |
| Orleans | 33 | 5,402 | 0.61% | 967 | 29.30 | 27.41% | 38.40% | 32.91% |
| Oswego | 790 | 15,843 | 4.99% | 835 | 1.06 | 3.36% | 1.39% | 2.37% |
| Otsego | 261 | 8,719 | 2.99% | 765 | 2.93 | 5.59% | 3.84% | 4.72% |
| Putnam | 238 | 8,637 | 2.76% | 711 | 2.99 | 6.08% | 3.91% | 5.00% |
| Queens | 473 | 209,722 | 0.23% | 20,285 | 42.89 | 74.25% | 56.20% | 65.22% |
| Rensselaer | 354 | 20,251 | 1.75% | 1,968 | 5.56 | 9.58% | 7.28% | 8.43% |
| Richmond | 894 | 45,649 | 1.96% | 5,582 | 6.24 | 8.55% | 8.18% | 8.37% |
| Rockland | 441 | 24,335 | 1.81% | 4,312 | 9.78 | 9.24% | 12.81% | 11.03% |
| Saratoga | 579 | 20,813 | 2.78% | 1,702 | 2.94 | 6.02% | 3.85% | 4.94% |
| Schenectady | 264 | 17,636 | 1.50% | 1,859 | 7.04 | 11.19% | 9.23% | 10.21% |
| Schoharie | 65 | 4,964 | 1.31% | 159 | 2.45 | 12.79% | 3.21% | 8.00% |
| Schuyler | 101 | 2,440 ³¹ | 4.14% | 309 | 3.06 | 4.05% | 4.01% | 4.03% |
| Seneca | 55 | 4,847 | 1.13% | 1,031 | 18.75 | 14.76% | 24.56% | 19.66% |
| St. Lawrence | 272 | 16,629 | 1.64% | 2,372 | 8.72 | 10.24% | 11.43% | 10.83% |
| Steuben | 445 | 14,869 | 2.99% | 1,070 | 2.40 | 5.60% | 3.15% | 4.37% |
| Suffolk | 356 | 129,856 | 0.27% | 15,481 | 43.49 | 61.08% | 56.98% | 59.03% |
| Sullivan | 194 | 11,515 | 1.68% | 1,816 | 9.36 | 9.94% | 12.27% | 11.10% |
| Tioga | 105 | 6,456 | 1.63% | 366 | 3.49 | 10.30% | 4.57% | 7.43% |
| Tompkins | 246 | 9,467 | 2.60% | 811 | 3.30 | 6.44% | 4.32% | 5.38% |
| Ulster | 572 | 23,952 | 2.39% | 3,048 | 5.33 | 7.01% | 6.98% | 7.00% |
| Warren | 524 | 8,025 | 6.53% | 740 | 1.41 | 2.56% | 1.85% | 2.21% |
| Washington | 344 | 7,061 | 4.87% | 1,477 | 4.29 | 3.44% | 5.63% | 4.53% |
| Wayne | 103 | 12,036 | 0.86% | 1,087 | 10.55 | 19.57% | 13.83% | 16.70% |
| Westchester | 821 | 81,330 | 1.01% | 11,650 | 14.19 | 16.59% | 18.59% | 17.59% |
| Wyoming | 25 | 4,768 | 0.52% | 1,531 | 61.24 | 31.94% | 80.25% | 56.09% |
| Yates | 11 | 2,897 | 0.38% | 339 | 30.82 | 44.10% | 40.38% | 42.24% |

³¹ There were no figures given the ACS-census data for the incidence of disability in Hamilton and Schuyler counties. The figures used above were derived from taking the average rate of disability in the 60 available counties (13.04%), multiplied by the total population of the individual county.

