Independent Living Research Utilization



We create opportunities for independence for people with disabilities through research, education, and consultation



Independent Living Research Utilization www.ilru.org







Statewide Needs Assessment Process: One State's Successful Committee Approach

June 23, 2015 3:00 pm - 4:30 EDT

Presenter: Brad Williams



Introduction and Objectives



- Identify SILC requirements related to needs assessments.
- Explain how needs assessment results and priorities dovetail with SPIL development and sections of the SPIL.
- Review a committee approach to address a statewide needs assessment for SILCs given the lack of fiscal resources.

SILC Needs Assessment Requirement



- Under Section 704 of the Rehabilitation Act, related to the State Plan, (I) Outreach
 - ...the plan shall set forth steps to be taken regarding outreach to populations that are unserved or underserved by programs under this title, including minority groups and urban and rural populations.
- A statewide needs assessment is an objective way to identify unserved and underserved target populations and geographic areas in your state.

SILC Needs Assessment Requirement, cont'd.



- Needs assessment results and priorities are used with public input priorities to validate the content of the SPIL during development.
- Needs assessment priorities not addressed in the SPIL can potentially be addressed by the SILC and IL network outside of the plan.

Direct Connection to the SPIL



- Unserved and underserved target populations and geographic areas are directly connected to the SPIL.
 - Section 1.2B Outreach to unserved/underserved populations in State.
 - Section 2.1B Service provision priorities related to populations and SPIL objectives.
 - Section 3.2 Expansion of Network related to unserved and underserved geographic areas in your state.





An EXAMPLE Committee Approach: Start Up

- Activate a Needs Assessment Committee (NAC) with a minimum of six members.
- Initial members might include the SILC Executive
 Director or Coordinator, a member of the DSE (formerly
 the DSU), at least one CIL representative, and three
 members who have interest and experience with
 disability issues, reports, and/or data.
- Identify a member to serve as chair of the NAC.
- If you have active consultants connected to the SILC, invite one to volunteer on the NAC.



A Committee Approach: Set Up, cont'd.



At your introductory meeting...

- Discuss the purpose of the NAC.
- Discuss preliminary key questions.
- Share and identify existing data sources.
- Discuss the need to potentially expand the NAC (up to four more members) and suggest individuals to invite before the next meeting.
- Discuss and share links to needs assessments from other SILCs. What do you like about them?



A Committee Approach: First Full Meeting



Two items of business important at the first full meeting:

- # 1: Review and finalize key questions to investigate.
- # 2: Review and expand upon existing data sources and reports.



A Committee Approach: First Full Meeting, cont'd.



Identify your mandatory key questions:

(Acknowledgement to California SILC)

- What geographic areas are most in need of Independent Living (IL) services?
- What unserved or underserved ethnic, minority and disability populations are most in need of IL services?

Identify your additional key questions:

- What needs must be addressed to strengthen (your State's) IL network?
- What are the most important issues (unmet service needs) faced by (your State's) people with disabilities who live, or want to live, independently?



A Committee Approach: First Full Meeting, cont'd. 2



- How do you answer each question?
 - With existing data, survey and collective responses, or both?
- Develop an existing data document to identify reports and data sources.
 - Connect them to relevant key questions.
- Example: Question # 1: What geographic areas are most in need of Independent Living (IL) services?
 - ACCES-VR Data of IL Network 2013-14 Served by County, Excel spreadsheet.
 - Race and Ethnicity of People with Disabilities in All Counties in NYS, Excel spreadsheet.



A Committee Approach: First Full Meeting, cont'd. 3



- Question # 2: What unserved or underserved ethnic, minority and disability populations are most in need of IL services?
 - Cornell report
 (http://www.disabilitystatistics.org/StatusReports/2
 012-PDF/2012-StatusReport_NY.pdf).
 - Disability Compendium/2014 Annual Disability
 Statistics Compendium
 (http://disabilitycompendium.org/compendium statistics. Search desired statistics per State.



A Committee Approach: Second Full Meeting

Organize the business of the second full meeting to:

- Break into logical work groups to investigate and draft work related to the key questions.
- Identify what questions each work group will work on and what method(s) they will use to answer the respective questions.
 - Work Group 1 will investigate Q1 (geographic areas) and Q2 (unserved/underserved populations) using mostly existing data sources.



A Committee Approach: Second Full Meeting, cont'd.



- Work Group 2 will investigate Q3 (IL network) and Q4 (unmet need/significant issues) using surveys and collective responses.
- For follow up, both groups:
 - Will develop work plans,
 - Use the month in between the next full meeting to make progress on assignments, and
 - Meet by conference call and trade work online with track changes.



Questions & Answers



Work Group 1 (WG1) Approaches to Organizing

How does WG1 use existing data to answer Q1 related to unserved/underserved areas? (Acknowledgement to California SILC)

- By conducting an analysis of "penetration rates" and "inundation indexes" of the counties in your State served by the IL network.
 - The <u>penetration rate</u> determines the extent the IL network and its services are reaching the identified population in a given county. It is calculated by <u>dividing</u> the <u>total number of consumers served in a county by the IL network for the identified year</u> by the <u>total number of civilian people with disabilities identified for the county</u> from a data source such as statistics from an American Community Survey (U.S. Census Bureau). The calculation must be done for every county in the State.





