NYSILC

New York State Independent Living Council, Inc.
"Empowering New Yorkers with disabilities"

2015 NYSILC Needs Assessment Report

2015 NYSILC Needs Assessment Report

Table of Contents

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.

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, monitoring, and evaluation of the three-year Statewide Plan for Independent Living (SPIL). The council is jointly responsible for the SPIL with its state plan partners, who will transition in 2015-2016 to the New York Federal CIL Directors. The partnership will work in cooperation with a new Designated State Entity (DSE) from the previous roles and relationships developed between the 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.

To gather additional data, NYSILC decided to conduct two needs assessment surveys; one of Center Directors and another of consumers. Two similar surveys were conducted in 2012 as part of the previous SPIL development. NYSILC again 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.

For more information about this needs assessment, please contact:
Brad Williams, Executive Director
Tel: 518 427-1060, Voice and TDD; Toll Free 1 (877) 397-4126
Email: bradw@nysilc.org
Fax: 518 427-1139

or send regular mail to:
New York State Independent Living Council, Inc.
111 Washington Avenue, Suite 101
Albany, NY 12210

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. The findings of this assessment very closely track the findings of the needs assessment conducted in 2012. This indicates that the most difficult challenges are difficult to overcome and continued efforts are needed to successfully address these.

1. **What geographic areas are most in need of additional Independent Living (IL) services?**

   Utilizing an analysis of penetration rates and inundation indexes, and their relative rankings, the eight counties with the greatest need for Independent Living (IL) services (listed from greatest to least need) have held mostly the same since the 2012 report was produced. Kings County has move to the top of the list, and Seneca, Genesee and Nassau have been added. Livingston County has moved down the list and New York, Wyoming and Yates have moved off the top 8.

Using most current data	From the 2012 Needs Assessment Report
• Kings	• Livingston
• Bronx	• Bronx
• Queens	• Queens
• Livingston	• New York
• Seneca	• Suffolk
• Suffolk	• Wyoming
• Genesee	• Kings
• Nassau	• Yates

2. **What unserved/underserved ethnic, minority and disability communities are most in need of IL services?**

   Based on what we know (existing data), the following needs were identified:
   • While there is still a high number of veterans with disabilities in New York (211,931) it has fallen since the 2012 report was issued (232,805). Twenty-seven percent of veterans in NYS have disabilities compared with the general population of 11%. The incidence of disability has risen slightly since the 2012 report (25.1%) possibly due to the aging of many veterans and the increase in disabilities in modern warfare due to higher rates of survival from serious wounds. Sixty-one percent of center directors identified veterans as a significantly unserved/underserved population.

- Rural residents were the next highest rated for being underserved, with 42.3% of Center Directors citing this group. Limited transportation and limited services in rural areas combine to make it difficult to reach this group.
- The other two groups cited by center directors include youth/young adults and Hispanics.
- Some of these underserved target populations have been identified for two prior State Plans and they continue to be high priorities. These include: veterans with disabilities, Hispanics with disabilities, and young adults with disabilities.

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

Based on input from the consumer and center director surveys, we identified the following as the greatest challenges facing consumers:
- Finances (paying bills)
- Transportation
- Social
- Employment
- Housing

These challenges were fairly consistent across rural, urban and suburban respondents. They are also very similar to the findings from three years ago.

In terms of the services consumers most need to live independently, benefits assistance, advocacy and transportation were rated most highly. When asked what services were least available in their area, consumers cited transportation, housing and recreation.

4. What are the most important needs that should be addressed to strengthen New York's independent living network?

Based on a survey of Center Directors, with more than half of the network responding, centers indicated that the following were barriers to existing services or expanding or starting new services:
- Lack of financial services
- Funding restrictions
- Lack of transportation to consumers
- Additional space/infrastructure
- Increased awareness about ILC.

This list is very similar to that of 3 years ago.

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/advertising

These were also the top two rated in 2012.

NYSILC Needs Assessment Report

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 to solicit feedback from the public, at various venues and through written comments.

In 2012, two needs assessment surveys were conducted to add to this process. These surveys were conducted again in 2015 for the 2017-2019 state plan. NYSILC established a committee of Council members to lead this process. Public input and needs assessment priorities then help to validate the content of the next SPIL.

The committee reviewed the previous surveys and recommended changes to increase clarity and update some of the terminology. The committee recommended that NYSILC focus its needs assessment on the same four questions that formed the basis of the 2012 assessment (which was in turn based on the California SILC's approach including their analysis of "penetration rates" and "inundation indexes"). Committee members also reviewed other data sources, primarily to answer the first two research questions.

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

1. What geographic areas are most in need of additional Independent Living (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 should be addressed to strengthen New York's independent living network?

Methodology:

The Needs Assessment Committee 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 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 2012 surveys 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 prior to our 2012 report, no known public data on the number of **people with disabilities who are in institutional settings** previously existed within the State. That was the first attempt recognized by the network to capture data about the State's institutionalized population in any meaningful way. In 2015, the State had not made significant progress in publically accounting for or conspicuously posting such figures online or in the proposed dashboard setting. As a result, a FOIL process was utilized again starting in April 2015 and most State agencies responded with the requested data within appropriate timeframes. Only the Department of Health prolonged the process along a seven-month time span, exchanging several irrelevant data records until the original data request was satisfied. Pro bono legal assistance was required. Substitute data almost had to be utilized based on certified capacity. Reference footnotes of specific FOILs and data in Table 1.2 on page 17.

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. There were 263 consumers who 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. Unfortunately, there were two other statewide disability surveys being conducted at the exact same time that included people with disabilities (an Office of Aging needs assessment and a Developmental Disability Planning Council survey). As a result, we had a much lower response than we did three years ago.

The **center director survey** was also an on-line survey with a text based/paper option available if the on-line version was not accessible. More than half of all Independent Living Centers in the state responded (26 out of 47 locations). Their responses are also summarized in the report that follows.

Appendix VII (page 62) 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 2014 Annual Disability Statistics Compendium[1] 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. This did not change much since the last survey.

- **Veterans:** There are 785,638 civilian veterans age 18 or older living in the community in New York State (a sharp decline compared to 928,961 in 2012), with 211,931 with disabilities (fewer than in 2012 at 232,805) but at a higher percentage 27% (compared to 25.1% in 2012). These individuals have a higher 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 30.3% (an increase compared to 28.6% in 2012), which is more than twice that of persons in our state without disabilities which increased proportionately to 13.1% (at 12.3% in 2012).

- **Employment:** The employment rate for a New Yorker with a disability (ages 18-64) slightly improved to 32.2% (31.2% in 2012) compared to 73.3% for a person without a disability (was 72% in 2012) resulting in a gap of 41.1% (40.8% in 2012). Full-time, year-round employment for a New Yorker with a disability (ages 18-64) barely moved to 18.8% (18.7% in 2012) compared to 50.5% for a person without a disability (which decreased from 52.2% in 2012) creating a reduced gap of 31.7% (compared to 33.5% in 2012).

- **Income:** Among civilians age 16 or older during the last 12 months, the income gap increased for New Yorkers with disabilities earning $11,267 less on average compared to a person without a disability ($23,217 versus $34,484).

- **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: 60% (16,411) graduated with diplomas, 18% (4,796) received certificates, 21% (5,618) dropped out, and 1% (322) died or aged out. Compared to 2012, the graduation number and rate increased (15,937/52%), the number and rate receiving certificates decreased (6,277/21%), the drop out number and rate decreased (7,785/26%), and the number who aged out or died decreased and the rate remained the same (390/1%).

- **Health:** For New Yorkers with disabilities age 18 or older, the number who are considered obese increased to 37.9% (up from 34.4% in 2012) compared to 21.8% for a

---

[1] 2014 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, 2013 American Community Survey, American FactFinder.

person without a disability (up just slightly from 21.1% in 2012). In addition, new this report, New Yorkers with disabilities are more likely to smoke, with 22.6% of disabled New Yorkers identified compared to 14.9% of New Yorkers without disabilities.

This background data provides a compelling picture about the challenges faced by New Yorkers with disabilities. However, what it doesn't tell us is:
- *How* this information varies by county and region
- *What* are the most unserved and underserved populations and groups.
- *What* the greatest needs are for services
- *Where* the greatest needs are for services
- *What* can be done to strengthen the Independent Living (IL) network to address these gaps

With this information as a backdrop 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.

Findings

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

A number of data sources were reviewed to help identify areas of New York State that were most in need of additional IL services. In addition, this question was asked on the Center Director's survey.

On the survey of Center Directors, when asked if there were specific geographic areas within or outside their service area that they felt are not adequately served or are difficult for their staff to access, 50% gave a response and of these, most cited rural sections of their service area. So while the data which follows identifies rural, urban and suburban areas, in rural areas the lack of services is frequently compounded by a severe lack of transportation. While lack of transportation is an issue in many urban and suburban areas as well (this shows up as a high priority need across the board – see Question 3), it is generally worse in rural areas.

Table 1.1 (page 14) depicts service needs by county and indicates the sources that were used to develop the data which follows.

Some key findings from this data are listed below:

1. **Which counties provide IL services to the most or least number of people?**
   This data is based on ACCES-VR year-end data, statewide totals for FY 2013-2014, plus FY 2013-2014 704 Report data from the RSA MIS for Federal only funded CILs (ATI Sullivan, CDR, and TLCIL). (Note: this data was expanded to include all people served by the IL network: people with disabilities (primary), family members, and other non-disabled.)

   The top five counties served by the IL network during this time period include:

NYS County	Total People Served by IL Network
Orange	10068
Erie	4620
Oneida	4309
Monroe	4066
Ulster	3693

   The five counties exhibiting the lowest service reach include:

NYS County	Total People Served by IL Network
Hamilton	27
Yates	69
Seneca	82
Livingston	99
Genesee	156

2. **Which counties have the highest incidence of people with disabilities?**
   This is based on data received from the Cornell University Employment and Disability Institute, Race and Ethnicity of People with Disabilities by All NYS Counties American Community Survey 2015.

   The counties with the five highest incidences of disability include:

NYS County	Incidence of Disability/County
Kings	249,893
Queens	220,433
Bronx	194,097
New York	162,018
Suffolk	113,040

3. **How well are people with disabilities reached in each county?**
   Penetration rate is a calculation of the extent the IL network and its services are reaching the identified population in a given county. It is calculated by dividing the total number of consumers served in a county by the IL network for the identified year by the total number of civilian people with disabilities identified for each county. The lower the penetration rate (a percentage), the greater the need. Penetration rates provide an objective process to identify need that equally filters unserved and underserved, as well as urban and rural areas. (This is based on a model developed by the California Statewide Independent Living Council.)

   The counties with the five lowest penetration rates (and greatest need) are:

NYS County	Penetration Rate
Kings	0.92%
Bronx	1.13%
Queens	1.14%
Livingston	1.56%
Suffolk	1.62%

4. **Which counties have the greatest number of people with disabilities who are institutionalized?**
   Census data is for the civilian population, excluding those in institutions. The total estimated number of institutionalized individuals in New York by county was derived as detailed in Table 1.2 (page 17). It should be noted that this is an estimate or "snapshot" based on the information obtained by the committee. The counties with the highest estimated institutionalized populations are:

NYS County	Total Institutionalized/County
Queens	17,559
Kings	15,081
Bronx	15,020
New York	11,433
Suffolk	11,221

5. **Which counties are most at risk of having too few services available if everyone in an institution was successfully transitioned to a community setting?**
This data is based on a model developed by the California Statewide Independent Living Council. An "inundation index" expresses a number by county, hypothesizing that if everyone identified in an institutional setting was successfully transitioned out into the community, how would the current service capacity of the IL network manage the number of consumers who might "inundate" the county. It is calculated by dividing the total number of individuals identified as being institutionalized by county by the total number of consumers currently served in a county by the IL network (an estimate for current system capacity). The higher the inundation index (a number), the greater the need. Inundation indexes objectively look at the gap between the current service capacity and the potential under full de-institutionalization.

The counties with the five highest inundation indexes (and greatest potential need) are:

NYS County	Inundation Index
Seneca	12.32
Livingston	11.80
Queens	6.97
Bronx	6.82
Kings	6.53

6. **Which counties overall seem to have the highest need for additional services?**
In an attempt to combine the penetration and inundation data to reach an overall assessment, counties were ranked separately on each of these two factors and then rankings were combined to produce an overall priority. Table 1.3 (page 19) provides a list of the top counties with the lowest penetration rates and highest inundation indexes, and shows how the combined ranking was calculated. When ranked and given a score for their relative positions, the following eight counties are identified as the geographic areas most in need of additional IL services:

- Kings
- Bronx
- Queens
- Livingston
- Seneca
- Suffolk
- Genesee
- Nassau

Table 1.1 Service Needs by County

This table below analyzes potential service needs by county across New York State. It looks at the number of consumers currently being served by the IL network and the total number of people with disabilities in that county to see how far the services extend. This is the "penetration rate" in column 3. The lower the rate, the greater the potential need.

The table also looks at the population of people with disabilities who are institutionalized and compares that to the current service capacity to determine the potential for too much demand if large numbers moved into the community. This is the "inundation index" in the last column. The higher the index, the greater the need.

See notes following the table for more information about the source of the data and the penetration and inundation calculations.