**Appendix III: Tables and charts from the consumer survey that provides a respondent profile.
Total number of respondents = 578**

Do you live in a rural, urban or suburban location?

| | | |
|--------------------------|-------|------------|
| Rural | 30.1% | 162 |
| Urban | 25.8% | 139 |
| Suburban | 44.2% | 238 |
| <i>answered question</i> | | 539 |

Race/ethnic group:

| Answer Options | Response Percent | Response Count |
|------------------------------|-------------------------|-----------------------|
| American Indian | 1.1% | 6 |
| Black non-Hispanic | 7.9% | 43 |
| Asian/Pacific Islander | 2.4% | 13 |
| Hispanic | 3.7% | 20 |
| White | 79.9% | 437 |
| Multi-ethnic (More than one) | 3.8% | 21 |
| Other (please specify) | 1.3% | 7 |
| <i>answered question</i> | | 547 |

Age range:

| Answer Options | Response Percent | Response Count |
|--------------------------|-------------------------|-----------------------|
| Under 6 years old | 0.0% | 0 |
| 6-17 years old | 9.2% | 51 |
| 18-22 years old | 7.4% | 41 |
| 23-54 years old | 49.5% | 275 |
| 55-64 years old | 22.2% | 123 |
| 65-74 years old | 7.0% | 39 |
| 75 years and older | 4.7% | 26 |
| <i>answered question</i> | | 555 |

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What region of the state do you live in? N = 535

| Region | Responses |
|---|-----------|
| NORTH COUNTRY: Franklin, Clinton, Essex, Hamilton, St. Lawrence, Warren, Washington, Jefferson, Lewis | 28 |
| CAPITAL DISTRICT: Albany, Schenectady, Rensselaer, Saratoga, Fulton, Montgomery, Schoharie, Columbia, Greene) | 84 |
| LOWER HUDSON VALLEY: Westchester, Rockland, Orange, Putnam, Sullivan, Dutchess, Ulster | 133 |
| SOUTHERN TIER: Delaware, Broome, Tioga, Chemung, Schuyler, Chenango, Otsego | 27 |
| CENTRAL: Herkimer, Madison, Oneida, Oswego, Onondaga, Cayuga, Tompkins, Cortland | 119 |
| WESTERN: Chautauqua, Cattaraugus, Erie, Allegany, Wyoming, Orleans, Niagara, Genesee | 59 |
| FINGER LAKES: Wayne, Steuben, Livingston, Yates, Ontario, Seneca, Monroe | 28 |
| NEW YORK CITY: Brooklyn, Queens, Staten Island, Manhattan, Bronx | 38 |
| LONG ISLAND: Nassau, Suffolk | 19 |
| Total responding | 535 |

Please describe your disability. (Respondents were asked to check all that apply, so the total number of responses (861) exceeds the number of respondents (536)).

| Answer Options | Response Percent | Response Count |
|----------------------------|--------------------------|----------------|
| Cognitive Disabilities | 28.4% | 152 |
| Mental Health Disabilities | 37.1% | 199 |
| Physical Disabilities | 45.1% | 242 |
| Sensory Disabilities | 14.6% | 78 |
| Multiple Disabilities | 17.0% | 91 |
| Other (please specify) | 18.5% | 99 |
| | <i>answered question</i> | 536 |

19 comments identified as autism; 11 listed a brain or head injury.

Appendix IV: Tables and charts from the Center and Consumer surveys that provide additional data for some of the questions.

Table 3.1 N= 539 total

| Rural respondents N= 162 | | Urban respondents N= 139 | | Suburban Respondents N=238 | |
|--|-----|--|-----|--|-----|
| Finances (paying bills) | 49% | Employment | 49% | Transportation | 47% |
| Transportation | 46% | Finances (paying bills) | 49% | Finances (paying bills) | 47% |
| Social (needing support from family and friends) | 39% | Transportation | 44% | Employment | 46% |
| Medical/health coverage | 38% | Housing (accessibility, affordability) | 38% | Social (needing support from family and friends) | 40% |
| Recreation | 36% | Social (needing support from family and friends) | 37% | Housing (accessibility, affordability) | 35% |
| Housing (accessibility, affordability) | 31% | Medical/health coverage | 35% | Medical/health coverage | 35% |
| Employment | 31% | Recreation | 31% | Recreation | 34% |
| Applying for benefits | 21% | Personal care (eating, bathing, housekeeping) | 26% | Education | 29% |
| Education | 21% | Applying for benefits | 24% | Personal care (eating, bathing, housekeeping) | 23% |
| Mobility (accessibility, assistive devices) | 20% | Mobility (accessibility, assistive devices) | 24% | Applying for benefits | 21% |
| Personal care (eating, bathing, housekeeping) | 20% | Education | 21% | Discrimination | 19% |
| Discrimination | 13% | Discrimination | 20% | Mobility (accessibility, assistive devices) | 17% |

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Table 3.2 N= 539 total

Consumer Survey Q2: What services are most important to you for Independent Living?

