

Operationalizing Effective SILCs

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Operationalizing Effective SILCs

Introduction

Welcome to *Operationalizing Effective SILCs*. As a Statewide Independent Living Council staff person or member, you've been given not only the responsibility for identifying the needs of the independent living community, but also the authority jointly with the designated state unit (DSU) to develop and monitor a plan to respond to those needs. Recent questions posed to the Rehabilitation Services Administration about the roles and responsibilities of SILCs have provided an opportunity for RSA to clarify these, and for the SILCs to review and, if necessary, update their policies and practices.

The goals of this training are to assist SILCs to foster strong state IL programs; build strong relationships with Designated State Units (DSUs), CILs, and other organizations; achieve full regulatory compliance while capitalizing on unique state strengths and environments; and be fully responsive to constituents.

To accomplish these goals, it is the intention of the training development team, which includes ILRU, NCIL, RSA, and all the course trainers, that at the end of the training participants will be able to:

- perform your SILC duties, roles, and responsibilities, as prescribed by the Rehabilitation Act and federal guidelines;
- utilize tools and techniques for strategic data gathering and analysis to identify community IL needs for planning and developing your next SPIL;
- engage in the development of a SPIL with your DSU(s) that prioritizes and addresses the independent living needs in your state and meets federal requirements;
- develop a focused plan for monitoring reviewing, and evaluating the implementation of your current SPIL;
- strengthen partnerships with your DSU, CILs, Statewide Rehabilitation Councils (SRCs) and other agencies to foster effective IL programs in your state; and
- apply effective practices in recruiting SILC members, collaborating with appointing authorities; and orienting new members to independent living, SILC functions, and member responsibilities.

The partners involved in the development of the course curriculum felt it was important to establish guiding principles for the training and text that reflect the vision and values that were set forth for the training. These include:

- Working with RSA to ensure interpretations and expectations are clear
- Providing best examples of implementation—we all learn best from good examples

- Improving working relationships and fostering mutual respect between SILCs and RSA
- Framing a training perspective and discussion focused on the things SILCs *can* do

Chapter One

A Little Independent Living History and Philosophy

You probably have already been exposed to basic philosophical concepts like consumer control, peer relationships, and a cross-disability orientation to the provision of services.¹

One of the first steps each new staff person or member of a SILC needs to take is to learn how the SILC fits into the overall context of independent living for people with disabilities. Understanding this framework will, in turn, facilitate understanding each of the roles and responsibilities of the SILC. There is a vital and rich history behind the independent living movement, of which the SILCs are a part. Each step in this history has provided a thread which has contributed to an inter-connected tapestry of social change and progress for citizens with disabilities.

One of the most important elements to understanding the nature and purpose of a SILC is to be aware of the role that consumer control plays in the independent living movement.

In the last half of the 20th Century, people with disabilities were given increasingly greater authority over the services they received. Terms like *informed consent*, *presumptive eligibility*, and *choice* began to pervade the language of rehabilitation professionals, placing greater decision-making in the hands of the people who were receiving services.

When these same individuals began creating a network of centers for independent living (CILs) in the 1980s, it was natural therefore, for these organizations to be consumer controlled, as well. The amendments to the Rehabilitation Act of 1973 (the Act), define consumer control of an independent living center as follows:

The term ‘consumer control’ means, with respect to a center for independent living, that the center vests power and authority in individuals with disabilities.²

Section 725 of the Act sets out a Standard that centers must meet related to consumer control:

“The center shall promote and practice the independent living philosophy of. . .consumer control of the center regarding decision-making, service delivery, management, and establishment of the policy and direction of the center. . .³

¹ For more on the history and philosophy of the independent living movement, see the readings in Appendix B and access the DVD *IL History and Philosophy: Orientation for IL Staff* at <http://www.ilru.org/DVD.html>.

² Rehabilitation Act of 1973 as amended, Title VII, Chapters 1 & 2, Sec. 702 (2).

³ Ibid., 725 (b)(1).

Indicators of compliance⁴ with the Standard were developed through regulations, and they require that:

The center shall provide evidence in its most recent annual performance report that—

- A) Individuals with significant disabilities constitute more than 50 percent of the center's governing board; and
- B) Individuals with disabilities constitute more than 50 percent of the center's—
 - 1. Employees in decision-making positions; and
 - 2. Employees in staff positions.

Naturally, as centers began cropping up across the country, the federal government looked for a way to coordinate activity with the states. Important questions arose, such as: How many centers do we create? Where do we place them? How much funding should they receive?

By the late 1980s, each state receiving IL funds for services was required to have an independent living advisory council, a majority of whose members were people with disabilities. While most states had these advisory bodies, these councils had no real authority. They had responsibility for developing a state plan, but the directors of the state agency were only required to “consider” their recommendations.

Advocates, including congressional staff, believed these councils could be the logical next step to consumer control. If given real authority to go along with their responsibilities, perhaps these councils could fulfill the need for planning and coordination between the federal government and states.

Truthfully, not all advocates in IL believed the councils could step into this role. The councils did not meet regularly, the members tended to be from the capital city and not sensitive to rural needs, and the people who served on them were the same faces that served on all VR committees. If Congress was going to use these councils, they would need to make significant changes, so in 1992 when Congress was reauthorizing the Rehabilitation Act of 1973, it greatly strengthened the responsibilities and authority of the SILCs. These changes will be addressed in more depth later.

The Rehabilitation Act

Learning and understanding the history of The Rehabilitation Act (The Act) is essential for anyone working at or serving as a member of a SILC. Much has been written about The Act, and that material will not be duplicated here, but if you are new to independent living, and want to get up to speed quickly, you will find a brief overview in Appendix B, *History of Independent Living* by Gina McDonald and Mike Oxford, and numerous more extensive documents on ILRU's Web site <http://www.ilru.org>. Type “Rehabilitation Act” into the search window on the home page and hundreds of documents with a Rehab

⁴ 34CFR366.63.

Act reference will appear. However, a good place to start is <http://www.ilru.org/html/publications/rehab/index.html> where you will find The Act, organized by links that break out various versions of The Act and the regulations into sections, a comparison of different versions of The Act, and links that connect to other supporting information such as a glossary of terms and history of the reauthorizations of The Act.