NYS County	(A)[2] Total People Served by IL Network FY 2013-2014	(B)[3] # Incidence of Disability/ County	(A)/(B)[4] Penetration Rate	(C)[5] Total Estimated # Institutionalized/ County	(C)/(A)[6] Inundation Index
Albany	2,396	36,315	6.60%	2,692	1.12
Allegany	974	5,714	17.05%	390	0.40
Bronx	2,201	194,097	1.13%	15,020	6.82
Broome	2,146	23,406	9.17%	3,951	1.84
Cattaraugus	425	9,610	4.42%	781	1.84
Cayuga	754	8,310	9.07%	1,745	2.31
Chautauqua	1,633	17,205	9.49%	1,502	0.92
Chemung	1,503	10,899	13.79%	1,854	1.23

[2] **Column one** identifies the total people served by the IL network for FY 2013-2014. It is based on ACCES-VR yearend data, statewide totals for FY 2013-2014, plus FY 2013-2014 704 Report data from the RSA MIS for Federal only funded CILs (ATI Sullivan, CDR, and TLCIL). It should be clarified that this data was expanded to include all people served by the IL network: people with disabilities (primary), family members, and other non-disabled.

[3] **Column two** identifies the incidence of disability by county. It is based on data received from the Cornell University Employment and Disability Institute, Race and Ethnicity of People with Disabilities by All NYS Counties American Community Survey 2015.

[4] **Column three** represents a calculation of penetration rates for the counties. It is based on a model developed by the California Statewide Independent Living Council. A penetration rate determines the extent the IL network and its services are reaching the identified population in a given county. It is calculated by dividing the total number of consumers served in a county by the IL network for the identified year (column one) by the total number of civilian people with disabilities identified for each county with a disability (column two). The lower the penetration rate (a percentage), the greater the need. Penetration rates provide an objective process to identify need that equally filters unserved and underserved, as well as urban and rural areas.

[5] **Column four** identifies an estimate of the State's institutionalized population. These figures are required because Census data is for the civilian population. The total estimated number of institutionalized individuals in New York by county is derived in Table 1.2 (located on page 17). The settings are identified at the top by column. Footnotes describe the sources and background information related to the data. It should be noted that this is an estimate or "snapshot" based on the information obtained by the committee.

[6] **Column five** represents a calculation of inundation indexes for the counties. It is based on a model developed by the California Statewide Independent Living Council. An inundation index expresses a number by county, hypothesizing that if everyone identified in an institutional setting was successfully transitioned out into the community, how would the current service capacity of the IL network proportionately compares to the "inundation" for each respective county. It is calculated by dividing the total number of individuals identified as being institutionalized by county (column four) by the total number of consumers served in a county by the IL network (column one). The higher the inundation index (a number), the greater the need. Inundation indexes objectively look at the gap between the service capacity and the potential institutional population respective of urban and rural differences.

NYS County	(A)[2] Total People Served by IL Network FY 2013-2014	(B)[3] # Incidence of Disability/ County	(A)/(B)[4] Penetration Rate	(C)[5] Total Estimated # Institutionalized/ County	(C)/(A)[6] Inundation Index
Chenango	417	5,906	7.06%	626	1.50
Clinton	975	11,277	8.65%	1,730	1.77
Columbia	513	9,828	5.22%	975	1.90
Cortland	3,282	5,586	58.75%	438	0.13
Delaware	397	7,133	5.57%	290	0.73
Dutchess	1,910	34,938	5.47%	4,791	2.51
Erie	4,620	96,496	4.79%	9,195	1.99
Essex	413	5,484	7.53%	539	1.31
Franklin	717	7,218	9.93%	1,892	2.64
Fulton	978	7,711	12.68%	696	0.71
Genesee	156	8,483	1.83%	848	5.44
Greene	180	7,507	2.40%	880	4.89
Hamilton	27	760	3.55%	6	0.22
Herkimer	989	8,821	11.21%	611	0.62
Jefferson	1,562	15,779	9.90%	1,250	0.80
Kings	2,308	249,893	0.92%	15,081	6.53
Lewis	775	3,804	20.37%	189	0.24
Livingston	99	6,363	1.56%	1,168	11.80
Madison	441	6,040	7.30%	429	0.97
Monroe	4,066	83,233	4.89%	6,848	1.68
Montgomery	703	6,962	10.10%	805	1.15
Nassau	2,197	96,970	2.27%	8,718	3.97
New York	3,669	162,018	2.26%	11,433	3.12
Niagara	1,047	23,931	4.38%	1,864	1.78
Oneida	4,309	38,726	11.13%	5,226	1.21
Onondaga	2,522	43,491	5.80%	3,921	1.55
Ontario	289	10,804	2.67%	951	3.29
Orange	10,068	38,924	25.87%	2,618	0.26
Orleans	228	6,207	3.67%	1139	5.00
Oswego	1,288	15,870	8.12%	740	0.57
Otsego	364	9,155	3.98%	520	1.43
Putnam	794	7,598	10.45%	462	0.58
Queens	2,519	220,433	1.14%	17,559	6.97
Rensselaer	1,264	18,164	6.96%	1,710	1.35
Richmond	1,405	48,346	2.91%	4,478	3.19
Rockland	2,966	21,039	14.10%	2,865	0.97
Saratoga	1,526	25,419	6.00%	944	0.62
Schenectady	682	16,707	4.08%	1,345	1.97
Schoharie	721	4,687	15.38%	104	1.46
Schuyler	347	2,302	15.07%	187	0.54
Seneca	82	4,535	1.81%	1,010	12.32
St. Lawrence	953	17,489	5.45%	1,727	1.81

NYS County	(A)[2] Total People Served by IL Network FY 2013-2014	(B)[3] # Incidence of Disability/ County	(A)/(B)[4] Penetration Rate	(C)[5] Total Estimated # Institutionalized/ County	(C)/(A)[6] Inundation Index
Steuben	1,377	11,830	11.64%	823	0.60
Suffolk	1,829	113,040	1.62%	11,221	6.14
Sullivan	2,940	11,508	25.55%	1,329	0.45
Tioga	348	5,360	6.49%	300	0.86
Tompkins	2,004	13,123	15.27%	559	0.28
Ulster	3,693	23,714	15.57%	2,532	0.69
Warren	1,299	8,746	14.85%	534	0.41
Washington	736	8,435	8.73%	1,553	2.11
Wayne	268	9,767	2.74%	731	2.73
Westchester	3,581	72,599	4.93%	9,120	2.55
Wyoming	319	4,296	7.43%	1,673	5.24
Yates	69	2,949	2.34%	247	3.58
TOTALS	**95,263**	**2,012,960**	**4.73%**	**175,514**	**1.84**

Table: 1.2   Estimated State Institutionalized Population by County

Total Number of People with Disabilities in Institutions in New York State, by county.
The total estimated number of institutionalized individuals in New York by county is derived in
Table 1.2 (on the next page). The settings are identified at the top by column. Footnotes describe
the sources and background information related to the data. It should be noted that this is an
estimate or "snapshot" based on the information obtained by the committee. The total number in
the right hand column was used to populate column 4 in table 1.1.

Table: 1.2   Estimated State Institutionalized Population by County

NYS County	DOH[7] Nursing Home	DOH[8] Assisted Living	OPWDD Develop-mental Center[9]	OPWDD All Other Group Home Care[10]	OMH Congregate Setting[11]	OMH Institu-tional Setting[12]	Correc-tional Facilities[13] *(Represents 31% total number)[14]*	Total Institution-alized Population[15]
Albany	1729	69	0	204	448	242	0	2692
Allegany	326	8	0	21	30	5	0	390
Bronx	11024	600	0	398	2581	417	0	15020
Broome	1453	83	124	93	252	95	0	2100
Cattaraugus	529	39	0	88	95	30	0	781
Cayuga	409	54	0	55	59	179	989	1745
Chautauqua	886	283	0	75	168	12	78	1502
Chemung	673	0[16]	0	42	145	286	708	1854
Chenango	523	0	0	63	22	18	0	626
Clinton	440	34	0	40	65	177	974	1730
Columbia	603	52	0	67	123	11	119	975
Cortland	372	0	0	25	32	9	0	438
Delaware	193	35	0	30	26	6	0	290
Dutchess	1834	211	0	200	412	631	1,503	4791
Erie	5493	340	0	439	1229	634	1,060	9195
Essex	252	27	0	65	5	0	190	539
Franklin	178	8	158	59	55	96	1,338	1892
Fulton	344	71	0	77	80	16	108	696
Genesee	444	0	0	27	91	12	274	848
Greene	234	31	0	22	21	92	480	880
Hamilton	0	0	0	6	0	0	0	6

[7] FOIL request # 15-04-431 to the NYS DOH sought the actual number of individuals in NYS nursing homes by county. After seven months and exchanges of data, along with the assisted of pro bono legal assistance, data was provided by county on 10/23/15 for the population requested dated 4/1/2015.

[8] FOIL request # 15-04-431 to the NYS DOH sought the actual number of individuals in NYS assisted living facilities by county. After seven months and exchanges of data, along with the assisted of pro bono legal assistance, data was provided by county on 10/23/15 for the population requested dated 4/1/2015.

[9] Based on NYS OPWDD FOIL request # 15-0053. The data is for the Bernard M. Fineson DDSO (Queens), Brooklyn (Kings), Broome (Broome), and Sunmount (Franklin) Developmental Centers. Residents are identified by location of facility.

[10] Based on NYS OPWDD FOIL request # 15-0053. All other group home care includes state or voluntary run Community Residences, Family Care Homes, Individualized Residential Alternatives, and Intermediate Care Facilities.

[11] Based on the FOIL request to NYS OMH and response by the Records Access Officer on April 29, 2015. A link was provided to the 2013 Patient Characteristics Survey Portal http://www.omh.ny.gov/omhweb/statistics/pcs-message.htm. Click "continue to portal." Click on "Summary Reports." On left column, click "Current Residence." Select each county from menu and click apply to obtain statistics. Congregate settings includes Licensed Mental Health Housing, Adult Homes, Foster Care, Youth Community Based, and Homeless.

[12] Based on the FOIL request to NYS OMH and response by the Records Access Officer on April 29, 2015. A link was provided to the 2013 Patient Characteristics Survey Portal http://www.omh.ny.gov/omhweb/statistics/pcs-message.htm. Click "continue to portal." Click on "Summary Reports." On left column, click "Current Residence." Select each county from menu and click apply to obtain statistics. Institutional settings include Youth Institutional Residential Treatment Center, Nursing Home, Incarcerated, Inpatient or Residential Treatment Facility, and Other.

[13] Based on NYS Department of Corrections and Community Supervision (DOCCS) FOIL Request # 15-1424 and Daily Population Capacity Report dated May 12, 2015" for all levels of correctional and treatment facilities in the State.

[14] 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 Institutional 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."

[15] 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.

[16] The zero reflects a redacted cell. Zeros were assigned for redacted cells for the following counties: Chemung, Chenango, Cortland, Genesee, Hamilton, Herkimer, Livingston, Orleans, Seneca, Wyoming and Yates.

NYS County	DOH[7] Nursing Home	DOH[8] Assisted Living	OPWDD Develop-mental Center[9]	OPWDD All Other Group Home Care[10]	OMH Congre-gate Setting[11]	OMH Institu-tional Setting[12]	Correc-tional Facilities[13] (Represents 31% total number)[14]	Total Institution-alized Population[15]
Herkimer	504	0	0	53	39	15	0	611
Jefferson	538	139	0	35	86	14	438	1250
Kings	10245	571	39	672	3187	367	0	15081
Lewis	143	10	0	25	8	3	0	189
Livingston	345	0	0	39	10	182	592	1168
Madison	341	11	0	47	30	0	0	429
Monroe	4804	175	0	421	1055	371	22	6848
Montgomery	576	44	0	60	119	6	0	805
Nassau	6871	434	0	358	915	140	0	8718
New York	5475	275	0	287	4462	856	78	11433
Niagara	1315	240	0	70	198	41	0	1864
Oneida	2394	186	0	141	287	949	1,269	5226
Onondaga	2663	411	0	227	491	129	0	3921
Ontario	730	37	0	57	108	19	0	951
Orange	1298	191	0	206	397	353	173	2618
Orleans	293	0	0	19	17	169	641	1139
Oswego	548	78	0	43	61	10	0	740
Otsego	374	34	0	76	32	4	0	520
Putnam	263	62	0	40	70	27	0	462
Queens	11455	1432	116	462	3383	620	91	17559
Rensselaer	1167	89	0	128	247	79	0	1710
Richmond	2902	398	0	231	759	188	0	4478
Rockland	1499	217	0	222	608	319	0	2865
Saratoga	704	18	0	106	95	21	0	944
Schenectady	1006	23	0	124	165	27	0	1345
Schoharie	0	33	0	35	35	1	0	104
Schuyler	115	40	0	11	18	3	0	187
Seneca	98	0	0	21	109	160	622	1010
St. Lawrence	582	54	0	70	177	135	709	1727
Steuben	674	11	0	32	103	3	0	823
Suffolk	7688	539	0	582	1903	509	0	11221
Sullivan	404	13	0	130	229	158	395	1329
Tioga	248	14	0	17	21	0	0	300
Tompkins	389	10	0	44	105	11	0	559
Ulster	1115	117	0	160	212	91	837	2532
Warren	357	24	0	67	80	6	0	534
Washington	499	16	0	39	51	219	729	1553
Wayne	522	25	0	92	70	22	0	731
Westchester	5922	274	0	256	1186	633	849	9120
Wyoming	209	0	0	13	29	262	1,160	1673
Yates	186	0	0	19	36	6	0	247
TOTALS	**105,400**	**8,190**	**437**	**7,833**	**27,132**	**10,096**	**16,426**	**175,514**

Table 1.3 Top 8 Counties with Combined Greatest Need Based on Penetration Rate and Inundation Index

This table provides a list of the counties which, when their penetration rates and inundation indexes were combined, emerged as the counties with the greatest need for increased independent living services.