(filtered by rural / urban / suburban)

| Rural respondents N= 162 | Urban respondents N= 139 | Suburban Respondents N=238 |
|--|--|--|
| Transportation 50% | Advocacy 49% | Transportation 51% |
| Medical / health services 48% | Transportation 49% | Advocacy 49% |
| Advocacy 44% | Benefits assistance and advice 49% | Medical / health services 48% |
| Information and referral to other services 44% | Medical / health services 45% | Employment / work readiness services 46% |
| Benefits assistance and advice 41% | Employment / work readiness services 41% | Benefits assistance and advice 44% |
| Employment / work readiness services 32% | Information and referral to other services 38% | Housing services 38% |
| Recreation services 31% | Housing services 37% | Information and referral to other services 36% |
| Home care / personal assistance services 29% | Home care / personal assistance services 29% | Education services 32% |
| Independent living skills training 28% | Independent living skills training 27% | Independent living skills training 32% |
| Housing services 27% | Education services 25% | Home care / personal assistance services 30% |
| Family services 20% | Peer counseling 25% | Recreation services 28% |
| Education services 16% | Recreation services 25% | Peer counseling 24% |
| Mobility services 15% | Mobility services 16% | Family services 14% |
| Assistive devices training 12% | Family services 14% | Mobility services 12% |
| Peer counseling 12% | Assistive devices training 13% | Assistive devices training 11% |

Appendix V: Copies of the two surveys used in the study

NYSILC Consumer Survey

(This is the text version of the survey as an alternative to the on-line version.)

1. What are the most challenging issues you face day to day? Check all that apply.

- Medical/health coverage
- Employment
- Transportation
- Finances (paying bills)
- Discrimination
- Applying for benefits
- Recreation
- Education
- Mobility (accessibility, assistive devices)
- Social (needing support from family and friends)
- Housing (accessibility, affordability)
- Personal care (eating, bathing, housekeeping)
- Other (please specify)

2. What services do you use that are most important for you to continue living independently? Check all that are most important.

If you have questions about the meaning of terms used in the next two questions, see the list at the end of this document.

- Advocacy
- Assistive devices training
- Benefits assistance and advice
- Education services
- Employment / work readiness services
- Family services
- Home care / personal assistance services
- Housing services
- Independent living skills training
- Information and referral to other services
- Medical / health services
- Mobility services
- Peer counseling
- Recreation services
- Transportation
- Other (please specify)

3. How available are the following services in your area? Please rate each one.

| | Readily available | Somewhat available | Not available | N/A |
|---|-------------------|--------------------|---------------|-----|
| a) Advocacy | | | | |
| b) Assistive devices training | | | | |
| c) Benefits Assistance and Advice | | | | |
| d) Education services | | | | |
| e) Employment / work readiness services | | | | |
| f) Family services | | | | |
| g) Home care/personal assistance services | | | | |
| h) Housing services | | | | |
| i) Independent living skills training | | | | |
| j) Information and referral to other services | | | | |
| k) Medical/health services | | | | |
| l) Mobility services | | | | |
| m) Peer counseling | | | | |
| n) Recreation services | | | | |
| o) Transportation | | | | |

Comment / Other (please specify)

4. Rank the following items in order of which would make it easiest for you to access services at your local Independent Living Center. Use 1 as the most important and 6 as the least important.

- Expand services
- Expand hours of operation (nights and weekends)
- Hire additional staff
- Advertise existing services
- Make home visits
- Expand transportation to / from the center

5. How else could your local Independent Living Center make it easier for you to access services? Please describe below.

6. Where else do you go to receive services or support to help you live independently?

Check all that apply.