For purposes of this training, we would like to share a few definitions here that are important to understand before you proceed with the material.

- **Bill:** A proposed law that has been introduced in either house of the Legislature. A bill creates new law or amends or repeals existing law.
- **Law:** A binding rule of a community that is enforced by controlling authorities. Statute law is enacted by the Legislature.
- **Code:** (1) A compilation of laws on a particular subject (e.g., the criminal code). (2) Published statutes (e.g., The U.S. Code). (3) The compilation of administrative rules, known as the “administrative code.”
- **Statute:** A formal written enactment of a legislative body that is codified.
- **Title:** The primary subunit of a bill or statute.
- **Rehabilitation Act of 1973:** This is the authorizing legislation for many disability-related programs and requirements including the vocational rehabilitation services program and the independent living programs. This was an outgrowth of several earlier statutes—the War Risk Insurance Act, the Smith-Fess Act, and the Borden-LaFollette Act among them.
- **Workforce Investment Act:** In 1998, the Rehab Act was absorbed into the Workforce Investment Act, a comprehensive piece of legislation intended to pull together dozens of vocationally-related programs. The Rehab Act became Title IV of the Workforce Investment Act (WIA). The breakdown of WIA by titles is as follows:
 - Title I: Workforce Investment Systems
 - Title II: Adult Education and Literacy
 - Title III: Workforce Investment-Related Activities
 - Title IV: Rehabilitation Act Amendments of 1998
 - Title V: General Provisions
- **Title IV, the Rehabilitation Act Amendments of 1998:** This includes the entire Rehabilitation Act of 1973, as amended. When the Rehab Act is looked at separately, we often still break it down by titles. The Rehab Act has seven titles as follows:
 - Title I: Vocational Rehabilitation Services - contains a description and guidelines for your state’s vocational rehabilitation program.
 - Title II: Research and Training
 - Title III: Professional Development and Special Projects and Demonstrations
 - Title IV: National Council on Disability

Title V: Rights and Advocacy

Title VI: Employment Opportunities for Individuals with Disabilities

Title VII: Independent Living Services and Centers for Independent Living - contains two chapters. Chapter 1 is "Individuals with Significant Disabilities" and Chapter 2 is "Independent Living Services for Older Individuals who are Blind."

Chapter 1 has three Parts: Sections devoted to the SILC and the State Plan for IL (Part A); sections guiding the use of funds for IL services (Part B); and sections directing funding for centers (Part C).

Following is an outline of the parts of Title VII which cover Independent Living Services and Centers for Independent Living:

Title VII--Independent Living Services and Centers for Independent Living

Chapter 1--Individuals with Significant Disabilities

Part A--General Provisions

Sec. 701. Purpose.

Sec. 702. Definitions.

Sec. 703. Eligibility for Receipt of Services.

Sec. 704. State Plan.

Sec. 705. Statewide Independent Living Council.

Sec. 706. Responsibilities of the Commissioner.

Part B--Independent Living Services

Sec. 711. Allotments.

Sec. 712. Payments to States from Allotments.

Sec. 713. Authorized Uses of Funds.

Sec. 714. Authorization of Appropriations.

Part C--Centers for Independent Living

Sec. 721. Program Authorization.

Sec. 722. Grants to Centers for Independent Living in States in which Federal Funding Exceeds State Funding.

Sec. 723. Grants to Centers for Independent Living in States in which State Funding Equals or Exceeds Federal Funding.

Sec. 724. Centers Operated by State Agencies.

Sec. 725. Standards and Assurances for Centers for Independent Living.

Sec. 726. Definitions.

Sec. 727. Authorization of Appropriations.

Chapter 2--Independent Living Services for Older Individuals Who are Blind

Sec. 751. Definition.

Sec. 752. Program of Grants.

Sec. 753. Authorization of Appropriations.

Rehabilitation Services Administration

When Congress passed and the President signed the Workforce Investment Act of 1998 into law, Title IV (the Rehab Act) was sent to the Department of Education (DOE), Rehabilitation Services Administration (RSA) for implementation of the law. Part of that responsibility was the development of regulations.

The Rehabilitation Services Administration is the entity that has the authority within the DOE to administer the Independent Living Program. The head of RSA is referred to as the Commissioner and the head of the Independent Living Unit is the Chief. The IL Unit is located in the State Monitoring and Program Improvement Division. Within the division there are five state teams, each including a member of the IL Unit. SILCs should communicate issues and concerns to their IL Unit representative.

Chapter Two Composition and Appointments

Most SILCs have a process that they have established to fill vacancies.⁵ It usually begins with the convening of a nominating committee that targets certain geographic areas, and people with different disabilities and ethnic backgrounds. The committee reaches out to the disability community for nominations, screens the recommendations, and refers them to the SILC for confirmation. Names are then sent to the governor's office with a recommendation for appointment.

The more advanced SILCs have a relationship with the person in the governor's office who is in charge of appointments. Creating this relationship can take time and energy since the governor's staff needs to be reassured that the recommended individuals will reflect positively on the governor.

Each state must have a functioning SILC that complies with the law in order to receive Title VII funds from the federal government. This fact is usually enough to convince the governor to work with the SILC to keep the appointment process smooth and efficient.

Who appoints the SILC?

In most cases, ALL members of the SILC are appointed by the governor. There is an exception to this when the state has delegated authority for appointments to boards and commissions to an elected body, such as the legislature.

The governor, or other approved appointing authority, selects members after soliciting recommendations. Technically, anyone who is interested may nominate people for membership on the SILC. Generally, the governor depends on the SILC to do this.

Who must sit on the SILC?

What the law says:

The Council shall include:

- A) at least one director of a center for independent living chosen by the directors of centers for independent living within the State;
- B) as ex officio, nonvoting members
 - a) a representative from the designated State unit; and
 - b) representatives from other State agencies that provide services for individuals with disabilities; and
- C) in a State in which 1 or more projects are carried out under section 121, at least 1 representative of the

⁵ See examples for membership recruitment and orientation from individual SILCs in Appendix C.

directors of the projects.⁶

This is the section of the statute that tells us who **MUST** be on the SILC.