- Each county was ranked separately by penetration rate (columns 2 & 3) and by inundation index (columns 4 & 5), with a ranking of "1" indicating the greatest need.

- These two ranking scores were then added together to get a total score. The lower the total score in column six, the higher the need and ranking.

1. NYS County	2. Top 10 Penetration Rates	3. Ranking Score (1-10)	4. Top 10 Inundation Indexes	5. Ranking Score (1-10)	6. Total Score Column 2+4 Lower score/ higher need
Kings	0.92%	1	6.53	5	6
Bronx	1.13%	2	6.82	4	6
Queens	1.14%	3	6.97	3	6
Livingston	1.56%	4	11.80	2	6
Seneca	1.81%	6	12.32	1	7
Suffolk	1.62%	5	6.14	6	11
Genesee	1.83%	7	5.44	7	14
Nassau	2.27%	9	3.97	10	19

Rankings not identified in chart (numbers skipped) represent counties that only scored as high need on one of the two categories.

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

The NYSILC Needs Assessment Committee (NAC) work group determined that the best way to address question 2 was to identify the known unserved and underserved populations and groups based on existing data, reports, and information and then write narrative summaries for each.

In addition, several questions on the Center Director's survey asked them to identify, within their service area, groups of people with disabilities that they felt are underserved or hard to reach by their organization.

The top rated groups with disabilities (percent of respondents who selected each item) were:

Male veterans	61.5%
Female veterans	53.8%
Rural residents	42.3%
Youth / young adults	38.5%
Hispanic	38.5%

For the full listing of responses, see Appendix II, Table 2.1.

Veterans with disabilities

Center Directors across the state identified disabled veterans as the most underserved population. A Center Director's comment on the survey included an emphasis on providing employment services for veterans with disabilities. Another said that:

- *"Despite significant efforts we have made little progress in increasing service provision to veterans."*

According to the US Department of Veterans Affairs, in 2014 New York State was home to nearly 900,000 veterans.[17]

One year after the 2014 outrage about long waiting lists for health care shook the Department of Veterans Affairs, the agency is facing a new crisis: The number of veterans on waiting lists of one month or more is now 50% higher than it was during the height of last year's problems, department officials say. The department is also facing a nearly $3 billion budget shortfall, which could affect care for many veterans.[18]

---

[17] US Department of Veterans Affairs
http://www.va.gov/vetdata/Quick_Facts.asp
[18] Wait Lists Grow as Many More Veterans Seek Care and Funding Falls Far Short
New York Times JUNE 20, 2015
http://www.nytimes.com/2015/06/21/us/wait-lists-grow-as-many-more-veterans-seek-care-and-funding-falls-far-short.html?_r=0

According to the 2013 US Census Bureau American Community Survey (ACS), of individuals **ages 18 and over** living in the community reported having a military service-connected disability rating of **70 percent or more**, there were:
- 965,943 nationally
- 27,109 in New York State

For civilian veterans' **ages 18 years and** over living in the community, there were:
- 19,344,883 nationally, 5,522,589 of whom were individuals with disabilities (28.5%).
- 785,638 in New York State, 211,931 of whom were individuals with disabilities (27.0%).

Additional data for veterans living in poverty **(ages 18-64 only):[19]**

	Veterans with Disability	Number living in Poverty	Percent of disabled veterans living in poverty	Veterans **without** Disability	Number living in Poverty	Percent of non-disabled veterans living in poverty
National	1,878,149	325,892	17.4%	8,326,520	621,714	7.5%
New York State	58,172	10,815	18.6%	301,187	23,461	7.8%

This data shows a significantly higher poverty rate (more than double) for veterans with disability compared to those without a disability. For further discussion about poverty and people with disabilities, see section Disability and Poverty (page 25).

According to the Center for Housing Policy, in 2013 there were 62,619 veterans are homeless on any night. Also, veterans who need permanent supportive housing cannot afford rent at the levels necessary for covering a property's operating costs, much less pay for supportive services. [20]

Rural Residents with Disabilities/Transportation

Center Directors also identified rural residents as a key underserved population and this aligns with feedback from the public hearings which identified transportation as a key barrier to service and to independent living for people with disabilities, especially in rural areas of the state.

Youth with Disabilities

---

[19] 2014 Annual Disability Statistics Compendium
http://disabilitycompendium.org/compendium-statistics
[20] Veterans Permanent Supportive Housing: Policy and Practice, 2013
National Housing Conference (NHC) and its research affiliate the Center for Housing Policy

Center Directors identified children and young adults as one of the five most underserved populations.

In 2012, the total number of youth ages 6 to 21 receiving IDEA special education services in New York State was 385,763.[21] These numbers were further broken down according to the following disabilities:[22]

- 149,694   specific learning disabilities
- 87,445   language impairments
- 59,616   other health disabilities
- 24,439   autism
- 16,959   multiple disabilities
- 4,225   hearing impairments
- 1,720   orthopedic disabilities
- 1,259   visual disabilities
- 14   deaf-blindness
- 1,081   traumatic brain injury

The IDEA students (with disabilities) in this age group left school for the following reasons:[23]

- 16,411 (60.5%) graduated with diplomas
- 4,796 (17.7%) received certificates
- 5,618 (20.7%) dropped out
- 322 (1.2%) died or aged out of services

There were two comments from the Center Director's survey related to serving youth with disabilities:

- *"Youth and adults who are incarcerated is another underserved group to whom we'd like to provide services."*

- *"There should be a focus on assisting the youth with mental, emotional and behavior disabilities who are in trouble in or have dropped out of school."*

---

[21] Disability Compendium, Table 11.3a: All Disabilities for NY: http://disabilitycompendium.org/compendium-statistics/special-education/11-3a-special-education-students-ages-6-21-served-under-idea-part-b-by-select-diagnostic-categories
[22] Disability Compendium, Tables 11.3a-11.3d.
[23] Disability Compendium, Table 11.5: http://disabilitycompendium.org/compendium-statistics/special-education/11-5-special-education-students-ages-14-21-served-under-idea-part-b-left-school-by-reason.

Minorities and Disability

Center Directors also identified people with disabilities who are Hispanic as another of the top five underserved populations.

The following observations are based on data from a chart that analyzes data from Cornell University of people with disabilities in all counties broken out by race and ethnicity.[24]

Hispanic:

Overall, in New York State, 10.6% of Hispanics sampled (344,199 out of 3,239,392) were people with disabilities. 78% of all Hispanics with disabilities in NYS are located in New York City. By county the breakdown is:
- Bronx County (104,219) 30.3%
- New York County (57,130) 16.6%
- Queens County (49,303) 14.3%
- Kings County (50,837) 14.8%.
- Suffolk County (11,947) 3.5%
- Westchester County (10,857) 3.2%
- Nassau County (10,454) 3%
- Monroe County (7,419) 2.2%
- Richmond County (6,158) 1.8%
- Orange County (5,538) 1.6%

The remaining Hispanics are distributed through the other counties in small numbers.

African American:
In New York State, 12.6% of African Americans/Blacks sampled (334,986 out of 2,651,864) were people with disabilities. The highest concentration of African American/Blacks with disabilities are located in New York City (67.6% of the statewide total). By county the breakdown is:
- Kings County (84,133) 25.1%
- Bronx (56,866) 17%
- Queens County (45,358) 13.5%
- New York County (35,446) 10.6%
- Monroe County (17,454) 5.2%
- Erie County (17,391) 5.2%
- Westchester County (12,688) 3.8%
- Nassau County (10,343) 3.1%
- Suffolk County (9,571) 2.9%

---

[24] Cornell University Employment and Disability Institute, Race and Ethnicity of People with Disabilities by All NYS Counties American Community Survey 2015.

The levels of African Americans/Blacks with disabilities in all other counties are less than 2% of the state total.

Asians:
In New York State, 6.2% of Asians sampled (85,447out of 1,376,933) were people with disabilities. The highest concentration of Asians with disabilities are located in New York City at 79.9%. By county the breakdown is:
- Queens County (34,122) 39.9%
- Kings County (14,694) 17.2%
- New York County (12,974) 15.2%
- Nassau County (4,039) 4.7%
- Bronx County (3,975) 4.7%
- Richmond County (2,480) 2.9%,
- Suffolk County (2,296) 2.7%
- Westchester County (1,874) 2.2%

The levels of Asians with disabilities in all other counties are less than 2%.

An "other" category was reported but not specific enough to merit comment. As with any sample, it is a snap shot. Any variations could be due to under-reporting of disabilities, cultural factors, and or lowered availability to services for minorities with disabilities.

In terms of other considerations for minorities with disabilities, there is an acknowledgement that individuals can experience "triple jeopardy" so that a person of race/ethnicity can also experience discrimination and challenges in life and employment as a person with a disability and based on gender. So an African American woman with a disability who is also gay may encounter formidable barriers.[25]

Other Groups

The Needs Assessment Committee identified several other groups as priorities for services. These include people with disabilities who are:
- Homeless
- Living in poverty
- Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ)
- 65 years old or older

Disability and Homelessness

Based on a 2008 Housing and Urban Development (HUD) annual report, people with disabilities are overrepresented in America's homeless population and people living in poverty. Specifically, "42.8% of all adults using homeless shelters had a disability compared to 17.7% of the general adult population reported as having a disability, meaning that a significantly larger percentage of

---

[25] Impact: https://ici.umn.edu/products/impact/211/13.html.

people with disabilities are homeless compared to the rest of the population. One reason for the high number of homeless people with disabilities may be that people in this population are more likely to be impoverished than those without disabilities … making it difficult for peers to retain permanent housing.[26]

In addition, "Adults with disabilities living in poverty comprise 30.7% [of] the population in America that experiences poverty as a whole. The number of persons with disabilities who are homeless is higher than the number of people who are living in poverty - something that tells everyone that people with disabilities are having a difficult time finding a place to live, or a landlord who is willing to rent to them. The resources people with disabilities need in order to survive in America are simply not present in the amount they need to be where housing is concerned.[27]

In a 2008 US Conference of Mayor's survey and report on hunger and homelessness, one aspect profiled the major characteristics of homeless people. The top aspects identified were mentally ill 26%, domestic violence victims 15%, veterans 13%, and physically disabled 13%.[28]

According to the Substance Abuse and Mental Health Services Administration, approximately 20 to 25 percent of the homeless population have a severe mental health disability. Serious mental illness impacts an individual's ability to carry out daily living activities such as self-care and household management.[29] About 9% of the homeless population are veterans and become homeless for a variety of reasons, from disabilities, post-traumatic stress, addictions, and difficulties readjusting to civilian life.[30] Youth experience short-term homelessness to avoid issues such as divorce, neglect, or abuse. LGBTQ youth have experienced increased homelessness and risk.

Issues of serving homeless people with disabilities were also raised strongly at the SPIL public hearings.

Disability and Poverty

For working aged New Yorkers with disabilities (18-64), 325,091 were living at or below the poverty level out of the sample of 1,072,985 individuals for a poverty rate of 30.3%. **To decrease the rate by 5% (and lower the poverty rate to 25.3%) a target goal of 16,255 peers**

---

[26] Disability Scoop, More Than Two-Fifths of Homeless Have Disabilities, http://www.disabilityscoop.com/2009/07/16/homeless-report/4153/.

[27] Disabled World, People with Disabilities and Homelessness, http://www.disabled-world.com/editorials/political/disability-homeless.php.

[28] US Conference of Mayors, Status Report on Hunger and Homelessness, 2008, http://usmayors.org/pressreleases/documents/hungerhomelessnessreport_121208.pdf.

[29] National Coalition for the Homeless, Mental Illness and Homelessness, http://www.nationalhomeless.org/factsheets/Mental_Illness.pdf.

[30] National Alliance to End Homelessness, Snapshot of Homelessness, http://www.endhomelessness.org/pages/snapshot_of_homelessness.

will need to successfully transition from poverty, benefits, and look to achieve economic self-sufficiency based on this sample. (16,255/325,091)[31] More than twice as many people with disabilities are living in poverty than other NY citizens (30.3% versus 13.1%). The 2013 figures represent an increase from 2012 (see footnotes for links to Cornell and Georgetown references).[32]

For the sample identified above (non-institutionalized persons aged 21 to 64 years with a disability in NY), there were 325,091 living below the poverty line in 2013 ($11,170 per year for one person). In 2015, the federal poverty guidelines are now $11,770 ($980.83/month).[33] The SSI benefit amount in NY in 2015 for people living alone is $820 ($733, federal and $87, state funds).[34] Therefore, peers who subsist on SSI, are all living below the federal poverty level.

The maximum monthly benefit for SNAP (food stamps) is $194. People who receive SSDI (if it is higher than the SSI amount), will receive less in food stamps. SNAP also looks at a person's rent in determining food stamp allocation. People who qualify for SNAP, may also qualify for HEAP by applying through the county Department of Social Services (DSS). There are no definitive figures or exact amounts cited. Based on a specific example, one individual received $400 in HEAP last year which is approximately $33.33/month.[35]

Based on these figures, if a New Yorker with a disability applied for these benefits, they could receive the following: SSI: $820 x 12 = $9,840, SNAP: $194 x 12 = $2,328, HEAP: $400 (estimate) = TOTAL: $12,568.

From 2008 to 2011, New York's poverty rate was 13.6%; the Current Population Survey's Annual Social and Economic Supplement found that SNAP and other assistance programs reduced the rate to 10.8%. However, other researchers found that significant numbers of people in the study under-report their assistance income, and when this income is taken into account, the poverty rate drops to 8.3%. These numbers show that SNAP and other poverty-fighting programs are even more effective than previously thought.