- | | |
|---|--|
| <input type="checkbox"/> School | <input type="checkbox"/> Park or gymnasium |
| <input type="checkbox"/> Hospital | <input type="checkbox"/> College or university |
| <input type="checkbox"/> Place of worship | <input type="checkbox"/> Internet resources |
| <input type="checkbox"/> Community center | <input type="checkbox"/> Group meetings |
| <input type="checkbox"/> Counseling / Therapy | <input type="checkbox"/> Physical therapy |
| <input type="checkbox"/> Place of employment | <input type="checkbox"/> Other disability agencies |
| <input type="checkbox"/> Social services | <input type="checkbox"/> Other (please specify) |

7. If you have problems with service agencies, how often are you able to resolve them?

Check one answer.

- Never
- Sometimes
- Most of the time
- Always
- Not applicable

8. Please check one answer for your age.

- Under 6 years old
- 6-17 years old
- 18-22 years old
- 23-54 years old
- 55-64 years old
- 65-74 years old
- 75 years and older

9. Please check one answer for your race/ethnic group.

- American Indian
- Black non-Hispanic
- Asian/Pacific Islander
- Hispanic
- White
- Multi-ethnic (More than one)
- Other (please specify)

10. Please describe your disability. Check all that apply.

- Cognitive Disabilities
- Mental Health Disabilities
- Physical Disabilities
- Sensory Disabilities
- Multiple Disabilities
- Other (please specify)

11. Do you have any other comments about the services that help you to live independently? Use this space to reply.

12. What county do you live in?

- | | |
|--|--|
| <input type="checkbox"/> Albany County | <input type="checkbox"/> New York County (Manhattan) |
| <input type="checkbox"/> Allegany County | <input type="checkbox"/> Niagara County |
| <input type="checkbox"/> Bronx County | <input type="checkbox"/> Oneida County |
| <input type="checkbox"/> Broome County | <input type="checkbox"/> Onondaga County |
| <input type="checkbox"/> Cattaraugus County | <input type="checkbox"/> Ontario County |
| <input type="checkbox"/> Cayuga County | <input type="checkbox"/> Orange County |
| <input type="checkbox"/> Chautauqua County | <input type="checkbox"/> Orleans County |
| <input type="checkbox"/> Chemung County | <input type="checkbox"/> Oswego County |
| <input type="checkbox"/> Chenango County | <input type="checkbox"/> Otsego County |
| <input type="checkbox"/> Clinton County | <input type="checkbox"/> Putnam County |
| <input type="checkbox"/> Columbia County | <input type="checkbox"/> Queens County |
| <input type="checkbox"/> Cortland County | <input type="checkbox"/> Rensselaer County |
| <input type="checkbox"/> Delaware County | <input type="checkbox"/> Richmond County (Staten Island) |
| <input type="checkbox"/> Dutchess County | <input type="checkbox"/> Rockland County |
| <input type="checkbox"/> Erie County | <input type="checkbox"/> St. Lawrence County |
| <input type="checkbox"/> Essex County | <input type="checkbox"/> Saratoga County |
| <input type="checkbox"/> Franklin County | <input type="checkbox"/> Schenectady County |
| <input type="checkbox"/> Fulton County | <input type="checkbox"/> Schoharie County |
| <input type="checkbox"/> Genesee County | <input type="checkbox"/> Schuyler County |
| <input type="checkbox"/> Greene County | <input type="checkbox"/> Seneca County |
| <input type="checkbox"/> Hamilton County | <input type="checkbox"/> Steuben County |
| <input type="checkbox"/> Herkimer County | <input type="checkbox"/> Suffolk County |
| <input type="checkbox"/> Jefferson County | <input type="checkbox"/> Sullivan County |
| <input type="checkbox"/> Kings County (Brooklyn) | <input type="checkbox"/> Tioga County |
| <input type="checkbox"/> Lewis County | <input type="checkbox"/> Tompkins County |
| <input type="checkbox"/> Livingston County | <input type="checkbox"/> Ulster County |
| <input type="checkbox"/> Madison County | <input type="checkbox"/> Warren County |
| <input type="checkbox"/> Monroe County | <input type="checkbox"/> Washington County |
| <input type="checkbox"/> Montgomery County | <input type="checkbox"/> Wayne County |
| <input type="checkbox"/> Nassau County | <input type="checkbox"/> Westchester County |
| | <input type="checkbox"/> Wyoming County |
| | <input type="checkbox"/> Yates County |