The SILC must have at least one center director. This person is chosen by the other directors of the CILs in the state, including any centers that are part of the center network of the state. SILCs may have by-laws, executive orders or state laws that dictate how many directors serve on the SILC, but it can never be less than one. The center director(s) is a voting member of the SILC and may hold an office, including chair.

The designated state unit is the state agency responsible for Vocational Rehabilitation. The governor must appoint a representative of the DSU to sit on the SILC. This representative serves as an ex officio nonvoting member of the SILC. Likewise, there may be representatives from other state agencies that serve people with disabilities and they are also nonvoting members.

Finally, if a state has one or more grants awarded by RSA to carry out the American Indian Vocational Rehabilitation Services program, there must be at least one representative on the SILC. (This is often referred to as a “121” program because the grant requirements are set out in Section 121 of the Act. Sections in the 100s are in Title I, 200s in Title II, etc.) The person appointed to serve is a voting member.

Who else **MAY** sit on the SILC?

The Council may include:

- A) other representatives from centers for independent living;
- B) parents and guardians of individuals with disabilities;
- C) advocates of and for individuals with disabilities;
- D) representatives from private businesses;
- E) representatives from organizations that provide services for individuals with disabilities; and
- F) other appropriate individuals.

What qualifications must members have?

What the law says:

The Council shall be composed of members:

1. who provide statewide representation;
2. who represent a broad range of individuals with disabilities from diverse backgrounds;
3. who are knowledgeable about centers for independent

⁶ Rehabilitation Act of 1973 as amended, Title VII, Chapters 1 & 2, Sec. 705 (b)(2).

- living and independent living services; and
4. a majority of whom are persons who are:
 - a) individuals with disabilities described in section 7(20)(B); and
 - b) not employed by any State agency or center for independent living.⁷

This part of the law tells us how the SILC must be constructed in terms of qualifications. The law says that the SILC must be composed of members that provide statewide representation. This reference grew out of a tendency to appoint members from the capital city. Similarly, SILCs must represent a broad range of individuals with disabilities.

Knowledge about CILs and IL services is another requirement. Several governors have appointed individuals who have never been in a center or heard of independent living. In some instances, these individuals ended up being very good members because time was taken to educate them.

Typically SILCs recruit, interview, and approve nominees that are then sent to the governor for appointment. Doing a quality job in this area will go far in providing the governor sufficient information to make quality and timely appointments.

Finally, the majority of the members must be people with disabilities who are not employees of the state or a center. This last qualification is confusing to many SILC members. Three who **cannot** be included in the majority are:

- CIL employees, even though they are voting members;
- State agency representatives;
- State employees who are not representing their agency, but are voting members.

CIL board members and volunteers **are** included in the 51%, as are all other people with significant disabilities.

How is the chairperson of the SILC selected?

The Chairperson is elected by the SILC from among the voting members of the Council.⁸ However, in states in which the governor does not have veto power pursuant to State law, the governor designates a voting member of the SILC as chairperson or allows the SILC to designate a voting member.

How long may members serve on the SILC?

Members of the Council serve three-year terms and may serve no more than two consecutive terms, unless they have completed someone else's term. In that case they

⁷ Ibid., Sec. 705 (b)(4)(A).

⁸ Ibid., Sec. 705 (b)(5) and 34CFR364.21.

may serve both three-year terms and the extra months or years of the person they replaced. This includes DSU representatives.

Some SILCs have terms of one, two, and/or three years to assure that there are staggered appointments with experienced and inexperienced members on the Council. Other SILCs believe they have enough diversity in term lengths, and they appoint members to three-year memberships regardless of the circumstances under which they assume their responsibilities.

The Act does not specify how long a SILC member must remain off the Council after their term expires before they may be reappointed. Often times, however, the SILC may be bound by state rules that specify the time period.⁹

How are SILCs set up across the nation?

According to a survey of 46 SILCs conducted by Bob Michaels in 2004 (the last time such a survey has been undertaken):

- The average SILC had 14-15 voting members and 3-4 non-voting members, or a total of about 18 members.
- Less than half of the states had all disability groups represented. All except one had most disabilities represented on the Council.
- The average SILC had 2.8 CIL employees.
- Of the 46 states surveyed, 38 had at least one representative who was African-American; 20 had at least one representative who was Native American; and 15 had at least one representative who was Hispanic.

⁹ Ibid., Sec. 705 (b)(6).

Chapter Three

SILC Duties and Responsibilities

The statute specifically identifies five duties that the SILC must carry out:

1. jointly develop and sign (in conjunction with the designated State unit) the State plan required in section 704;
2. monitor, review, and evaluate the implementation of the State plan;
3. coordinate activities with the State Rehabilitation Council established under section 105, if the State has such a Council, or the commission described in section 101(a)(21)(A), if the State has such a commission, and councils that address the needs of specific disability populations and issues under other Federal law;
4. ensure that all regularly scheduled meetings of the Statewide Independent Living Council are open to the public and sufficient advance notice is provided; and
5. submit to the Commissioner such periodic reports as the Commissioner may reasonably request, and keep such records, and afford such access to such records, as the Commissioner finds necessary to verify such reports.^{10, 11}

Every three years, the SILC together with the DSU(s), jointly submits a new state plan for independent living (SPIL). The SPIL is signed by the chair of the SILC on behalf of the other Council members. Usually, this is done by an up and down vote following a motion of one of the members during a regularly-scheduled SILC meeting. There have been variations of this process, but under no circumstances should the chair sign the SPIL without the approval of the majority of the rest of the Council.

The SPIL is also signed by the head of the designated state unit, usually VR, as well as the head of the VR agency that serves people who are blind, if a separate agency has been created by law in the state.

The SPIL is then sent to RSA, where it is reviewed and approved. The SPIL may be sent back to the state to be amended prior to the approval of the Commissioner.

The SILC then has an obligation to “monitor, review, and evaluate the implementation of the State plan.” Each SPIL must include the goals and objectives of the state’s IL programs and services. The SILC then has the responsibility to monitor, review, and evaluate the implementation of the SPIL. The more conscientious SILCs will set up a process to review each goal and adjust it as necessary.

¹⁰ Ibid., Sec. 705 (c).

¹¹ See Appendix D for RSA’s January, 2008 clarification of the roles and responsibilities of SILCs.