The projected total amount of $12,568 is $798 above the 2015 poverty level. However, cost of rent, utilities, and other necessities, can vary across the state, county by county. For example, not everyone who has a disability is able to qualify for Section 8 or other forms of rental subsidies or vouchers. Transportation including the availability of accessible and affordable public transportation is another key issue. In rural counties, housing may be less expensive, but lack of public transportation may mean limited access to groceries and other community services which adds to the cost of living overall.

---

[31] Disability Statistics Compendium, http://disabilitycompendium.org/compendium-statistics/poverty/4-1-poverty-civilians-with-disabilities-ages-18-64-years-living-in-the-community-for-the-u-s-.

[32] Cornell: http://www.disabilitystatistics.org/reports/acs.cfm?statistic=7. Georgetown: http://ccf.georgetown.edu/wp-content/uploads/2012/04/Federal-Poverty-Guidelines.pdf.

[33] Federal Poverty Guidelines: http://www.medicaid.gov/medicaid-chip-program-information/by-topics/eligibility/downloads/2015-federal-poverty-level-charts.pdf.

[34] SSI benefit: https://otda.ny.gov/programs/ssp/2015-Maximum-Monthly-Benefit-Amounts.pdf.

[35] HEAP: http://otda.ny.gov/programs/heap/.

Therefore, when looking at poverty, one needs to consider a whole picture that includes cost of living expenses in a specific community.

Cost of living

The cost of living in New York is high.[36] A resource is provided for a Family Budget Calculator which allows the user to figure out what the cost of living is by regional areas for selected categories (I.e., one adult, one child families, etc.).[37] It identifies Binghamton over $51,000; Buffalo over $52,000; Rochester over $54,000; Poughkeepsie over $62,000; Nassau-Suffolk nearly $71,000, and Rural at $47,000. Even if each figure is cut in half (assuming a single adult and no child), the cost of living is still higher (and in some cases double) than the projected annual benefits/poverty rate of $12,568 for a New Yorker with a disability.

NYS ranks 24th in the nation in hunger and food insecurity as a component of poverty.[38] The percentage of income spent on food will be higher for those with lower incomes. NY ranks 44th in the nation in affordable housing. The need for accessible and affordable housing is a need well documented in county plans. For example, in Suffolk County:
- 854 families requested accessibility features
- 854 were using tenant base housing vouchers
- "Over 15,000 renters are paying over 50% of their income on their housing expenses."

A comment in the plan noted: "The most immediate need of Voucher holders is the ability to find safe, affordable rental housing. For those applicants that may require accessible units, it is very difficult to find those types of housing. Single family homes, the predominant housing type on Long Island, are often not affordable and/or not accessible (page 48 of the Suffolk County plan)." Pages 53-58 provide more detailed disability statistics, including: There are 50,398 persons over the age of 18 with an independent living difficulty in the county. The lack of affordable and accessible housing contributes to individual poverty and institutionalization. See article about "The Best and Worst Places to Grow Up: How Your Area Compares". Children who grow up in some places go on to earn much more than they would if they grew up elsewhere.[39]

---

[36] Cost of Living: http://cost-of-living.startclass.com/d/d/New-York.
[37] Family Budget Calculator: http://www.epi.org/resources/budget/.
[38] COL NY: http://www.numbeo.com/cost-of-living/city_result.jsp?country=United+States&city=New+York%2C+NY. Talk Poverty NY: http://talkpoverty.org/state-year-report/new-york-2014-report/.
[39] NY Times: http://www.nytimes.com/interactive/2015/05/03/upshot/the-best-and-worst-places-to-grow-up-how-your-area-compares.html?_r=1&abt=0002&abg=1.

Health and Disability

A review of data from different sources highlights the importance and need to address health and disability.

Obesity

Among persons ages 18 and over in New York State, people with disabilities have nearly twice the rate of obesity as individuals without disabilities (37.9% compared to 21.8%).[40] In addition, obesity raises a concern with another health issue - diabetes. About 80-90% of people who are obese are also diagnosed with type II diabetes.[41] No direct data was found related to New York State, but 29.1 million or 9.3% Americans have diabetes while 8.1 million are undiagnosed. Diabetes can ultimately lead to multiple disabilities and medical conditions such as cardiovascular disease, stroke, kidney failure, loss of vision, and amputation. Diabetes is the 7th leading cause of death in the United States (2010) with death certificates listing diabetes as an underlying or contributing cause of death.[42]

Smoking

Among persons ages 18 and over in New York State, people with disabilities smoke at a much higher rate than individuals without disabilities (22.6% compared to 14.9%).[43] It is an established fact that smoking is detrimental to an individual's heath. Basic statistics include: "90% of lung cancer cases are caused by smoking, 30% of all cancer fatalities are caused by smoking, and smokers have dramatically shorter lives than non-smokers - on average a smoker will die 15 - 20 years before a non-smoker."[44] There is a significant cost attached to supporting the addictive habit of smoking that will lead some people with disabilities on fixed incomes to further sacrifice healthy eating choices and lifestyles.

Another health issue was raised by a comment from a Center Director on the survey: "*NY State needs to maintain state funded services for people who do not have Medicaid or who need services not covered in managed care.*"

Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) Community

A study found that lesbian, gay, and bisexual adults showed higher prevalence of disability than did their heterosexual counterparts. "About 25% of heterosexual women, 36% of lesbians, and 36% of bisexual women were disabled … About 22% of heterosexual men, 26% of gay men, and

---

[40] Disability Compendium, Percent (%) Obesity among Persons Ages 18 and Over, by Disability Status: 2013
http://disabilitycompendium.org/compendium-statistics/health/8-4-health-behavior---obesity-among-persons-aged-18-and-over-by-disability-status
[41] A Codependent Relationship: Diabetes & Obesity, http://www.diabeticcareservices.com/diabetes-education/diabetes-and-obesity
[42] Statistics about Diabetes Data from the National Diabetes Statistics Report, 2014 (released June 10, 2014) - http://www.diabetes.org/diabetes-basics/statistics/
[43] Disability Compendium, Percent (%) Smoking among Persons Ages 18 and Over, by Disability Status: 2013
http://disabilitycompendium.org/compendium-statistics/health/8-3-health-behavior---smoking-among-persons-aged-18-and-over-by-disability-status
[44] Quitter's Guide.com http://www.quittersguide.com/dangers-smoking.shtml

40% of bisexual men were disabled. The likelihoods of being disabled for gay men and bisexual men were significantly higher than that for heterosexual men even after we controlled for age. Among LGB adults, 36% of women and 30% of men were disabled.[45]

The LGBTQ community faces tremendous adversity in society that often leads to harassment, marginalization, and can evoke hostility and or violence. LGBTQ youth experience high rates of attempted and completed suicides, violence victimization, substance abuse, teenage pregnancy, and HIV/STI associated risky behaviors. Providers estimate that up to 40% of homeless youth may be LGBTQ. Fifty percent of gay teens experienced a negative reaction from their parents when coming out and 26% were kicked out of their home. In a nationwide survey, 84% of LGBTQ students reported being verbally harassed, 40% physically harassed, and 19% physically assaulted at school during the past year. LGBTQ youth of color are at a high risk for harassment. A nationwide study found that more than a third of LGBTQ students of color had experienced physical violence because of their orientation.[46]

In the SPIL formulation public hearings, strong support was indicated for programs to provide outreach, training and support to this community, especially around issues of suicide prevention and depression.

Aging and Disability

There is a high rate of disability among people ages 65 and older. Among this group, the percent of those with disabilities is higher in New York City than either nationally or statewide. Within NYC, Brooklyn has the highest number of seniors with disabilities, although the Bronx has the highest percent of those 65-74 and Manhattan has the highest percent of those ages 75 and up:

	People with disabilities as a percent of the overall population	
	Ages 65-74	Ages 75+
Nationally	27.3%	56.5%
New York State	25.2%	56.6%
New York City	28.4%	59.8%
The Bronx	36.4%	
Manhattan		61%

---

[45] Fredriksen-Goldsen KI, Kim H-J, Barkan SE. Disability Among Lesbian, Gay, and Bisexual Adults: Disparities in Prevalence and Risk. *American journal of public health*. 2012;102(1):e16-e21. doi:10.2105/AJPH.2011.300379. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3490559/

[46] Gay, Lesbian, Bisexual, Transgender, and Questioning (GLBTQ) Youth, http://www.advocatesforyouth.org/publications/424-glbtq-youth.

Older blacks with disabilities are almost twice as likely to live in poverty (23.7%) as the national average of 12.6 %. Older women with disabilities are more likely to be living in poverty than their male counterparts (15.2% vs. 9.2%).

New York State has a slightly higher percentage of seniors with disabilities living alone (32.2%) compared to the national average (29.9%), and a higher incidence (12.2%) of those living in "group quarters" (i.e., nursing homes) than the national average of 9.2%.[47]

<u>Institutionalized Population</u>

The 1999 Olmstead US Supreme Court decision provided the most-integrated setting mandate. While New York State has created a Most-Integrated Setting Coordinating Council (MISCC) and the Governor issued an Executive Order related to Olmstead, progress has been slow. An Olmstead Plan was issued by the Olmstead Cabinet in October 2013.[48] The State needs to put significant resources behind the implementation of the plan with target dates for achievement. The State also needs to identify its institutionalized population. In this report in Table 1.2 we estimated the total number at 175,514 individuals for each area identified. Resources, providers, and options need to be available to our institutionalized peers (and those at risk of being institutionalized) so that they can reclaim quality of life and live independently in the community of their choice.

---

[47] Molton IR, <u>Aging with and Aging into Disability</u>. Presentation for the Gerontological Professionals Network sponsored by the University of Washington's School of Nursing de Tournyay Center for Healthy Aging, Seattle, WA, 2015.
[48] Olmstead Report: http://www.criminaljustice.ny.gov/opca/pdfs/9-Olmstead-Cabinet-Report101013.pdf.

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 daily challenges were:
1. Finances (paying bills) (45.2%)
2. Transportation (43.6%)
3. Social (34.0%)
4. Employment (32.4%)
5. Housing (31/7%)

As shown by the percentages noted, no single challenge was universally felt. Approximately 12% of respondents also added a comment to this question. These comments included transportation, finances and housing issues, as well as health issues and individual rights/empowerment, among those that were the most noted. The housing issues noted were either a lack of adequate affordable and accessible housing options or a lack of finances available, which relates back to the top challenge noted above.

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)	Housing (accessibility, affordability)	Finances (paying bills)
Transportation	Transportation	Transportation
Employment	Finances (paying bills)	Personal care (eating, bathing, housekeeping)

Social (needing support from family and friends), interestingly enough, was number four for all respondents. Employment was number five for urban respondents and number six for suburban 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 46.)

Consumers were also asked which services were most important to help them live independently. The top three were:
- Benefits assistance and advice (51% of the respondents selecting this)
- Advocacy (50% response rate)
- Transportation (42.8%)

The results were again fairly consistent when this data was filtered by whether consumers lived in rural, urban or suburban settings.

Rural	Urban	Suburban
Advocacy	Benefits assistance and advice	Advocacy
Benefits assistance and advice	Advocacy	Benefits assistance and advice
Transportation	Transportation	Transportation

As noted above, transportation was also cited as a significant challenge in daily life; suggesting it is an important area to focus efforts on.

Interestingly enough, the three next highest responses were the same across all three groups, despite their community setting:

- Medical /health services (35% overall)
- Home care / personal assistance services (32%)
- Employment / work readiness services (28%)

For a full display of the responses for each item in this question sorted by rural, urban and suburban, see Table 3.2 page 48.

Center Directors were asked to rate what services needed to be expanded or started in their community to better meet local needs of people with disabilities. The two needs ranking highest were benefits advisement and employment, which relate closely with consumer identification of greatest barriers as finances and employment and with benefits advisement as their top rated service. Transportation and architectural barrier services were also noted highly by Center Directors.

Consumers were also asked what services were most readily available and which were lacking in their area. The most readily available services were:

- Advocacy
- Information and referral to other services
- Medical / health services

Advocacy and medical / health services were also cited as among the top four 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 of limited availability or not available in their area. Very few were rated as completely not available. Transportation was cited most highly as not available, but only by 15% of respondents. When Not Available was combined with Limited Availability, the numbers increased dramatically:

- Transportation 56% of respondents
- Housing services 54%
- Recreation 47%
- Employment 44%
- Home care / personal assistance 42%

Lack of transportation was a theme throughout all the input. Since employment and home care were rated by respondents as highly important to independent living and were then rated as having very limited availability, these may be areas to focus on along with transportation.

Among those who gave comments regarding the availability of services, transportation was by far the most common, with the lack of reliable, timely and accessible transportation being cited. One respondent noted:

- *"Transportation is really the key area - with many* [of the services on the survey] *checked above, the problem is getting to the service in a reliable, efficient, timely way."*

Another respondent commented specifically about Access-A-Ride and the treatment of New Yorkers with disabilities:

- *"Access-A-Ride is extremely abusive and seems designed to discourage use. 90% of rides are well over one hour late. Complaints go nowhere, there is no accountability. After very late pick up, rides can last well over 2.5 hours due to very bad dispatching and scheduling. The excuse given is "traffic" as if NYC traffic is a daily surprise to those running Access-A-Ride. Disabled New Yorkers are treated like garbage by Access-A-Ride, we are merely a source of income for those running this corrupt system. Sick people are subjected to interminably long rides, and long waits. It is inexcusable and should be investigated and totally reformed."*

On their survey, Center Directors were also asked to focus on issues/areas that are not sufficient to meet demands/needs of two specific population groups – youth and senior citizens with disabilities.