13. What region of the state do you live in?

- __NORTH COUNTRY:** Franklin, Clinton, Essex, Hamilton, St. Lawrence, Warren, Washington, Jefferson, Lewis
- __CAPITAL DISTRICT:** Albany, Schenectady, Rensselaer, Saratoga, Fulton, Montgomery, Schoharie, Columbia, Greene)
- __LOWER HUDSON VALLEY:** Westchester, Rockland, Orange, Putnam, Sullivan, Dutchess, Ulster
- __SOUTHERN TIER:** Delaware, Broome, Tioga, Chemung, Schuyler, Chenango, Otsego
- __CENTRAL:** Herkimer, Madison, Oneida, Oswego, Onondaga, Cayuga, Tompkins, Cortland
- __WESTERN:** Chautauqua, Cattaraugus, Erie, Allegany, Wyoming, Orleans, Niagara, Genesee
- __FINGER LAKES:** Wayne, Steuben, Livingston, Yates, Ontario, Seneca, Monroe
- __NEW YORK CITY:** Brooklyn, Queens, Staten Island, Manhattan, Bronx
- __LONG ISLAND:** Nassau, Suffolk

14. Do you live in a rural, urban or suburban location?

- Rural Urban Suburban

THANK YOU FOR COMPLETING THIS SURVEY!

If you would like to be entered into our drawing for a gift or gas card, please give us your name, address and phone number below so we can contact you if you've won:

Name: _____

Mailing address: _____

Phone number: _____

Email address: _____

Please send the completed survey to Patty Black at NYSILC

Email: patty@nysilc.org or

Surface mail: New York State Independent Living Council, 111 Washington Avenue, Suite 101, Albany, NY 12210

Please complete this by July 12 to be entered in our drawing for a \$50 Mobil gift card.

DEFINITIONS OF TERMS USED IN QUESTIONS #2 AND #3

1. Advocacy/legal services - assistance with accessing benefits, services or programs to which you may be entitled but are having difficulty obtaining.
2. Assistive devices/equipment – help receiving specialized equipment such as TTYs, wheelchairs and lifts. This includes equipment repair and loan as needed.
3. Benefits advisement - assistance provided with applying for economic benefits. This service does not include the representation at hearings or appeals.
4. Education services – classroom or individual educational programs at the primary, secondary or college levels; this includes home tutoring.
5. Employment / work readiness services - training in job-seeking skills such as interviewing and resume writing, and/or providing supported employment opportunities and/or integrated job placement services.
6. Family services - services provided to family members of individuals with disabilities when help is needed for helping the individual to live more independently, or to engage or continue in employment. This may include respite care.
7. Home care / personal assistance services - includes providing attendant care to consumers and/or training consumers to supervise their own attendants.
8. Housing or shelter services - information, advice, and assistance related to finding or keeping affordable, accessible and/or integrated housing. Includes assistance with looking through newspaper ads, how to talk with landlords, finding lists of available accessible housing, and information and assistance in applying for housing support.
9. Independent living skills development and life skills services - Instruction to develop independent living skills in areas such as personal care, coping skills, use of assistive technology, financial management, social skills, and household management, including education and training necessary for living in the community and participating in community activities.
10. Information and referral services (I&R) – information about other needed services in the area, and/or being referred directly to specific agencies.
11. Medical / health services – services needed to treat specific medical conditions.
12. Mobility training - variety of services involved in assisting individuals with cognitive and sensory impairments to get around their homes and communities.
13. Peer counseling - counseling, teaching, information sharing, and similar kinds of services provided by other individuals with disabilities. This may include information about disability laws, civil rights and other available protections, and strategies and resources to support personal empowerment.