Historically, this is where many SILCs and centers have encountered problems. The duty says nothing about monitoring, reviewing, and evaluating centers, yet more than a few SILCs see this as part of what they do. Throughout this training, we will be exploring the partnership between centers and the SILCs. It is critical that SILCs do not adopt an adversarial position with a center or do anything to undermine the authority of the center's board.

The State Rehabilitation Council (SRC) is the advisory council to the state VR agency. Although the SRC does not have sign-off authority for the state VR plan in Title I, it does have extensive responsibilities related to the VR program. The SRCs are required to have a representative from the SILC on their Council. This section of the Act requires that the SILC coordinate activities with the SRC.

The Act also requires that regularly scheduled meetings be open to the public. Every state has an open meeting law and Councils are required to follow their state guidelines.

Finally, each SILC must submit a report to the Commissioner. The guidelines for reporting are set out in Section 704, thus, the "704 Report" that must be completed in the quarter following the end of the federal Fiscal Year (October to December).

What other responsibilities do the SILCs have? In order to develop the state plan for independent living identified in the first duty, SILCs together with the DSU(s), must respond to specific requirements outlined in the Act and the implementing regulations. The following are excerpts from Title VII that address these expectations:

- A) The plan shall set forth the steps that will be taken to maximize the cooperation, coordination, and working relationships among . . . public and private entities determined to be appropriate by the Council. (Sec. 704 (i))
- B) The plan shall set forth steps to be taken regarding outreach to populations that are unserved or underserved by programs under this title. . . (Sec. 704 (l))
- C) The SILC must prepare a (resource) plan that "ensure(s) the existence of appropriate planning, financial support and coordination, and other assistance to appropriately address, on a statewide and comprehensive basis, needs in the State . . ." (Sec. 704 (a)(3)).

In a future chapter, we will look closer at the use of funds authorized under Part B. These funds are specifically intended to provide financial assistance to states to support and enhance IL programs and services (Sec. 713). The uses include such activities as demonstrating ways to expand and improve independent living services; conducting studies and analyses and presenting the findings to policymakers; training on the IL philosophy; and providing outreach to populations that are unserved or underserved.

Chapter Four Developing a State Plan

The primary task of the SILC, as we saw in the last chapter, is carrying out its joint responsibilities with the DSU for developing and implementing the SPIL.

The Department of Education published and updated the SPIL preprint, and posted it at: http://www.ed.gov/policy/speced/guid/rsa/spil_instrument_2007.pdf. The instructions for the preprint may be found at:

http://www.ed.gov/policy/speced/guid/rsa/spil_instructions_2007.pdf. The current State Plan covers the three-year time period October 1, 2007 through September 30, 2010.

The major parts of the State Plan are:

- The state's goals, objectives, and strategies
- A detailed description of how the state's Part B funds will be spent
- An account of the outreach efforts to identify unserved and underserved populations
- A detailed report of the services currently provided in the state
- A description of the state's network of CILs, including how the network will develop in the future
- A narrative on the working relationships of providers in the state's IL network
- The SILC's budget
- The process for evaluating progress on the SPIL

Developing a SPIL is an ongoing process that begins the day the current SPIL is turned in to RSA. This means that a SPIL takes about three years of work to ensure it is well developed. Good planning begins with good research and the best SPILs are those that reflect thorough planning. Whether the SILC and the DSU use surveys, outreach meetings, focus groups, conferences, or some combination of these, it's never too early to get started.¹²

Sometimes a SILC and DSU will appoint a SPIL-writing task force to put together the plan. It may make more sense to have an ongoing committee whose responsibility is to gather information throughout the three-year period, analyze the data, and discuss it with the rest of the Council.

In addition to reports from this committee, the SILC should receive periodic presentations from special interest groups, updates from CILs and state agencies, and reports on outreach efforts. The CILs are required by law to conduct consumer satisfaction surveys and share the results with their state's SILC. They also must send

¹² See excerpt from SILC-NET Webcast/teleconference *Involving the Community in Decisions: Data Gathering for SILCs* in Appendix E.

copies of their 704 reports to the SILC. In combination with other information gathered, the SILC may wish to use this data to assess needs within the state.

This periodic and ongoing process is critical to assuring that the SPIL is responding to current issues. Needs that appeared significant two years ago may no longer be relevant. And single-minded advocates may be persuaded by emerging facts that support placing priorities elsewhere.

If there is an ongoing process to gather, analyze, and discuss the above information, when the SILC and DSU finally sit down to write the plan, the goals and objectives will naturally fall into place.

Chapter Five

Managing SILC Finances

SILCs need to understand the sources of funds, the availability of different funds, and the manner in which the funds are managed.

There are three major fund sources included in this chapter: Title VII Part B, Innovation and Expansion funds, and Social Security Reimbursement Funds.

Part B Funds:

The primary source of funding for SILCs is Title VII Part B, Independent Living Services. There are eight different ways Part B funds may be used.

What the law says:

The State may use funds received under this part to provide the resources described in section 705(e), relating to the Statewide Independent Living Council, and may use funds received under this part:

1. to provide independent living services to individuals with significant disabilities;
2. to demonstrate ways to expand and improve independent living services;
3. to support the operation of centers for independent living that are in compliance with the standards and assurances set forth in subsections (b) and (c) of section 725;
4. to support activities to increase the capacities of public or nonprofit agencies and organizations and other entities to develop comprehensive approaches or systems for providing independent living services;
5. to conduct studies and analyses, gather information, develop model policies and procedures, and present information, approaches, strategies, findings, conclusions, and recommendations to Federal, State, and local policymakers in order to enhance independent living services for individuals with disabilities;
6. to train individuals with disabilities and individuals providing services to individuals with disabilities and other persons regarding the independent living philosophy; and
7. to provide outreach to populations that are unserved or underserved by programs under this title, including minority groups and urban and rural populations.

The opening paragraph gives the authority jointly to the DSU and the SILC to use whatever portion of the Part B funds they wish for the support of the SILC's operations. Historically, most of these funds are used to support the other seven activities.

In many states prior to the reauthorization of the Act in 1992, Part B funds (then called Part A) were used to support a DSU services and/or durable medical equipment program. To this day, there are several states that still use these funds this way (#1), although several more have converted this service to contracts with the centers in the state.