Penetration Rate Example

	<u>County</u>	IL Network	PWD County	Pen Rate
•	Albany	2,396	36,315	6.60%
•	Bronx	2,201	194,097	1.13%
•	Cortland	3,282	5,586	58.75%
•	Genesee	156	8,483	1.83%
•	Livingston	99	6,363	1.56%
•	Queens	2,519	220,433	1.14%
•	Suffolk	1,829	113,040	1.62%

• The lower the penetration rate, the greater the need.



- Penetration rates account for differences between unserved and underserved, as well as urban and rural areas.
- The five counties identified with the lowest penetration rates, ranging from 1.13-1.83%, are a mix of downstate/urban high population density and upstate rural low population areas.



- This analysis accounts for civilian population in your State. It is also important to include your State's institutionalized population. In an "ideal" world, data will be available online through a State Olmstead compliance initiative. However, you may need to submit Freedom Of Information Law (FOIL) requests to State agency public information officers to obtain necessary data.
- To know what data to request, you will first need to identify your State's institutional settings.
- This data will be needed to calculate the inundation index.





- 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 compare to the "inundation" for each respective county.
- It is calculated by <u>dividing</u> the <u>total number of individuals</u> <u>identified as being institutionalized by county for the</u> <u>identified year</u> by the <u>total number of consumers served</u> <u>in a county by the IL network for the identified year</u>. The calculation must be done for every county in the State.



Inundation Index Example:

	<u>County</u>	#PWD/Inst*	IL Network	Inn Index
•	Albany	3,686	2,396	1.54
•	Bronx	17,250	2,201	7.84
•	Cortland	528	3,282	0.16
•	Genesee	662	156	4.24
•	Livingston	1,221	99	12.33
•	Queens	20,285	2,519	8.05
•	Suffolk	15,481	1,829	8.46

The higher the inundation index, the greater the need.



- The lowest penetration rates and the highest inundation indexes are put in a relative ranking. Combined, a new list emerges that identifies your State's top ten geographic areas most in need of IL services.
- Note that <u>Livingston County</u> has a low penetration rate and a high inundation index and thus would be high on the list.
- The analysis is based on objective data and reconciles urban and rural needs.
- This list should appear in Section 3.2 of the SPIL, Expansion of the Network.





How does WG1 use existing data to answer Q2 related to unserved/underserved populations?

- Our group made the decision to identify populations and themes based on trends from the data sources.
- Once a member selected a theme/population, they then agreed to write a brief "what we know" narrative related to the topic and people with disabilities based on the data.
 - Committee members acknowledged that (for the most part) they are not research scientists or statisticians, but volunteers contributing to the process.





<u>Health and Disability</u>

A review of data from different sources highlights the importance and need to address health and disability. For obesity among persons ages 18 and over, New Yorkers with disabilities are nearly twice the rate of individuals without disabilities in the State (37.9% compared to 21.8% creating a gap of 16.1%). In addition, obesity raises concern with another health issue - diabetes. About 80-90 % of people who are obese are also diagnosed with type II diabetes. ² 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.3





For smoking among persons ages 18 and over, New Yorkers with disabilities experience an increase trend versus individuals without disabilities in the State (22.6% compared to 14.9% creating a gap of 7.7%).4 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 nonsmokers - on average a smoker will die 15 - 20 years before a nonsmoker."5 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.



¹ 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

² A Codependent Relationship: Diabetes & Obesity, http://www.diabeticcareservices.com/diabetes-education/diabetes-and-obesity

³ Statistics about Diabetes Data from the National Diabetes Statistics Report, 2014 (released June 10, 2014) -http://www.diabetes.org/diabetes-basics/statistics/





⁴ Disability Compendium, Percent (%) Smoking among Persons Ages 18 and Over, by Disability Status: 2013 http://disability-status

⁵ Quitter's Guide.com http://www.quittersguide.com/dangers-smoking.shtml

ALERT: How a Needs Assessment Priority Becomes a SPIL Objective and Project



Using the "Health and Disability" example, it can emerge as a priority in Section 1.2B of the SPIL: (Listed among other identified priorities)

 "Health and wellness, including medical and health care and most-integrated setting issues for people with disabilities."



ALERT: How a Needs Assessment Priority Becomes a SPIL Objective and Project, cont'd.

- ilra
- With enough support and resources, it can become an objective:
 - Objective 5: Improve the capacity of the IL network to address priority unserved and underserved populations from the statewide needs assessment by providing eight \$25,000 capacity building selfsustaining grant opportunities that can be evaluated by the council, disseminated and documented for replication and the benefit of the statewide network.