14. Recreational services – providing or identifying opportunities for individuals with disabilities to participate in accessible, integrated leisure time activities; community affairs and/or other accessible, integrated recreation activities that may be competitive, active or quiet.
15. Transportation services - provision of, or arrangements for provision of accessible transportation.

NYSILC Centers Survey

(This is the text version of the survey as an alternative to the on-line version.)

- 1. Agency Name:**
- 2. Name of person completing the survey:**
- 3. Please review this list of potential barriers to effective service delivery of existing services and check those that are currently the most significant barriers for your Center. Please check or highlight up to a maximum of 5 (five) barriers.**
 - a) Lack of financial or other resources
 - b) Funding restrictions
 - c) Lack of adequate transportation for consumers
 - d) Lack of cooperation from other providers (e.g. schools, agencies, etc)
 - e) Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits
 - f) Staffing issues – inability to recruit due to shortage of qualified staff
 - g) Staffing issues – difficulty retaining staff
 - h) Staffing issues – lack of resources to train staff
 - i) Lack of space or other infrastructure
 - j) Lack of interpretation services
 - k) Lack of awareness from people with disabilities of ILC services
 - l) Size of service area is too large
 - m) Lack of support from key agencies or other groups in the community
 - n) Low demand or interest from target population
 - o) Lack of board support
 - p) Other– please specify and/or Comments:
- 4. What resources would you need to overcome these barriers to providing existing services? Please select up to a maximum of 3 (three) resources.**
 - a) Additional Funding
 - b) Training/Technical Assistance
 - c) Examples of successful model programs
 - d) A well-designed and funded public relations plan
 - e) Additional space/Infrastructure
 - f) More assistance cooperation from local and state providers
 - g) Transportation for consumers

- h) __Grassroots support
- i) __Political support
- j) __Other **If you checked "Other" above, please specify.**

5. With respect to current unmet needs in your area, are there services you currently provide that you would like to expand, or new services you would like to start , or are there some services listed that you think are no longer needed?

Please circle, underline or highlight up to 5 (five) choices in each column.

| | | | |
|--|-----------|--------|------------|
| Advocacy/legal services | Start new | Expand | Not needed |
| Architectural barrier services | Start new | Expand | Not needed |
| Assistive devices/equipment | Start new | Expand | Not needed |
| Benefits advisement | Start new | Expand | Not needed |
| Business/Industry/Agency services | Start new | Expand | Not needed |
| Children’s services | Start new | Expand | Not needed |
| Communication services | Start new | Expand | Not needed |
| Counseling services | Start new | Expand | Not needed |
| Family services | Start new | Expand | Not needed |
| Housing and shelter services | Start new | Expand | Not needed |
| Information and referral | Start new | Expand | Not needed |
| Independent living skills development and life skills services | Start new | Expand | Not needed |
| Mobility training | Start new | Expand | Not needed |
| Peer counseling | Start new | Expand | Not needed |
| Personal assistant services | Start new | Expand | Not needed |
| Plan for achievement for self support | Start new | Expand | Not needed |
| Recreational services | Start new | Expand | Not needed |
| Transportation services | Start new | Expand | Not needed |
| Vocational services | Start new | Expand | Not needed |
| Voter registration | Start new | Expand | Not needed |
| Youth services | Start new | Expand | Not needed |

Other (please specify) - Start new / expand / not needed

6. For the services you indicated above, what barriers, if any, are there to you starting or expanding services? Please check up to 5 barriers.