Likewise, there are several states that have traditionally divided part of these funds among the centers in the state (#3), with varying degrees of accountability.

The remaining uses for Part B are ways to enrich the IL program in the state. SILCs can play a role in facilitating discussions and recommending changes.

Hopefully you can see how these uses tie into the planning discussed in the last session. As you begin putting together the SPIL, the SILC and the DSU must decide how it will cover the costs of projects identified in the goals and objectives. It is absolutely essential that the SILC and the DSU identify in the SPIL how each project is funded, whether it is covered as one of the eight uses of Part B, operational funds under Innovation and Expansion, or Social Security Reimbursement funds.

Innovation and Expansion Funds (I&E):

What the law says:

The State plan shall: [underlining added]

- A) include an assurance that the State will reserve and use a portion of the funds allotted to the State under section 110
 - a) for the development and implementation of innovative approaches to expand and improve the provision of vocational rehabilitation services to individuals with disabilities under this title, particularly individuals with the most significant disabilities, consistent with the findings of the statewide assessment and goals and priorities of the State as described in paragraph (15); and
 - b) to support the funding of
 - i) the State Rehabilitation Council, if the State has such a Council, consistent with the plan prepared under section 105(d)(1); and
 - ii) the Statewide Independent Living Council, consistent with the plan prepared under section 705(e)(1);
- B) include a description of how the reserved funds will be utilized; and
- C) provide that the State shall submit to the Commissioner

an annual report containing a description of how the reserved funds were utilized during the preceding year.¹³

Essentially, the state may use a portion of the funds that they receive for vocational rehabilitation to do two activities: 1) try innovative ways to expand and improve VR (which is similar to the use of Part B for IL) and 2) to support the SRC and SILC. If the DSU and SILC agree to use Innovation and Expansion funds to support the SILC, these funds must be identified in the SILC's resource plan. When I&E funds are used to support the SILC, the purpose must be included in the resource plan.

Social Security Reimbursement Funds

What the law says:

a) Expenditure

Amounts described in subsection (b) may not be expended by a State for any purpose other than carrying out programs for which the State receives financial assistance under this title, under part B of title VI, or under Title VII.

b) Amounts

The amounts referred to in subsection (a) are amounts provided to a State under the Social Security Act (42 U.S.C. 301 et seq.) as reimbursement for the expenditure of payments received by the State from allotments under section 110 of this Act.¹⁴

Social Security Reimbursement Funds (SSRF) are dollars that the DSU receives when the VR agency files for reimbursement of the money it spent for services to someone who is on Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). This reimbursement is contingent upon the individual achieving and maintaining employment. In effect, what the law says is that this money can be used in Title VII, as well as other specific parts of the Act.

Many SILCs, or others in independent living such as CILs, currently receive SSRF. SILCs should be aware that these funds are program income funds generated by the state VR agency, and they may not be a stable source of funds. As state resources decrease, there may be more pressure for state VR agencies to use SSRF in the VR program. Therefore, SILCs and others in IL should take this into consideration when justifying their request for the use of SSRF.

How are SILCs funded across the nation?

According to the survey conducted in 2004 (Michaels), the average SILC budget was \$395,539, of which \$167,535 was operating expenses (what it cost to run the SILC) and \$228,004 was for projects.

¹³ Rehabilitation Act of 1973 as amended, Title I, Sec. 101 (a)(18)

¹⁴ Ibid., Sec. 108 (a) and (b).

Chapter Six Your Center Network

Most CILs are partially funded through Title VII Part C of the Act. In every state except Massachusetts and Minnesota these funds flow directly from the Department of Education/Rehabilitation Services Administration (DOERSA) to the center. In the other two states, because the states contribute more funds than the federal government for the operation of CILs and they have elected to receive the money directly, the funds flow to the states for distribution to the centers.

In order to receive the funds, the centers must compete for the grant or contract in a geographic area designated by the SILC in the SPIL. Once awarded the grant or contract, however, the centers have some protections in subsequent years.

What the law says:

ORDER OF PRIORITIES: The Commissioner shall be guided by the following order of priorities in allocating funds among centers for independent living within a State, to the extent funds are available:

1. The Commissioner shall support existing centers for independent living, as described in subsection (c), that comply with the standards and assurances set forth in section 725, at the level of funding for the previous year.
2. The Commissioner shall provide for a cost-of-living increase for such existing centers for independent living.
3. The Commissioner shall fund new centers for independent living, as described in subsection (d), that comply with the standards and assurances set forth in section 725.¹⁵

Because one of the responsibilities of a center is to advocate on behalf of people with disabilities, the law protects them from retribution. Centers that receive funds in the previous year have the first priority for receiving an equal allotment the next, assuming that they continue to provide services as set out in the statute (Section 725).

If there are additional funds available in a state, the DOE/RSA will add a cost of living allowance (COLA) to each center's allotment.

Finally, if there are still funds available after the continuation and COLA, the DOE/RSA will make them available for the development of new CILs.

Sometimes, there are insufficient funds to create a new center, or the SILC determines that the existing centers are so under-funded that any new funds should be distributed among them. A regulation was developed by DOE/RSA to permit this. It states:

¹⁵ Rehabilitation Act of 1973 as amended, Title VII, Chapters 1 & 2, Sec. 722 (e).

If, after meeting the priorities . . . there are insufficient funds . . . to fund a new center. . . , the Secretary may:

Use the excess funds in the State to assist existing centers consistent with the State plan; or

Re-allot these funds (give them to another state).¹⁶

About 80% of the states have set a base funding level for their centers. In other words, the centers must reach a certain level of funding before any funds are directed toward the development of a new center. Most states have set this level at \$250,000/center. Regardless of whether a state has a base funding level, the SILC should still identify the area, usually counties within the state, where the next center should be established in order of priority.

Currently, the federal government allots approximately \$75 million for the operation of CILs.

Other sources of funding for CILs

The second major source of funding for the operation of centers is individual states. Usually, this allocation comes from the state's general revenue fund and is disbursed through the designated state agency (most often, VR). Approximately 50% of the states contribute to the operation of centers.