For senior citizens with disabilities, the top rated services they identified as currently not sufficient to meet demand were:
- Affordable housing (73%)
- Adequate income (54%)
- Transportation (35%)

In addition, several Directors added these comments:

- *"Most of the services listed are needed but minimally available in this rural, poor county because of minimal funding to support a few agencies that are able to provide only limited services. Less populated areas (most of the county) have little access to services."*
- *"Home care options for people who are not eligible for Medicaid to stay in the community."*
- *"Many more than five areas are lacking."* [Directors were asked to only select up to 5 areas on the survey.]

For youth with disabilities, the top rated items were:
- Employment opportunities (69%)
- Affordable, accessible opportunities to socialize (42%)
- Affordable housing (39%)
- Transition services (39%)

Additional comments from Directors regarding services to youth included:

- *"Adequate educational opportunities."*
- *"Most services are underfunded by OMH, OPWDD, OASAS, IL and HHS/ACL which greatly limits their availability and the numbers of people able to be served. Federal and State funding has not been increased in years while needs have increased, especially mental health and addictions."*
- *"There are many more than just five areas where services are not sufficient to meet demand."* [Directors were asked to only select up to 5 areas on the survey.]

Access to Services

In addition to assessing the availability of the services, consumers were also asked to rank by importance from 1-6 with 1 being highest importance, what would make it easier to get services. There were six options offered and in order of importance they were:
- Expand services (2.87)
- Transportation to and from the services (3.01)
- Expand hours of operation (3.36)
- Advertise existing (3.46)
- Hire additional staff (3.65)
- Home visits (4.02)

While availability of home visits scored lowest in terms of importance, it was selected by 242 of the 260 people who responded to this question, or 93%. This was the highest among the six items, so home visits are important to more respondents than all other items (which ranged from 83%-88%). While it was selected most frequently, it was not given many #1 rankings. Transportation received the most number 1 rankings (55), but was only selected by 226 respondents overall.

For those respondents who selected "Other" for this question, the bulk of the comments were related to assistance navigating the system, availability of information regarding services, and transportation.

Additionally, respondents were asked to provide comments on how else their service providers could make it easier to access services. Of the 109 respondents who answered the question, more than one-third referred to communication from service providers and advertisement/outreach of the programs and services. Transportation needs (18%) was the next most common. Less common were: staff/availability, increased services, and having a collaborative healthcare team, rather than having separate service providers that don't communicate with each other.

When asked for the best ways for a service provide to communicate with them, respondents rated by phone (66.0%) and email (63.7%) as the top two choices. Mail was rated by 39% and the rest all fell below 30% (in order highest to lowest: texting, internet, social media and fax). Of the 18 respondents who selected "Other" on this question, 84% responded with face to face, in person communication, whether at home or in an office.

New Yorkers with disabilities indicated the following as top selections for where they go to receive services or support:

Independent Living Center (cited by 56.3%)
Internet resources (cited by 33.7%)
Counseling/Therapy (cited by 31.3%)
At home (cited by 26%)
Social services (cited by 26%)

The remainder were selected by 20% or fewer. "Other" was selected by 78 respondents who mostly cited specific agencies by name, as their selection here.

For those who receive services at home, common types of services received were housekeeping and home health aide services, followed by Consumer-Directed Personal Assistance and habilitation. 76.5% of respondents receive all services within their county while 20.6% do travel outside of their county to get some of their independent living services. (Only 7 respondents, 3%, indicated that they have to go outside their county for all services.)

Respondents were also asked to indicate what types of organizations they had trouble receiving services or where accommodations were not made. The organizations with the highest number of responses were:
- Social services (27.5%)
- Park or gymnasiums (25.5%)
- College or universities (23.5%)
- Hospitals (22.8%)
- Place of employment (22.8%)
- Place of worship (22.1%)

For those who selected "Other" here, the most common concern from those respondents was accommodations out in the community (schools, voting places, restaurants, etc.).

The survey also focused a question specifically on Independent Living Centers. 39% of respondents noted they do currently receive services at an ILC, and another 24%. said they have received services from an ILC in the past. Ten percent of the respondents did not know what an ILC is and 5 % did not know where the nearest ILC was. The remaining 23% indicated that they have never received services from an ILC, but knew what and where they were.

The remaining questions on the survey focused on the respondents' demographic information. The respondents' ages were primarily 23-74 years old (86.3% of the respondents) with the age range of 23-54 years old being the most common (54.6%).

The racial/ethnic group breakdown was 78.7% white with a disproportionately smaller representation from people of color. When asked to describe their disability, the respondents' largest numbers reported physical disabilities (46.7%), followed by mental health disabilities (33.7%) and developmental disabilities (26/1%). [For a complete listing see tables in Appendix III.]

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

The Center survey addressed this question by asking Center Directors to prioritize the needs of both ILC consumers and the Centers themselves. They were also asked what services they might want to start or expand and barriers to service provision. Finally, they were asked to prioritize the resources they would need to increase their service mix. The purpose of this survey was to provide input to the NYS Independent Living Council as they developed their next three-year Statewide Plan for Independent Living (SPIL).

When asked about the greatest need for **expanded** services, Directors rated the following as high priorities:
- benefits advisement
- employment services
- architectural barrier services
- advocacy / legal services
- housing and shelter services
- youth transition services

While not selected by the largest number of respondent, advocacy/legal services had by far the largest number of #1 ratings (highest importance).

When rated by degree of importance (most strongly valued by the respondents) and not the total number of response, the order shifts to (based on a 5 point scale with 1 the highest importance):
- advocacy / legal services (2.00)
- youth transition services (2.11)
- employment services (2.64)
- benefits advisement (2.67)
- architectural barrier services (3.38)
- housing and shelter services (3.60)

Ratings were somewhat similar when asked about the greatest need for **new** services. Directors rated four of the same six services highest, with the exception of benefits advisement and advocacy/legal services. Under the category of new services, they also added recreational and transportation services to the top six. Architectural barriers and employment services were most strongly valued for new services. (See Appendix IV for the full table.)

In addition, there were three comments adding an "other" category:
- Respite for families who have children with disabilities not covered under OPWDD.
- Community education program about the benefits of integrating people with developmental disabilities into the community. There has been a lot of fall-out due to the proposed closure of BDC.
- Education program for consumers and families about the benefits of community integration.

When asked about barriers to providing or expanding current services or starting new services, the top three barriers were:
- the lack of financial or other resources
- funding restrictions
- lack of transportation for consumers

Transportation was also strongly commented on in the public hearings, in terms of the need for more transportation and more accessible vehicles.

Other highly rated barriers to providing existing services were lack of awareness of ILC services – both from the general public and from people with disabilities, and inability to recruit qualified staff due to non-competitive wages/benefits. For starting or expanding services, only the top three noted above received a large number of responses.

When asked to identify "other" barriers, to providing current services, one Director commented: *"Lack of staff capacity to flexibly shift priorities and multitask."* This highlights the fact that center staff often have to manage a number of different responsibilities due to the wide range of services offered and limited staff resources. A related comment for a barrier to expanding or starting new services: *"Not enough time in the day. We are focusing where we can right now."*

When asked about the resources needed to overcome these barriers, additional funding was the highest rated for existing, expanded, or new services.
- For overcoming barriers to existing services, increased transportation for consumers and increased public relations and political support were all rated highly.
- For overcoming barriers to new or expanded services, additional space/satellite office/equipment was the only resource besides funding mentioned by more than 35% of respondents.

One comment related to training and technical assistance was help with a *"County specific development plan."*

The final question asked respondents to comment on any other priority areas that the Council should consider when developing the next three year Strategic Plan for Independent Living. Most of these comments reflected earlier responses, but some additional ones were:

- The push towards regionalization often results in a "one size has to fit all" mentality.
- More systems advocacy (especially with all the proposed changed to the waivers, moving them to managed care (TBI, NHTD and OPWDD).
- Public education about community integration and its desirability.
- Public education about ILCs and what they do (IL philosophy).
- Increased awareness on the state level by politicians of ILC success.
- Universal funding for employment-related initiatives (all centers should receive additional funding earmarked for employment specialists in their communities) ... consistent with Governor's Employment First Commission and related initiatives.

In addition, some comments that were raised in the public hearings included:

- Strong support for the statewide systems advocacy network recognizing its value to the network.
- Funding for a legal advocate at a center to file complaints and actions. The Protection & Advocacy (P & A) network only focusses on specific areas and not necessarily the business within a community.
- Provide best practices for accessibility programs to help centers to develop their own new programs.

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: Consumer comments.

Appendix VI: Feedback on survey design and completion.

Appendix VII: Copies of the two surveys used in the study.

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

Council Members:

o Chair, Susan Ruff, NYSILC, STIC, advocate@stic-cil.org.

o Chad Underwood, NYSILC Chair, ATI Cortland, cwunderwood@aticortland.org.

o Joe Bravo, Former NYSILC Chair, WILC, jbravo@wilc.org.

o Julie Cardone, NYSILC, CBVH, Julie.cardone@ocfs.state.ny.us

o Carla Lewis-Irizarry, NYSILC, Carlalewis34@gmail.com.

o Helen Fang, NYSILC, hfang888@gmail.com.

Non-Council Members:

o Doug Usiak, Former NYSILC Chair, WNYIL, djusiak@buffalo.edu.

o Fred Ayers, ACCES-VR, fayers@mail.nysed.gov.

o Brad Williams, NYSILC Executive Director, bradw@nysilc.org.

o Adam Prizio, CDR, aprizio@cdrnys.org.

o Alan Krieger, Krieger Solutions, Consultant, alan@kriegersolutions.com.

Appendix II. Data Tables for Question 2: Population Groups in Greatest Need

Table 2.1   High need groups as identified on the Center Director's survey

Directors were asked to identify, within their service area, groups of people with disabilities that they felt are underserved or hard to reach by their organization.

Answer Options	Response Percent	Response Count
Male veterans	61.5%	16
Female veterans	53.8%	14
Rural residents	42.3%	11
Children / young adults	38.5%	10
Hispanic	38.5%	10
Homeless	26.9%	7
Asian/Pacific Islander	23.1%	6
Immigrant groups / Non-native English speakers	23.1%	6
Black non-Hispanic	19.2%	5
Blind	19.2%	5
Seniors	15.4%	4
Multi-ethnic	15.4%	4
Deaf / Blind	11.5%	3
Dual diagnosis - developmental / mental health	11.5%	3
Deaf	7.7%	2
Physical disabilities	7.7%	2
Mental / emotional disabilities	7.7%	2
Dual diagnosis - mental health / chemical abuse	7.7%	2
American Indian	3.8%	1
LGBTQIA	3.8%	1
Other	3.8%	1
Cognitive disabilities	0.0%	0

Appendix III: Tables and charts from the consumer survey that provides a respondent profile. Total number of respondents = 263

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

Rural	28.4%	73
Urban	42.0%	108
Suburban	29.6%	76
answered question		**257**

Race/ethnic group:

Answer Options	Response Percent	Response Count
American Indian	0.8%	2
Asian/Pacific Islander	1.2%	3
Black non-Hispanic	7.0%	12
Hispanic	4.7%	20
White	78.7%	203
Multi-ethnic (More than one)	5.0%	13
Other (please specify)	2.7%	7
answered question		**258**

Age range:

Answer Options	Response Percent	Response Count
Under 6 years old	0.4%	1
6-17 years old	6.1%	16
18-22 years old	6.5%	17
23-54 years old	54.6%	143
55-64 years old	21.0%	55
65-74 years old	10.7%	28
75 years and older	0.8%	2
answered question		**262**

What region of the state do you live in?   N = 245

Region	Responses
NORTH COUNTRY: Franklin, Clinton, Essex, Hamilton, St. Lawrence, Warren, Washington, Jefferson, Lewis	42
CAPITAL DISTRICT: Albany, Schenectady, Rensselaer, Saratoga, Fulton, Montgomery, Schoharie, Columbia, Greene)	46
LOWER HUDSON VALLEY: Westchester, Rockland, Orange, Putnam, Sullivan, Dutchess, Ulster	14
SOUTHERN TIER: Delaware, Broome, Tioga, Chemung, Schuyler, Chenango, Otsego	29
CENTRAL: Herkimer, Madison, Oneida, Oswego, Onondaga, Cayuga, Tompkins, Cortland	40
WESTERN: Chautauqua, Cattaraugus, Erie, Allegany, Wyoming, Orleans, Niagara, Genesee	21
FINGER LAKES: Wayne, Steuben, Livingston, Yates, Ontario, Seneca, Monroe	8
NEW YORK CITY: Brooklyn, Queens, Staten Island, Manhattan, Bronx	37
LONG ISLAND: Nassau, Suffolk	9
Total responding	246

Please describe your disability. (Respondents were asked to check all that apply, so the total number of <u>responses</u> (542) exceeds the number of <u>respondents</u> (261).

Answer Options	Response Percent	Response Count
Blind/vision difficulties	12.6%	33
Deaf/Hard of Hearing	11.9%	31
Developmental Disabilities	26.1%	68
Mental Health Disabilities	33.7%	88
Physical Disabilities	46.7%	122
Sensory Disabilities	12.3%	32
Substance Abuse	5.0%	13
TBI/Neurological	13.4%	35
Multiple Disabilities	18.4%	48
Dual Diagnosis – developmental / mental health	8.0%	21
Dual Diagnosis – mental health / substance abuse	4.2%	11
Other (please specify)	15.3%	40

answered question   **261**

Of those 40 that did select "Other" here, 15 noted a developmental/neurological disability (Autism most noted). 13 noted a physical disability and 8 noted multiple disabilities.