- a) Lack of financial or other resources
- b) Funding limitations or restrictions
- c) Lack of adequate transportation for consumers
- d) Lack of cooperation from providers (e.g. schools, agencies, etc)
- e) Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits
- f) Staffing issues – inability to recruit due to shortage of qualified staff
- g) Staffing issues – difficulty retaining staff
- h) Staffing issues – lack of resources to train staff
- i) Lack of space or other infrastructure
- j) Lack of interpretation services
- k) Lack of public awareness of ILC services
- l) Size of service areas
- m) Lack of support from key agencies or other groups in the community
- n) Low demand or interest from target population
- o) Lack of board support
- p) Other, please specify:

7. **What resources would you need to overcome the barriers to *expanding* existing services or *starting* new services? Please select up to 3 (three) resources.**

- 1. Additional Funding
- 2. Training/Technical Assistance
- 3. Examples of model programs
- 4. A well-designed and funded public relations plan
- 5. Additional space/Infrastructure
- 6. More assistance from local and state government agencies
- 7. More collaborating partners from local community service providers
- 8. Transportation for consumers
- 9. Grassroots support
- 10. Political support
- 11. Other, please specify:

8. **If there are particular geographic areas within or outside your service area that you feel are not adequately served by you or other service providers, please describe those areas below. (e.g. rural areas, specific counties, specific neighborhoods)**

9. If there are particular groups of people with disabilities WITHIN your service area that you feel are underserved or hard to reach by your organization, please check them below. (Check all that apply):

1. Children/young adults
2. Seniors
3. Rural Residents
4. American Indian
5. Black non-Hispanic
6. Asian/Pacific Islander
7. Hispanic
8. Multi-ethnic
9. Male Veterans
10. Female Veterans
11. Homeless
12. LGBT
13. Deaf
14. Blind
15. Deaf/Blind
16. Physical disabilities
17. Mental/emotional disabilities
18. Cognitive disabilities
19. Dual diagnosis – intellectual/mental health
20. Dual diagnosis – mental health/chemical abuse
21. Immigrant groups / Non-native English speakers (please specify in “comments/other” box below)

Comments/ Other Underserved or Hard to Reach Groups (please specify):

10. If you checked any of the groups in the previous question, please describe how you might strengthen your services to reach these groups.

11. In thinking about how the *larger* community serves people with disabilities, please indicate from the following list how well each of these needs are met overall for people with disabilities in your service area. Circle, underline or highlight your choice.

| | | | |
|--|----------|----------------|--------------|
| Accessible Health Care | Well Met | Adequately Met | Not Well Met |
| Affordable Health Care | Well Met | Adequately Met | Not Well Met |
| Disability Awareness among Service Providers | Well Met | Adequately Met | Not Well Met |
| Health Insurance | Well Met | Adequately Met | Not Well Met |
| Affordable Housing | Well Met | Adequately Met | Not Well Met |

NYSILC Needs Assessment Report

| | | | |
|---|----------|----------------|--------------|
| Integrated Housing | Well Met | Adequately Met | Not Well Met |
| Emergency Services | Well Met | Adequately Met | Not Well Met |
| Access to Assistive Technology | Well Met | Adequately Met | Not Well Met |
| Transition Services | Well Met | Adequately Met | Not Well Met |
| Special Education | Well Met | Adequately Met | Not Well Met |
| Employment Opportunities | Well Met | Adequately Met | Not Well Met |
| Vocational Training | Well Met | Adequately Met | Not Well Met |
| Transportation | Well Met | Adequately Met | Not Well Met |
| Information about Disability Rights | Well Met | Adequately Met | Not Well Met |
| Access to Information and Resources | Well Met | Adequately Met | Not Well Met |
| Assistance with Disability Benefits | Well Met | Adequately Met | Not Well Met |
| Consumer Directed Personal Assistance | Well Met | Adequately Met | Not Well Met |
| Affordable, Accessible Exercise Opportunities | Well Met | Adequately Met | Not Well Met |
| Affordable, Accessible Opportunities To Socialize | Well Met | Adequately Met | Not Well Met |
| Community Based Long-Term Care Services and Support | Well Met | Adequately Met | Not Well Met |
| Service Coordination | Well Met | Adequately Met | Not Well Met |
| Adequate Income | Well Met | Adequately Met | Not Well Met |
| Culturally Sensitive Services | Well Met | Adequately Met | Not Well Met |
| Systems Advocacy | Well Met | Adequately Met | Not Well Met |

12. Are there other major needs not included above that are not well met for people with disabilities in your service area? Please explain.

13. Of the unmet needs cited in question 11 and 12 above, are any more pronounced for the youth, adult or senior populations? Please describe below.