In order to receive Part C funds from the federal government, the state plan includes **all** funds designated for the **operation** of centers. The purpose of this is to encourage the partnership between the state and federal government for the growth of the IL network. This includes funds only for the 'operation' of centers, not funds that support programs within centers, such as attendant care.

Over the years, several states have used Social Security Reimbursement Funds (see Chapter Five) to support the operation of centers. Usually this has been a short-term strategy to fill a funding gap caused by the withdrawal of state general revenue or other program-related funding.

¹⁶ 34CFR366.22.

Chapter Seven Our Future

As the latest addition to the IL movement, SILCs are still finding their way. In 1998, representatives from all of the state SILCs met in Houston, Texas to begin identifying common solutions to universal issues.

To begin naming these issues prior to the conference, ILRU staff used a modified Delphi survey technique, contacting each SILC chair by mail and asking them to identify the most prominent issues facing SILCs. Results were compiled into a list of 21 items. This list was then re-sent to SILC chairs, asking them to rank them in terms of importance. Four issues clearly emerged as top ranking and were used to form the basis of the work groups at SILC Congress '98. The issues were:

- the SILCs' relationship with independent living centers,
- the SILCs' relationship with the designated state unit,
- SILC autonomy, and
- the SILC as a systems advocate.

With some modification in how they are presented, these four issues have continued to be the centerpiece of discussions ever since. In 2005, the eighth SILC Congress voluntarily adopted a set of Standards and Indicators addressing these issues. A copy of the Standards and Indicators for the SILCs may be found in Appendix A. However, the Act and its implementing regulations do not include standards and indicators for SILCs.

Summary

Statewide Independent Living Councils have been given an important trust that brings with it exciting opportunities and enormous responsibilities. Each SILC member can bring their own individuality, wisdom, and creativity to the work of the SILC and by the same token each member must understand the requirements that come with membership. The competencies and the concerted efforts of each SILC member are essential to achieving the goal of the SILCs—to identify and respond to the needs of the independent living community within each state. Hopefully, this course has provided you with a framework that will support your work and assist you in becoming the best SILC member you can be.

Resources

The following is a list of links to monographs and training materials that are related to your work on the SILC:

1. Advocacy: Unite in Power (Training manual)
http://www.ilru.org/html/publications/training_manuals/Advocacy_UnitePower_2000.doc
2. A Little History Worth Knowing (Video)
http://www.ilru.org/html/publications/filmlibrary/film_library_details.html#history
3. Composition of Statewide Independent Living Councils
http://www.ilru.org/html/publications/faqs/ilnet_composition.htm
4. Cultivating Cultural Competence
http://www.ilru.org/html/publications/newsletters/2003/ilnet_Oct2003.html
5. Development of State Plans for Independent Living
http://www.ilru.org/html/publications/faqs/ilnet_development.htm
6. Effective Rural Outreach
http://www.ilru.org/html/publications/training_manuals/Outreach.doc
7. Frequently Asked Questions about the Rehab Act & the Role of the SILC
http://www.ilru.org/html/publications/faqs/ilnet_rehab-silc.htm
8. Guidelines for Disability Policy Change Agents
http://www.ilru.org/html/publications/bookshelf/change_agents.html
9. History of Independent Living
http://www.ilru.org/html/publications/information/ilnet_HistoryIL.htm
10. How IL History and Philosophy Shape Our Future (Training manual)
http://www.ilru.org/html/publications/training_manuals/History.doc
11. How to Influence Policy-Makers and the Policy-Making Process
http://www.ilru.org/html/publications/bookshelf/influence_policy-makers.html
12. Identifying a Minimum Budget for Centers: Results of an ILRU Research Project (Web cast)
<http://www.ilru.org/html/training/webcasts/archive/2001/09-26-BM.html>
13. IL 201 - History & Philosophy of the Independent Living Movement (Training manual)
http://www.ilru.org/html/publications/training_manuals/IL201.doc
14. Issues in Rural Independence Revisited
http://www.ilru.org/html/publications/bookshelf/rural_revisited.html
15. Managing Diversity (Video)
http://www.ilru.org/html/publications/filmlibrary/film_library_details.html#diversity
16. Prototype Job Descriptions
http://www.ilru.org/html/publications/faqs/ilnet_jobdescriptions.htm
17. Putting the Public into the Plan

http://www.ilru.org/html/publications/newsletters/1999/ilnet_dec1999.htm

18. Readings and Resources for the Independent Living and Disability Rights Movements

http://www.ilru.org/html/publications/information/ilnet_ReadingsResourcesList.htm

19. Rehabilitation Act of 1973, as amended

http://www.ilru.org/html/publications/rehab/Rehab_Act.doc

20. Searchable Database (704 Reports)

<http://www.ilru.org/html/publications/704/Samindex.html>

21. Should SILCs Become 501(c) (3) s? (Training Manual)

http://www.ilru.org/html/publications/training_manuals/501.doc

22. SILC Trends: A Review of Past SILC Surveys (Web cast)

<http://www.ilru.org/html/training/webcasts/archive/2002/06-05-BM.html>

23. State IL Plans--Use Of Part B Funds

http://www.ilru.org/html/publications/faqs/ilnet_partBuses.htm

24. Survey Gives "Big Picture" View of SILCs

http://www.ilru.org/html/publications/newsletters/2000/ilnet_Sept2000.html#survey

25. Systems Advocacy: Using Your Power to Effect Change (Training manual)

http://www.ilru.org/html/publications/training_manuals/SystemsAdvocacy_EffectChange.pdf

26. The SILC Difference: "Yes, You Can!" (Training manual)

http://www.ilru.org/html/publications/training_manuals/Yes,youcan.txt

27. Title VII of the Rehabilitation Act of 1973, as amended

http://www.ilru.org/html/publications/rehab/Title_VII12.doc

28. Title VII of the Rehabilitation Act of 1973, as amended—Regulations

<http://www.ilru.org/html/publications/rehab/TitleVIIRegs.doc>

29. To be or not to be 501(c) (3)? SILCs as nonprofits?

http://www.ilru.org/html/publications/newsletters/2001/ilnet_july2001.html

30. What Every SILC Member Should Know: A Self-Administered Test

http://www.ilru.org/html/publications/faqs/ilnet_shouldknow.htm

31. Work Smarter, Not Harder: "Outreach Made Simple" (Training manual)

http://www.ilru.org/html/publications/training_manuals/work_smarter.doc

Appendix A: Standards and Indicators for Statewide Independent Living Councils

Preamble

These standards and indicators are intended to assist states to fully implement the requirements outlined in Title VII of the Rehab Act.