Respondents were also asked to check any of the following that describes them:

Answer Options	Response Percent	Response Count
Homeless	16.7%	8
Veteran	16.7%	8
Non Native English Speaker	27.1%	13
LGBTQIA	45.8%	22
answered question		**48**
skipped question		**215**

Forty-eight of the 263 respondents (18%) responded to one or more of these.

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

Table 3.1 N=256 total

Consumer Survey Q1: What is most difficult for you in your daily life?

Issues/challenges to be rated:	Percent who selected this	Number of responses
Finances (paying bills)	45.2%	117
Transportation	43.6%	113
Social (needing support from family and friends)	34.0%	88
Employment	32.4%	84
Housing (accessibility, affordability)	31.7%	82
Personal care (eating, bathing, housekeeping)	24.7%	64
Medical/health coverage	23.6%	61
Recreation (community events, parks, movies, etc.)	23.6%	61
Applying for benefits	20.8%	54
Mobility (accessibility, assistive devices)	20.1%	52
Discrimination	19.3%	50
Education	14.7%	38

Thirty respondents selected "other" and these included comments relating to financial, health, housing, self-advocacy, and accommodations at work

Here is the same data filtered by rural / urban / suburban respondents

Rural respondents N=73		Urban respondents N=108			Suburban Respondents N=76	
Finances (paying bills)	47%	Housing (accessibility, affordability)	43%		Finances (paying bills)	46%
Transportation	45%	Transportation	42%		Transportation	42%
Employment	40%	Finances (paying bills)	40%		Personal care (eating, bathing, housekeeping)	30%
Social (needing support from family and friends)	36%	Social (needing support from family and friends)	36%		Social (needing support from family and friends)	28%
Medical/health coverage	26%	Employment	31%		Recreation	28%
Recreation	25%	Mobility (accessibility, assistive devices)	26%		Employment	26%
Housing (accessibility, affordability)	22%	Personal care (eating, bathing, housekeeping)	24%		Medical/health coverage	25%
Discrimination	22%	Medical/health coverage	20%		Applying for benefits	23%
Applying for benefits	21%	Discrimination	19%		Housing (accessibility, affordability)	23%
Personal care (eating, bathing, housekeeping)	18%	Recreation	19%		Mobility (accessibility, assistive devices)	18%
Education	14%	Applying for benefits	19%		Discrimination	14%
Mobility (accessibility, assistive devices)	10%	Education	13%		Education	13%

Table 3.2 N= 257 total

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

Services	Percent selecting	Number of responses
Benefits assistance and advice (SSI/SSDI/Food stamps, etc.)	51.4%	132
Advocacy (assisting with getting rights, services)	50.6%	130
Transportation	42.8%	110
Medical / health services	35.0%	90
Home care / personal assistance services	31.9%	82
Employment / work readiness services	27.6%	71
Information and referral to other services	23.3%	60
Independent living skills training	22.6%	58
Housing services	19.8%	51
Assistive devices training (medical equipment, wheelchairs, etc.)	18.7%	48
Education services	16.7%	43
Mental health services	16.7%	43
Recreation services	16.7%	43
Supported services for apartment living	16.0%	41
Peer counseling	14.8%	38
Family services	11.3%	29
Mobility training/services	6.6%	17

There were 13 "other" responses.

Same data filtered by rural / urban / suburban

Rural respondents N= 73		Urban respondents N= 108		Suburban Respondents N=76	
Advocacy	55%	Benefits assistance and advice	49%	Advocacy	46%
Benefits assistance and advice	53%	Advocacy	49%	Benefits assistance and advice	42%
Transportation	38%	Transportation	49%	Transportation	39%
Medical / health services	36%	Medical / health services	45%	Medical / health services	36%
Home care / personal assistance services	27%	Home care / personal assistance services	41%	Home care / personal assistance services	34%
Employment / work readiness services	26%	Employment / work readiness services	38%	Employment / work readiness services	30%
Information and referral to other services	25%	Housing services	37%	Independent living skills training	29%
Independent living skills training	23%	Assistive devices training	29%	Information and referral to other services	21%
Mental health services	21%	Information and referral to other services	27%	Education services	18%
Family services	19%	Supported services for apartment living	25%	Supported services for apartment living	17%
Recreation services	19%	Independent living skills training	25%	Recreation services	16%
Education services	15%	Mental health services	25%	Housing services	16%
Housing services	14%	Education services	16%	Assistive devices training	16%
Assistive devices training	12%	Recreation services	14%	Mental health services	12%
Supported services for apartment living	10%	Family services	13%	Mobility training/services	8%
Mobility training/services	4%	Mobility training/services	7%	Family services	7%

Table 3.3 N= 262 total

Consumer Survey Q3: How available are each of the following services in your area?
(sorted by those rated most "limited" availability)

Answer Options	Limited Availability (waiting list, etc.)	Not Available
Housing services	111	30
Transportation	109	38
Employment / work readiness services	98	17
Recreation services	96	26
Home care / personal assistance services	94	17
Mental health services	86	14
Education services	82	11
Mobility services	78	17
Family services	77	13
Independent living skills training	76	13
Benefits Assistance and Advice	74	16
Medical / health services	71	7
Information and referral to other services	64	13
Peer counseling	59	25
Assistive devices training	59	21
Supported services for apartment living	53	17
Advocacy	44	12

Table 3.4

Consumer Survey Q3: **How available are each of the following services in your area? (same data as Table 3.3, with all responses shown and sorted alphabetically)**

Answer Options	Readily Available	Limited Availability (waiting list, etc.)	Not Available	Don't Know	Rating Average	Response Count
Advocacy	168	44	12	31	1.30	255
Assistive devices training	75	59	21	90	1.65	245
Benefits Assistance and Advice	138	74	16	26	1.46	254
Education services	100	82	11	53	1.54	246
Employment / work readiness services	94	98	17	40	1.63	249
Family services	104	77	13	54	1.53	248
Home care / personal assistance services	89	94	17	47	1.64	247
Housing services	63	111	30	49	1.84	253
Independent living skills training	114	76	13	46	1.50	249
Information and referral to other services	153	64	13	24	1.39	254
Medical / health services	152	71	7	22	1.37	252
Mental health services	98	86	14	28	1.58	226
Mobility services	68	78	17	77	1.69	240
Peer counseling	101	59	25	66	1.59	251
Supported services for apartment living	36	53	17	39	1.82	145
Recreation services	66	96	26	62	1.79	250
Transportation	79	109	38	27	1.82	253
Comment / Other (please specify and indicate how available they are)						20
					answered question	**262**

Center Director Survey

Q7. With respect to current unmet needs in your area, are there services you currently provide that you would like to expand? (1 is top priority)

Answer Options	1	2	3	4	5	Rating Average	Response Count
Advocacy / legal services	7	2	0	2	1	2.00	12
Architectural barrier services	0	5	2	2	4	3.38	13
Assistive devices/equipment	0	0	0	0	1	5.00	1
Assistive technology assessment/training	2	0	0	1	0	2.00	3
Benefits advisement	3	4	4	3	1	2.67	15
Business /industry / agency services	0	1	1	0	0	2.50	2
Children's services	1	0	0	0	0	1.00	1
Communication services	0	0	1	0	0	3.00	1
Counseling services	0	1	1	0	1	3.33	3
Employment services	4	3	3	2	2	2.64	14
Family services	0	0	1	1	0	3.50	2
Housing and shelter services	2	0	1	4	3	3.60	10
Information and referral	1	0	0	0	0	1.00	1
Independent living skills training	0	2	0	2	1	3.40	5
Mobility / orientation training	0	0	0	0	0	0.00	0
Nursing home transition services	1	0	4	3	0	3.13	8
Peer counseling	1	2	0	1	1	2.80	5
Personal assistant services	1	1	1	1	1	3.00	5
Recreational services	0	0	1	0	1	4.00	2
Transportation services	0	0	1	0	1	4.00	2
Vision rehabilitation therapy	0	0	0	0	0	0.00	0
Vocational services	0	1	2	0	2	3.60	5
Voter registration	0	0	0	0	0	0.00	0
Youth transition services	3	3	2	1	0	2.11	9
Other (please specify in comment box below)	0	0	0	0	0	0.00	0

Q9. Rating services to start new: (With respect to current unmet needs in your area, are there new services you would like to start?) (1 is top priority)

Answer Options	1	2	3	4	5	Rating Average	Response Count
Advocacy / legal services	1	1	0	0	0	1.50	2
Architectural barrier services	5	2	0	0	1	1.75	8
Assistive devices/equipment	1	1	1	1	0	2.50	4
Assistive technology assessment/training	1	1	2	1	0	2.60	5
Benefits advisement	0	0	0	0	0	0.00	0
Business /industry / agency services	1	0	0	1	0	2.50	2
Children's services	3	0	1	0	1	2.20	5
Communication services	0	1	0	2	0	3.33	3
Counseling services	0	1	0	0	0	2.00	1
Employment services	3	4	0	1	0	1.88	8
Family services	0	0	1	2	1	4.00	4
Housing and shelter services	2	3	0	0	1	2.17	6
Information and referral	0	0	0	0	0	0.00	0
Independent living skills training	1	0	1	0	1	3.00	3
Mobility / orientation training	1	0	1	0	0	2.00	2
Nursing home transition services	1	0	0	0	1	3.00	2
Peer counseling	0	0	1	0	0	3.00	1
Personal assistant services	0	0	0	0	0	0.00	0
Recreational services	1	1	3	2	0	2.86	7
Transportation services	2	2	2	0	3	3.00	9
Vision rehabilitation therapy	0	0	0	1	0	4.00	1
Vocational services	0	0	1	2	2	4.20	5
Voter registration	0	0	1	0	0	3.00	1
Youth transition services	1	2	2	1	0	2.50	6
Other (please specify in comment box below)	1	1	0	0	0	1.50	2

Appendix V: Consumer Comments

How else could your service providers make it easier for you to access services?

1.   In the Accessibility of Disability and Non-Disability Rights Movement make the senses of political amendment if we don't have an interpretation for Disability People that toward Political Dysfunctional Difficulties.
2.   Service providers need to have more latitude.
3.   In 15 years of dealing with TBI, I have received no services from any agencies. I have expressed over & over my limitations, but have received little to no help. Just because I can carry on a somewhat "normal" conversation doesn't mean I'm alright.
4.   Office of the aging was of NO help to me because I needed services after surgery and would NOT help me because I'm not 60 years old.
5.   Help me and others understand my options and help me advocate for myself and fill out forms.
6.   Making sure I have the resources I need.
7.   Schedules.
8.   Weekend hours and/or hours after 5 pm.
9.   They would open an office in our apartment building.
10.   By offering services at night or weekend such as doctors and dentist.
11.   Design services for the convenience of users, not for the convenience of providers who seem to view users as 'an inconvenience' to their daily lives.
12.   MORE HOURS...
13.   Have emergency after-hours phone numbers for wheelchair or van emergencies.
14.   They start the day too early; that means they leave early.
15.   By making these services available for working disabled such as myself. I should never have to take off to access services.
16.   To have more available services without having to be on the HCBS Waiver.
17.   Not to have to call MAS in Syracuse for prior approval. It's possible, it's just a pain. There's always a new clerk . They have all levels of skill. Many are new to the job. I have to repeat so much basic info each time. Again, an extra pain in my day I don't need. It's difficult to be kind to anyone after talking with MAS. Oh & the WAIT TIME is intolerable!!
18.   Speed up the eligibility process.
19.   By email to leave a reminder.
20.   Call me back.
21.   Keeping better communication with me.
22.   Monthly communication of what's new or available.
23.   Update me monthly on services available.
24.   Need more open communication.
25.   If there were weekend and nightly providers.

26. Come to me.

27. Be informed of other services that are available.

28. Let me know as soon as they know about something available.

29. Increased awareness, but this is difficult. There was a time when I read the newspaper almost daily and watched local TV stations regularly. Neither is true now. The problem is where the service can outreach that I and others will access - and the problem isn't deficiency on the part of the providers as much as the lack of consistently accessed venues.

30. Greater advertisement needs to take place so that those persons in need of services/information will allow said population to participate in information dissemination; thereby, increasing the ability of individuals to advocate for themselves.

31. Contact us by phone

32. I'd need to know both what's available and how to apply, and right now I don't know much of either

33. Most people don't know what an ILC is & does. Certain centers are rigid about not doing any outreach to individuals.

34. Be more understanding of disabilities and lack of resources.

35. Know the different types of services and how to get information about them.

36. Need internet and computer.

37. Return phone calls in a timely manner.

38. For service providers that use legal language in their forms, layman's language, "plain English" would be helpful.

39. Maybe a website or a newsletter letting us know what is out there.

40. Bilingual and sign language interpreters on staff.

41. Accommodation of sign language interpreters.

42. Understanding the needs.

43. Advertise that they exist in every form of media possible (television, ads, social media).

44. Returning calls sooner. Available via email would be great.

45. Communication, communication, communication.

46. Sometimes just answering the phone & checking voice mail more frequently would help. One practice is notorious for not answering their phone then claiming they didn't understand VM message!

47. Actually look at the services they recommend. Better reporting.

48. When advertising services make so all people with disabilities understand the advertisement.

49. Send better information through email and advertise their websites more.

50. Advertise their offerings. We often have stumbled upon things that would interest our son, or work through the grape vine to find what others were involved in. We want to know what is out there for our son for now and his future when we are no longer able to care for him. It is a true concern for parents to make their children as independent as possible while they are still here to help.

51. Service providers could come to special needs schools to prepare parents about the next steps.

52. By providing complete information on a more timely basis and making home visits.

53. Fortunately, I am pretty mobile and can assist others with benefits. However, making your services known would be a tremendous help.