ALERT: How a Needs Assessment Priority Becomes a SPIL Objective and Project, cont'd. 2

- The State distributed an RFP to the field for the grant opportunity. An independent panel reviewed and awarded ten (two additional) capacity building grants to centers to serve the identified unserved underserved populations.
- Healthy living projects were funded at the following centers: BILS/Bronx, NCCI/Plattsburgh, WILC/Putnam ILS, and WILC/White Plains.

Questions & Answers



Work Group 2 (WG2) Approaches to Organizing ilru

How does WG2 use surveys and collective responses to answer Q3 (IL network) and Q4 (unmet need/significant issues).

 Create survey instruments that ask questions designed to provide answers.



Consumer Survey Example



What are the most challenging issues you face day to day? Check <u>all</u> that apply.

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





2012 Collective Response to question:

Consumers indicated that their greatest challenges were:

- 1. finances (paying bills)
- 2. transportation
- 3. Employment

When analyzed by general geographic areas:

Rural	<u>Urban</u>	<u>Suburban</u>
Finances (paying bills)	Employment	Transportation
Transportation	Finances (paying bills)	Finances (paying bills)
Social (support from	Transportation	Employment
family & friends)		



Center Survey Example



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 check or highlight up to a maximum of 5 (five) barriers.

Lack of financial or other resources Lack of space or other infrastructure __ Lack of adequate transportation for consumers Lack of interpretation services Lack of cooperation from other providers ___ Lack of awareness from people with disabilities of ILC services (schools, agencies, etc.) Staffing issues – inability to recruit qualified __ Size of service area is too large staff due to non-competitive wages/benefits __ Lack of support from key agencies or __ Staffing issues – inability to recruit due to other groups in the community shortage of qualified staff Low demand or interest from target Staffing issues – difficulty retaining staff population Staffing issues – lack of resources to train staff __ Lack of board support __ Other – please specify and/or Comments



2012 Collective Response to question:

- The major barriers to current, expanded or new services were lack of financial resources and the restrictions that were part of current funding. The other high ranking barrier was lack of transportation for consumers.
- Refer to the 2012 NYSILC Needs Assessment Report, Appendix V, for a copy of the two surveys distributed to consumers (p. 34) and the center network (p. 40).

ilra

- Once the surveys are completed, identify plans for their distribution. Identify deadlines, stakeholders to expand distribution, website and social media plans, and a strategy to provide access.
- Identify a policy of what is a completed survey (100%/75% of the questions completed and returned).
- Do you provide an incentive to encourage participation? (Gift cards, etc.) If so, you may have to obtain additional information from consumers and or centers, develop messaging and a process to randomly select a winner(s), including notification, and certified delivery of the gift.
- Protect data confidentiality.



Pulling it all together



- Follow up conference call meetings will be necessary to report back the progress of the work groups.
- A major accomplishment will be the completion of the work group assignments – answering the key questions by providing draft data in charts, narratives, and or summarized collective survey responses.
- A small group, individual, or technical writer must take the lead to build the connective narrative of the needs assessment draft report.
- When the draft report is completed, the NAC can review it online or meet via conference call. The final report is submitted to the SILC. Timeline: 10 months.



Resources



- Needs Assessment: An Overview, James W. Altschuld and David Devraj Kumar, Copyright © 2010 by SAGE Publications, Inc.
- SILC-Net, Introduction to Needs Assessment for SILCs (A Five-Part Teleconference Series) August-September 2011, James Altschuld.
- SILC Needs Assessments
 - California SILC Needs Assessment for 2014-2016
 SPIL Word/English (Visit website for other options):
 http://www.calsilc.org/SILC_Needs_Assessment_Mar ch2013-121613.doc.

ilra

Resources, cont'd.

- Michigan SILC 2014 Comprehensive Statewide Needs Assessment PDF:
 - https://static1.squarespace.com/static/504129abe4b0991b7266e748/t/5385db44e4b0ced978f629eb/1401281348462/2014_CSNA_0_ALL.pdf.
- New York SILC 2012 Statewide Needs Assessment
 Report Word: http://www.nysilc.org/images/FINAL 2012-NYSILC-Needs-Assessment-Report-10-11-12.doc.
- Idaho SILC 2005 Assessment of Idahoans with Disabilities PDF:
 - http://www.silc.idaho.gov/PDF/Final%20Survey%205-31-05%20no%20appendicies%20rfs.pdf.



Questions & Answers



Contact



Brad Williams - bradw@nysilc.org, (518) 427-1060 X5.

Evaluation Survey



- Click the link below to complete your evaluation of today's program:
- http://www.surveygizmo.com/s3/2165698/SILC-NET-Webinar-Evaluation-June-23-2015



SILC-NET Attribution



Support for development of this training was provided by the Department of Health and Human Services, Administration for Community Living under grant number 90TT0001-01-00. No official endorsement of the Department of Health and Human Services should be inferred. Permission is granted for duplication of any portion of this PowerPoint presentation, providing that the following credit is given to the project: Developed as part of the SILC-NET, a project of the IL-NET, an ILRU/NCIL/APRIL National Training and Technical Assistance Program.