They are intended as a guide for states in administering programs and services in compliance with the Act and Independent Living values and principles.

Definitions

Consumer Control- The term “consumer control” means, with respect to a SILC, that the SILC vests power and authority in individuals with disabilities regarding decision making, SPIL Development and approval, establishment of policies, direction, management and operations of the SILC.

Disability-The term “disability” means a person who has a physical, mental, cognitive, and/or sensory impairment, which substantially limits one or more of such person’s major life activities, has a record of such impairment or is regarded as having such impairment.

SILC Philosophy

Standard #1

The purpose of the SILC is to promote the philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.

Indicators

1. SILC membership shall always remain at or above 51% people with significant disabilities who represent a broad range of disabilities and are knowledgeable about CIL’s and Independent Living services.
2. The SILC will provide statewide representation, include a broad range of individuals with disabilities from diverse backgrounds, and consist of individuals who are knowledgeable about CILs and Independent Living Services; additional members may include other representatives from centers for independent living, parents and guardians of individuals with disabilities, advocates of and for individuals with disabilities, representatives from private businesses, representatives from organizations that provide services for individuals with disabilities, and other appropriate individuals.

3. The majority of voting SILC membership shall consist of individuals with disabilities who are not employed by any state agency or CIL.
4. In a state in which one or more projects are carried out under section 121, the SILC shall include at least one representative of the directors of the projects.
5. The SILC will participate in the appointment process by developing a method for recruiting applicants and receiving applications and, on at least an annual basis, forwarding a list of qualified, knowledgeable, and diverse candidates to be considered for appointment by the Governor or designee.
6. The SILC will offer training to its members, CILs, other providers, and consumers on items such as the Rehabilitation Act and Independent Living.

Minimum Standard: once a year

Acceptable Standard: twice a year

Optimal Standard: three times a year

7. The SILC shall provide each newly appointed member with training and orientation prior to voting on the rights and responsibilities of Council membership.
8. The SILC shall complete and submit an assessment of the SILC training needs to RRCEP, RTC (ILRU) on an annual basis.

Standard #2

SILC has an active and equal role in the development of the State Plan.

Indicators

1. A majority vote of the SILC membership is required to approve the State Plan as evidenced in meeting minutes.
2. Any revisions and changes made to the SPIL by the DSU Director, Staff, SILC Chair, SILC Committee or any other entity will be submitted and approved by the full SILC, prior to inclusion in the final approved SPIL.

Standard #3

The SILC has the responsibility to advocate for issues of its own choice as evidenced in the state plan and/or in a list of advocacy issues.

Indicators

1. The SILC will, on an annual basis, develop a list of advocacy issues.
2. Minutes of SILC meetings, public forums, 704 Reports and member activity reports will demonstrate evidence of advocacy action and accomplishments.

SILC Relationship with CILs

Standard #1

The SILC will, in partnership with CILs, maximize cooperation, coordination, and working relationships to strengthen independent living within the state.

Indicators

1. The SILC will have as a voting member at least one CIL director chosen by the directors of CILs that comply with Section 725 in that state.
2. The SILC will promote opportunities for CILs to acquire technical assistance and training.

Standard #2

The SILC will collaborate with CILs in the design, development, implementation, and evaluation of the SPIL.

Indicators

1. The SILC will partner with CILs to conduct public forums and other mechanisms to gather information from people with disabilities in the development of the state plan.
2. The SILC will utilize 704 reports and other tools to identify the trends for development of the state plan.
3. The SILC will cooperate, collaborate, and coordinate with CILs in the development of the design of the statewide network of CILs.
4. The SILC and CILs will collaborate on the design and implementation of tools to assess consumer satisfaction with the state plan.

Autonomy

Standard # 1:

The SILC shall not be established as an entity within a state agency.

Indicator:

The SILC

- Develops its own vision and mission statement
- Reviews and monitors its own progress
- Participates in the appointment process by recommending members
- Has the responsibility to advocate about issues of its own choice

- Develops statutory authority, procedures and other systematic methods for gaining, maintaining and protecting its autonomy
- Accounts for its decisions and actions
- The SPIL describes the status of the council and how that status demonstrates the autonomy of the council
- Has a conflict of interest policy for council members
- Has a plan for training/mentoring of new members
- Is responsible and accountable for the actions of the SILC

Standard # 2

The SILC shall prepare, in conjunction with the DSU, a plan for the provision of such resources as may be necessary and sufficient to carry out the functions of the council.

Indicator:

The SILC

- Develops, adopts and controls its own budget
- Develops, implements and maintains sound fiscal policies and procedures

Standard # 3

Each SILC shall, consistent with state law, supervise and evaluate personnel necessary to carry out the functions of the council.

Indicator:

The SILC develops, implements and maintains sound personnel policies and procedures in accordance with its organizational structure

Standard # 4

The SILC shall develop and sign the SPIL in conjunction with the DSU.

Indicators:

The SILC:

- Develops, implements and monitors its SPIL
- Chairperson shall sign the SPIL upon a majority vote of the council
- Has a process for reviewing and determining if the SPIL has been implemented

SILCs as System Advocates

Standard #1:

The Council shall direct and develop the resources (including but not limited to funds, staff, volunteers, council members, and partners) necessary to advocate for systems change.

Indicators:

1. The Council will identify in the SPIL the resources necessary to implement advocacy efforts for systems change. The Council will identify in the SPIL the process for acquiring resources to carry out those advocacy efforts.
2. The Council will identify in the SPIL a contingency process to address unexpected emerging issues.
3. The Council will report the resources being used to implement advocacy efforts for systems change.

Standard #2:

The Council will develop and implement advocacy efforts that promote the IL philosophy and results in meaningful and measurable systemic change.

Indicators:

1. The Council will identify and prioritize systems change issues through statewide consumer input.
2. The Council will develop an action plan for implementation of advocacy efforts.
3. The Council will establish a method for periodic evaluation of the effectiveness of their action plan.