54. Return phone calls. Provide accommodations. Dare to do it differently than what you've always done. Stop demanding information provided on a specific form when all necessary information has been otherwise provided. Those are your internal issues and should not prevent necessary services. Start advocating for what WE SAY we want, not what you think is best.

55. Knowing what services are available to help me would definitely help. I don't know what I need sometimes until the struggle becomes so great that my family is desperate to find how to help me. Wondering if it would have been easier if I had gotten a diagnosis earlier in life for my Autism Spectrum disorder.

56. I need to know about services before I can apply.

57. Don't know. I think when I report it to my Service Coordinator either she should e-mail or set up a time to take a look at the important thing.

58. Provide info in large print format.

59. Lessen paperwork burden of receiving services. We have a self-determination plan and the paperwork to hire a new employee is UNBELIEVABLY cumbersome. Require fewer service coordinator visits.

60. DDSO kicked me and many others off services 10y ago. More services for people who NEED HELP but are not IQ 60, not a danger to self or other.

61. Things would be a lot easier for me if I received more than $740 per month for SSI/SSDI. More services would be provided and I would be able have a choices of who I would like for my at home care.

62. Team approach to health care instead of multiple individual specialists in and out of town who do not coordinate.

63. They need to collaborate rather than be so territorial. Sharing resources and information internally would cut down on a lot of unnecessary drama for the person seeking or receiving services.

64. The only services we receive now are through private providers...and they don't talk to one another. Desperately need social recreational. Desperately need therapy groups. Desperately need help with transportation.

65. If the wait to see my doctor was not as long.

66. Helping set appointments.

67. More and better referrals.

68. Our insurance covers no cognitive care everything is on private pay or volunteer basis.

69. Offer more services for ADULTS with developmental disabilities (e.g autism).

70. Understand not all in NYC have stable housing. Couchsurfing and homeless New Yorkers are also in need of advocacy services.

71.   Complete services to recreation.

72.   More staff so needs can be addressed sooner.

73.   Hiring staff is very complicated and time consuming, is there a way to make this easier?

74.   More providers.

75.   Keep a list of available service staff to pull from if ours is out sick.

76.   There just need to be more of them. OT and mental health services in particular are scarce.

77.   Have more highly trained personal care service employees ready and able to cover gaps in coverage.

78.   With so many services (especially benefits) being delivered through technology offering additional access to technology and helper staff at office and other sites would be helpful.

79.   Provide services in rural areas where those living there can also participate as transportation is the major factor for lack of participation in these areas.

80.   Make services accessible.

81.   Help with transportation and staffing.

82.   By making the steps to getting help easier such as transportation.

83.   Making sure they are on bus line.

84.   More staff and better transportation.

85.   Provide transportation.

86.   Provide through their organizations or partner with transport agencies other than ACESSARIDE… which doesn't provide good service...they don't show up on time to p/u riders to appts or constant late arrival to appts which results in re-scheduling (sometimes months later where client is held responsible for lateness).

87.   We need night and Sunday transportation.

88.   Improve transportation.

89.   Need bus transportation ---use Capitaland Taxi to go to 2 doctors.

90.   They do a great job. Maybe take me to more things I need to go to.

91.   Not sure, but a program that would have door to door assistance for those with disabilities would help. Also, if an aid is willing to drive someone to an appointment when assistance is otherwise unavailable, why would a program deny that transportation?

92.   Access a ride let people know when they will be more than 5 minutes late and estimated arrival without you standing and waiting wondering.

93.   Access a ride to be on time in the afternoon.

94.   Have Transportation more available.

95.   Make transportation easier.

96.   Either provide ride or make home visits.

97.   More access to transportation for us who can't get Medicaid. Able to get help paying my Medicare premium that comes out of my SSDI check. We are low income but due to the fact my husband is on Medicaid I can't get this help. Also because I wasn't notified of the need to renew my LIS for my insurance I have had hardship just in the last couple of weeks. They

waited until the bill was 480.00 before they notified me of the problem. Thankfully, I have the ability to advocate for myself. I have had training on advocacy at our ILS center. If left to my own devices I would have been lost. My food stamp worker is of no help. She just says the same thing whenever I speak to her. We only get 32 dollars of help. This doesn't go far. My husband has Crohns and I am diabetic. I have to depend on friends to take me to the doctor because I can't get Medicaid. I also haven't gotten glasses in 6 years.

98. Make home visits and/or provide transportation, especially for rural area.
99. Not Sure.
100. See answer to question five.
101. Through the Internet. Communities should come together to help with small business.
102. Not sure.
103. Better organization. Easier hiring process.
104. Good.
105. Make the transition easier when having to find new services.
106. Not sure.
107. To get some help.
108. Generally things are good.
109. NA

If you receive services at home, please describe the types of services you receive.
(list below is sorted alphabetically with "n/a" responses deleted)

1. A behaviorist visits the house once or twice a month.
2. A worker comes to take me out into the community to do errands or recreational activities.
3. Advocating.
4. Aide service 3 days per week.
5. Case management.
6. CD PASS and SELF DIRECTIVE SERVICES.
7. CDPA.
8. CDPA.
9. CDPA, CSS, SEMP.
10. CDPA, CSS, SEMP.
11. CDPAP.
12. CDPAS.
13. CDPAS, NYSARC, CP of the N C Medicaid service coordination, still in school for 3 more years.

14. Cleaning only.
15. Day Hab.
16. Community Hab.
17. Community habilitation services.
18. Community Habilitation.
19. Community Habilitation.
20. Community Habituation.
21. Community Habilitation.
22. Community Integration; looking for a job.
23. Consumer directed personal assistance for home care.
24. Consumer-directed personal assistance service (CDPAS); respiratory therapy.
25. Counseling.
26. Counseling/social services occasionally.
27. Daily Living.
28. DNA.
29. Family Care.
30. Family respite.
31. Food services.
32. Friends.
33. Habilitation services. I do not live independently.
34. HCSS-through waiver.
    CIC-counseling
35. Help with my ADLs. Drive me places like work. Assistance with household tasks, running errands and assistance at my job.
36. Home care when I fractured my hand and they were very good to me my aid Bertina Francis.
37. Home care, Very important!
38. Home delivery of oxygen.
39. Home health aid.
40. Home health aide.
41. Home oxygen.
42. House cleaning, other household help for tasks I can't do.
43. Housecleaning, cooking, house chores.
44. Housekeeping.
45. I am refused as I don't stay in same place 90 days.
46. I have received vision rehabilitation at home.
47. I hire domestic help to help me clean.
48. I private pay for housekeeping help which I need due to my physical disabilities.

49.　　I receive Concepts of Independence Home Health Aid assistance.

50.　　I receive home care through CDPAP. I also use Nursing services.

51.　　I receive physical therapy at home and home health care services at home.

52.　　ILST, infrequently, CIC comes to my home.

53.　　Individual support services.
　　　　MSC services.
　　　　Parenting classes.

54.　　In home respite, MSC (both children), Access VR.

55.　　Long term care.

56.　　Medicaid Service Coordination.

57.　　Medicaid Service Coordination for my son.

58.　　Medicaid service coordinator.

59.　　Medicaid.
　　　　Medicare.

60.　　Medical supplies delivered.

61.　　MSC Services.
　　　　ISS Services (monthly rent subsidy).

62.　　My care manager stops and sees me sometimes to make sure I'm doing ok.

63.　　My husband gets home health aides and a nurse. He has two aides each week and the nurse comes once every two weeks.

64.　　My spouse provides some guidance in day to day living matters.

65.　　My staff help me with figuring out my chores, the coordinate my finances and my Daily transportation, they help me with communication by helping me get cellphone minutes, they help me with cooking.

66.　　NHTD Waiver Services home care, structured day program, service coordination and respite.

67.　　No limb respite.
　　　　Community respite.

68.　　No limits respite.
　　　　Community respite.
　　　　Recreational respite.

69.　　Nursing home transition waiver and PCS.

70.　　PCA.

71.　　Personal assistance, did not start yet.

72.　　Personal Care Aid; Counseling.

73.　　Personal care Aide/home health aide that helps with my shopping, cleaning and miscellaneous chores.

74.　　Personal care attendant services (split shift 24 hour care), physical therapy (twice a week), occupational therapy (twice a week).

75.　　Personal housekeeping and home maintenance, mental health counseling.

76.   Physical therapist.

77.   PT/OT/ MSC.

78.   Public Health DPAO RCIL CP.

79.   RCIL. ALL PERSONAL CARE FOR QUAD...

80.   Rep Payee through DSS.
         Community Hab.

81.   Res hab, Community support, Special Education, respite.

82.   Respite, community rehab, transitioning support.

83.   See above.

84.   Self direction services Medicaid waiver. Laundry, cooking, menu planning, yard work,
         organization in the home, bill paying.

85.   Self direction, health aide.

86.   Self-directing Community Habilitation and respite.

87.   SEMP, CDPAS, CSS.

88.   Senior Citizen Volunteer.

89.   Service Coordination.

90.   Small amount of personal assistance services.

91.   Some home care services and some counseling.

92.   SPOA, MIT team.

93.   SSI .

94.   Staff helps me to live independently by assisting with cooking, laundry household chores
         etc.

95.   Staff support.

96.   Staff to help me with cooking, cleaning, recreation, job coaching and transportation.

97.   The Independent Living Skills, Daily Basis Skills, Council Advisory Board of the Tanya
         Towers Residence, Community Organizations with Mental Health, Economy of The
         Inequality Rights for Congregate Residences and Congregate Care Programs, Housing
         Opportunity, Rental Committees and other things to do it.

98.   Visits to assist with house keeping, grocery shopping and budgeting and random outings in
         the community.

99.   Worker installed or hook up assistive technology.

Appendix VI: Consumer Feedback on Survey Design and Completion

Q20: If you had someone assist you in completing this survey, was it a:

Family member   51.9%

Friend   11.5%

Service provider   36.5%

Q21: How difficult was the survey to complete:

Very difficult   6.2%

Somewhat difficult   19.6%

Not difficult   60.8%

Not difficult, but took longer than expected   13.5%

Q22: How did you learn about this survey?

Family member   4.8%

Friend   17.1%

Service provider (please specify below)   53.5%

Website (please specify below)   24.6%

Q23: Did you complete this survey:

On your own computer   47.6%

At an agency where you receive services   34.3%

On a friend or relative's computer   12.9%

On a computer available in the community   5.2%

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

NYSILC Consumer Survey

1. What is most difficult for you in your daily life? Check up to four from the list below.

__ Applying for benefits

__ Discrimination

__ Education

__ Employment

__ Finances (paying bills)

__ Housing (accessibility, affordability)

__ Medical/health coverage

__ Mobility (accessibility, assistive devices)

__ Personal care (eating, bathing, housekeeping)

__ Recreation (community events, parks, movies, etc.)

__ Social (needing support from family and friends)

__ Transportation

__ Other (please specify)

2. What services do you use that are <u>most important</u> for you to continue living independently? <u>Check up to five (5) services</u>.

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 (assisting with getting rights, services)

__ Assistive devices training (medical equipment, wheelchairs, etc.)

__ Benefits assistance and advice (SSI/SSDI/Food stamps, etc.)

__ 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

__ Mental health service

__ Mobility training/services

__ Peer counseling

__ Recreation services

__ Supported services for apartment living

__ Transportation

__ Other (please specify)

3. How available are the following services in your area?

a) **Advocacy**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

b) **Assistive devices training**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

c) **Benefits Assistance and Advice**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

d) **Education services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

e) **Employment / work readiness services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

f) **Family services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

g) **Home care/personal assistance services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

h) **Housing services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

i) **Independent living skills training**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

j) **Information and referral to other services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

k) **Medical/health services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

l) **Mental health services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

m) **Mobility services**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

n) **Peer counseling**

___ Readily Available ___ Limited availability ___ Not available ___ Don't know

o) Recreation services

__ Readily Available   __ Limited availability   __ Not available   __ Don't know

p) Supported services for apartment living

__ Readily Available   __ Limited availability   __ Not available   __ Don't know

q) Transportation

__ Readily Available   __ Limited availability   __ Not available   __ Don't know

r) Other (please specify and indicate how available they are)

4. Please number by importance what would make it easier for you to get services. Use 1 as the <u>most</u> important and 6 as the <u>least</u> important.

__ Advertise existing services

__ Expand hours of operation (nights and weekends)

__ Expand services

__ Expand transportation to / from service providers

__ Hire additional staff

__ Make home visits

__ Other

5. Please specify, if you checked "other"

6. How else could your service providers make it easier for you to access services? Please describe below.

7. **Where do you go to receive services or support to help you live independently? Check <u>all</u> that apply.**

  __ College or university

  __ Community center

  __ Counseling / Therapy

  __ Group meetings

  __ Hospital

  __ Independent Living Center

  __ Internet resources

  __ Park or gymnasium

  __ People come to my home

  __ Physical therapy

  __ Place of employment

  __ Place of worship

  __ School

  __ Social services

  __ Other disability agencies (please specify below)

  __ Other (please specify)

8. **If you receive services at home, please describe the types of services you receive.**

9. Please indicate the types of organizations, if any, where needed services have not been accessible or accommodations were not made.

  __ College or university

  __ Community center

  __ Counseling / Therapy

  __ Group meetings

  __ Hospital

  __ Independent Living Center

  __ Internet resources

  __ Park or gymnasium

  __ People come to my home

  __ Physical therapy

  __ Place of employment

  __ Place of worship

  __ School

  __ Social services

  __ Other disability agencies (please specify below)

  __ Other (please specify)

10. Are you currently receiving services at an Independent Living Center (ILC)?

  __ Yes

  __ No, but I have received services from an ILC in the past

  __ No, I have never received services from an ILC

  __ No, I do not know where the nearest ILC is

  __ No, I do not know what an ILC is

11. Do you have to go outside your county to get independent living services?

　　　__ Yes, for all services

　　　__ Yes, for some services

　　　__ No, I receive all services within my county

12. What would be the best ways for a service provider to communicate with you and for you to communicate with them? (Check all that apply)

　　__ Email

　　__ Fax

　　__ Internet/Website

　　__ Mail

　　__ Phone

　　__ Social Media (Facebook, Twitter etc.)

　　__ Texting

　　__ Other (please specify)

13. Please select the range within which your age falls.

　　__ 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

14. Please check <u>one</u> answer for your race/ethnic group.

    __ American Indian

    __ Asian/Pacific Islander

    __ Black non-Hispanic

    __ Hispanic

    __ White

    __ Multi-ethnic (More than one)

    __ Other (please specify)

15. Please describe your disability. Please check all that apply.

    __ Blind/vision difficulties

    __ Deaf/Hard of Hearing

    __ Developmental Disabilities

    __ Mental Health Disabilities

    __ Physical Disabilities

    __ Sensory Disabilities

    __ Substance Abuse

    __TBI/Neurological

    __ Multiple Disabilities

    __ Dual Diagnosis – developmental / mental health

    __ Dual Diagnosis – mental health / substance abuse

    __ Other (please specify)

16. Please check any of the following that describe you:

- _ Homeless

- _ Veteran

- _ Non Native English Speaker

- _ LGBTQIA

17. What county do you live in?

- __ Albany County
- __ Allegany County
- __ Bronx County
- __ Broome County
- __ Cattaraugus County
- __ Cayuga County
- __ Chautauqua County
- __ Chemung County
- __ Chenango County
- __ Clinton County
- __ Columbia County
- __ Cortland County
- __ Delaware County
- __ Dutchess County
- __ Erie County
- __ Essex County
- __ Franklin County
- __ Fulton County
- __ Genesee County
- __ Greene County
- __ Hamilton County
- __ Herkimer County
- __ Jefferson County
- __ Kings County (Brooklyn)
- __ Lewis County
- __ Livingston County
- __ Madison County
- __ Monroe County
- __ Montgomery County

__ Nassau County
__ New York County (Manhattan)
__ Niagara County
__ Oneida County
__ Onondaga County
__ Ontario County
__ Orange County
__ Orleans County
__ Oswego County
__ Otsego County
__ Putnam County
__ Queens County
__ Rensselaer County
__ Richmond County (Staten Island)
__ Rockland County
__ St. Lawrence County
__ Saratoga County
__ Schenectady County
__ Schoharie County
__ Schuyler County
__ Seneca County
__ Steuben County
__ Suffolk County
__ Sullivan County
__ Tioga County
__ Tompkins County
__ Ulster County
__ Warren County
__ Washington County
__ Wayne County
__ Westchester County
__ Wyoming County
__ Yates County

18. **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

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

__ Rural (Country setting)   __ Urban (City)   __ Suburban (Just outside city)

The following questions ask about the survey itself.

20. **If you had someone assist you in completing this survey, was it a:**

__ family member

__ friend

__ service provider

21. How difficult was the survey to complete:

__ Very difficult

__ Somewhat difficult

__ Not difficult

__ Not difficult, but took longer than expected

Comment:

22. How did you learn about this survey? From a:

__ Family member

__ Friend

__ Service provider (please specify below)

__ Website (please specify below)

Please specify service provider or website:

23. Did you complete this survey:

__ On your own computer

__ At an agency where you receive services

__ On a friend or relative's computer

__ On a computer available in the community

THANK YOU FOR COMPLETING THIS SURVEY! (mailing instructions on next page)

If you would like to be entered into our drawing for a $50 gift card, please give us your name, address and phone number on the next page so we can contact you if you've won: *Identifying information will be kept confidential and separate from survey results.*

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 September 30th to be entered in our drawing for a $50 gift card.

DEFINITIONS OF TERMS USED IN QUESTIONS #2 AND #3
NOTE – for the online version this will have to be embedded somewhere as a link

1. <u>Advocacy/legal services</u> - assistance with accessing benefits, services or programs to which you may be entitled but are having difficulty obtaining.

2. <u>Assistive devices/equipment</u> – help receiving specialized equipment such as TTYs, wheelchairs and lifts. This includes equipment repair and loan as needed.

3. <u>Benefits advisement</u> - assistance provided with applying for economic benefits. This service does not include the representation at hearings or appeals.

4. <u>Education services</u> – classroom or individual educational programs at the primary, secondary or college levels; this includes home tutoring.

5. <u>Employment / work readiness services</u> - training in job-seeking skills such as interviewing and resume writing, and/or providing supported employment opportunities and/or integrated job placement services.

6. <u>Family services</u> - 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. <u>Home care / personal assistance services</u> - includes providing attendant care to consumers and/or training consumers to supervise their own attendants.

8. <u>Housing or shelter services</u> - 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. <u>Independent living skills development and life skills services</u> - 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. <u>Information and referral services (I&R)</u> – information about other needed services in the area, and/or being referred directly to specific agencies.

11. <u>Medical / health services</u> – services needed to treat specific medical conditions.

12. <u>Mental heath services</u> – services to treat mental health needs

13. <u>Mobility training</u> - variety of services involved in assisting individuals with cognitive and sensory impairments to get around their homes and communities.

14. <u>Peer counseling</u> - 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.

15. <u>Recreational services</u> – 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.

16. <u>Supported services for apartment living</u> – a wide range of services to assist individuals who are transitioning to live independently in the community

17. <u>Transportation services</u> - provision of, or arrangements for provision of accessible transportation.

NYSILC Centers Survey

1. **Agency Name:** _____

2. **Name of person completing the survey:** _____

3. **Please review this list of potential barriers to effective service delivery of <u>existing services</u> and check those that are currently the most significant barriers for your Center. Please select and rank up to a maximum of 5 (five) barriers, with 1 being the most significant barrier, 2 next most significant, down to a maximum of 5.**

    __ Funding restrictions

    __ Lack of adequate transportation for consumers

    __ Lack of administrative support (clerical, bookkeeping, IT, telephones)

    __ Lack of awareness of ILC services from people with disabilities

    __ Lack of board support

    __ Lack of cooperation/support from other providers (e.g. schools, agencies, etc.)

    __ Lack of financial or other resources

    __ Lack of interpretation services

    __ Lack of public awareness of ILC services

    __ Lack of space or equipment

    __ Lack of support from key agencies or other groups in the community

    __ Low demand or interest from target population

    __ Size of service area is too large

    __ Staffing issues – difficulty retaining staff

    __ Staffing issues – inability to recruit due to shortage of qualified staff

    __ Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits

    __ Staffing issues – lack of resources to train staff

    __ Other (please specify below)

4. If you selected "other," please specify:

5. What resources would you need to overcome these barriers to providing existing services? Please select and rank up to a maximum of 4 (four) resources with the most important rated as a 1 and the least important rated as a 4.

__ A well-designed and funded public relations plan

__ Additional fund development staff / development plan

__ Additional funding

__ Additional space / satellite office / equipment

__ Examples of successful model programs

__ Increased grassroots support

__ Increased political support

__ Increased transportation for consumers

__ More assistance / cooperation from local and state providers

__ More collaborating partners from local community service providers

__ Training / technical assistance (in the comment box, please indicate what type of training / technical assistance)

__ Other (please specify below)

6. If you selected "other" and/or "training / technical assistance" above, please provide a brief description:

7. With respect to current unmet needs in your area, are there services you currently provide that you would like to <u>expand</u>?   Please select and rank up to 5 (five) choices with 1 being most important.

      __ Advocacy / legal services

      __ Architectural barrier services

      __ Assistive devices/equipment

      __ Assistive technology assessment/training

      __ Benefits advisement

      __ Business /industry / agency services

      __ Children's services

      __ Communication services

      __ Counseling services

      __ Employment services

      __ Family services

      __ Housing and shelter services

      __ Information and referral

      __ Independent living skills training

      __ Mobility / orientation training

      __ Nursing home transition services

      __ Peer counseling

      __ Personal assistant services

      __ Recreational services

      __ Transportation services

      __ Vision rehabilitation therapy

      __ Vocational services

      __ Voter registration

      __ Youth transition services

      __ Other

8. If you selected "other," please specify:

9. With respect to current unmet needs in your area, are there new services you would like to start?   Please select and rank up to 5 (five) choices, with 1 being most important.

      __ Advocacy / legal services

      __ Architectural barrier services

      __ Assistive devices/equipment

      __ Assistive technology assessment/training

      __ Benefits advisement

      __ Business/industry/agency services

      __ Children's services

      __ Communication services

      __ Counseling services

      __ Employment services

      __ Family services

      __ Housing and shelter services

      __ Information and referral

      __ Independent living skills training

      __ Mobility/orientation training

      __ Nursing home transition services

      __ Peer counseling

      __ Personal assistant services

      __ Recreational services

      __ Transportation services

      __ Vision rehabilitation therapy

      __ Vocational services

      __ Voter registration

      __ Youth transition services

      __ Other (please specify below)

10. If you selected "other," please specify:

11. For the services you indicated above, what barriers, if any, are there to you <u>starting or expanding</u> services? Please select and rank up to a maximum of 5 (five) barriers, with 1 being the most significant barrier.

_ Lack of financial or other resources

_ Funding restrictions

_ Lack of adequate transportation for consumers

_ Lack of cooperation from other providers (e.g. schools, agencies, etc.)

_ Staffing issues – inability to recruit qualified staff due to non-competitive wages/benefits

_ Staffing issues – inability to recruit due to shortage of qualified staff

_ Staffing issues – difficulty retaining staff

_ Staffing issues – lack of resources to train staff

_ Lack of space or equipment

_ Lack of interpretation services

_ Lack of awareness of ILC services from people with disabilities

_ Lack of public awareness of ILC services

_ Size of service area is too large

_ Lack of support from key agencies or other groups in the community

_ Low demand or interest from target population

_ Lack of board support

_ Lack of administrative support (clerical, bookkeeping, IT, telephones)

_ Other

If you selected "other," please specify:

12. What resources would you need to <u>overcome the barriers</u> to *expanding* existing services *or starting* new services? Please select and rank up to a maximum of 4 (four) resources, with 1 being the most important.

  __ A well-designed and funded public relations plan

  __ Additional fund development staff / development plan

  __ Additional Funding

  __ Additional space / satellite office/ equipment

  __ Examples of successful model programs

  __ Increased grassroots support

  __ Increased political support

  __ Increased transportation for consumers

  __ More assistance / cooperation from local and state government agencies

  __ More collaborating partners from local community service providers

  __ Training / technical assistance (in the comment box, please indicate what type of training or technical assistance)

  __ Other

13. If you selected "other" and/or "training / technical assistance" above, please provide a brief description:

14. Please indicate any specific geographic areas within <u>*or*</u> outside your service area that you feel are not adequately served by you or other service providers, or are difficult for your staff to access.

15. 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):

__Children/young adults

__Seniors

__Rural residents

__American Indian

__Black non-Hispanic

__Asian/Pacific Islander

__Hispanic

__Multi-ethnic

__Male Veterans

__Female Veterans

__Homeless

__LGBTQIA

__Deaf

__Blind

__Deaf/Blind

__Physical disabilities

__Mental/emotional disabilities

__Cognitive disabilities

__Dual diagnosis – developmental/mental health

__Dual diagnosis – mental health/chemical abuse

__Immigrant groups / Non-native English speakers (please specify below)

__Other Underserved or Hard to Reach Groups (please specify below)

16. Please check from the list below, a maximum of five (5) issues/areas that are currently not sufficient to meet the demand and/or need for _youth with disabilities_ in your service area.

__ Access to Assistive Technology

__ Access to Information and Resources

__ Accessible Health Care

__ Adequate Income

__ Affordable Health Care

__ Affordable Housing

__ Affordable, Accessible Exercise Opportunities

__ Affordable, Accessible Opportunities to Socialize

__ Assistance with Disability Benefits

__ Community Based Long-Term Care

__ Consumer Directed Personal Assistance

__ Culturally Sensitive Services

__ Disability Awareness among Service Providers

__ Emergency Services

__ Employment Opportunities

__ Health Insurance

__ Information about Disability Rights

__ Integrated Housing

__ Service Coordination

__ Services and Support

__ Special Education

__ Systems Advocacy

__ Transition Services

__ Transportation

__ Vocational Training

__ Other (please specify below)

17. Please check from the list below, a maximum of five (5) services that are currently not sufficient to meet the demand and/or need for _seniors with disabilities_ in your service area.

__ Access to Assistive Technology

__ Access to Information and Resources

__ Accessible Health Care

__ Adequate Income

__ Affordable Health Care

__ Affordable Housing

__ Affordable, Accessible Exercise Opportunities

__ Affordable, Accessible Opportunities to Socialize

__ Assistance with Disability Benefits

__ Community Based Long-Term Care

__ Consumer Directed Personal Assistance

__ Culturally Sensitive Services

__ Disability Awareness among Service Providers

__ Emergency Services

__ Employment Opportunities

__ Health Insurance

__ Information about Disability Rights

__ Integrated Housing

__ Service Coordination

__ Services and Support

__ Special Education

__ Systems Advocacy

__ Transition Services

__ Transportation

__ Vocational Training

__ Other (please specify below)

18. Please comment below on any other priority areas that the Council should consider when developing the next three year Strategic Plan for Independent Living.

Please send the completed survey no later than September 30, 2015, to Patty Black at NYSILC

Email: patty@nysilc.org or

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