Standard #3:

The Council will develop and strengthen the network of CILs, including supporting their advocacy efforts.

Indicators:

1. The Council will partner with the CILs to implement statewide advocacy efforts towards systemic change.
2. The Council will share with CILs, statewide consumer input data gathered from unserved and underserved populations regarding systems change issues that need to be addressed by the network of CILs.

Standard #4:

The Council shall set forth the steps that will be taken to maximize the cooperation,

coordination, and working relationships with other advocates working towards systemic change.

Indicators:

1. The Council will work with the CILs to establish statewide advocacy networks that partner with coalitions and others who are addressing common systemic change issues.
2. The Council will identify its systems change partners in the SPIL.
3. The Council will outreach to additional organizations and partners in order to effectively address systems change issues.
4. The Council will provide evidence of those partnerships in the resource plan and evaluation process.

Appendix B: Readings on Independent Living

History of Independent Living¹

By Gina McDonald and Mike Oxford

This account of the history of independent living stems from a philosophy which states that people with disabilities should have the same civil rights, options, and control over choices in their own lives as do people without disabilities.

The history of independent living is closely tied to the civil rights struggles of the 1950s and 1960s among African Americans. Basic issues--disgraceful treatment based on bigotry and erroneous stereotypes in housing, education, transportation, and employment--and the strategies and tactics are very similar. This history and its driving philosophy also have much in common with other political and social movements of the country in the late 1960s and early 1970s. There were at least five movements that influenced the disability rights movement.

Social Movements

The first social movement was deinstitutionalization, an attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities. This movement was led by providers and parents of people with developmental disabilities and was based on the principle of "normalization" developed by Wolf Wolfensberger, a sociologist from Canada. His theory was that people with developmental disabilities should live in the most "normal" setting possible if they were expected to behave "normally." Other changes occurred in nursing homes where young people with many types of disabilities were warehoused for lack of "better" alternatives (Wolfensberger, 1972).

The next movement to influence disability rights was the civil rights movement. Although people with disabilities were not included as a protected class under the Civil Rights Act, it was a reality that people could achieve rights, at least in law, as a class. Watching the courage of Rosa Parks as she defiantly rode in the front of a public bus, people with disabilities realized the more immediate challenge of even getting on the bus.

The "self-help" movement, which really began in the 1950s with the founding of Alcoholics Anonymous, came into its own in the 1970s. Many self-help books were published and support groups flourished. Self-help and peer support are recognized as key points in independent living philosophy. According to this tenet, people with similar disabilities are believed to be more likely to assist and to understand each other than individuals who do not share experience with similar disability.

¹ From IL NET Training Manual, *Standards and More: Beyond Compliance* (1995).
http://www.ilru.org/html/projects/ilnet/ilnet_manuals.htm

Demedicalization was a movement that began to look at more holistic approaches to health care. There was a move toward “demystification” of the medical community. Thus, another cornerstone of independent living philosophy became the shift away from the authoritarian medical model to a paradigm of individual empowerment and responsibility for defining and meeting one’s own needs.

Consumerism, the last movement to be described here, was one in which consumers began to question product reliability and price. Ralph Nader was the most outspoken advocate for this movement, and his staff and followers came to be known as “Nader’s Raiders.” Perhaps most fundamental to independent living philosophy today is the idea of control by consumers of goods and services over the choices and options available to them.

The independent living paradigm, developed by Gerben DeJong in the late 1970s (DeJong, 1979), proposed a shift from the medical model to the independent living model. As with the movements described above, this theory located problems or “deficiencies” in the society, not the individual. People with disabilities no longer saw themselves as broken or sick, certainly not in need of repair. Issues such as social and attitudinal barriers were the real problems facing people with disabilities. The answers were to be found in changing and “fixing” society, not people with disabilities. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional.

Using these principles, people began to view themselves as powerful and self-directed as opposed to passive victims, objects of charity, cripples, or not-whole. Disability began to be seen as a natural, not uncommon, experience in life; not a tragedy.

Independent Living

Ed Roberts is considered to be the “father of independent living.” Ed became disabled at the age of fourteen as a result of polio. After a period of denial in which he almost starved himself to death, Ed returned to school and received his high school diploma. He then wanted to go to college. The California Department of Rehabilitation initially rejected Ed’s application for financial assistance because it was decided that he was “too disabled to work.” He went public with his fight and within one week of doing so, was approved for financial aid by the state. Fifteen years after Ed’s initial rejection by the State of California as an individual who was “too” disabled, he became head of the California Department of Rehabilitation--the agency that had once written him off.

After Ed earned his associate’s degree at the College of San Mateo, he applied for admission to the University of California at Berkeley. After initial resistance on the part of the university, Ed was accepted. The university let him use the campus hospital as his dormitory because there was no accessible student housing (none of the residential buildings could support the weight of Ed’s 800-lb. iron lung). He received attendant services through a state program called “Aid to the Totally Disabled.” This is a very important note because this was consumer-controlled personal assistance service. The attendants were hired, trained, and fired by Ed.

In 1970, Ed and other students with disabilities founded a disabled students' program on the Berkeley campus. His group was called the "Rolling Quads." Upon graduation, the "Quads" set their sights on the need for access beyond the University's walls.

Ed contacted Judy Heumann, another disability activist, in New York. He encouraged her to come to California and along with other advocates; they started the first center for independent living in Berkeley. Although it started out as a "modest" apartment, it became the model for every such center in the country today. This new program rejected the medical model and focused on consumerism, peer support, advocacy for change, and independent living skills training.

In 1983, Ed, Judy, and Joan Leon, co-founded the World Institute on Disability (WID), an advocacy and research center promoting the rights of people with disabilities around the world. Ed Roberts died unexpectedly on March 14, 1995.

The early 1970s was a time of awakening for the disability rights movement in a related, but different way. As Ed Roberts and others were fighting for the rights of people with disabilities presumed to be forever "homebound" and were working to assure that participation in society, in school, in work, and at play was a realistic, proper, and achievable goal, others were coming to see how destructive and wrong the systematic institutionalization of people with disabilities could be. Inhuman and degrading treatment of people in state hospitals, schools and other residential institutions such as nursing facilities were coming to light and the financial and social costs were beginning to be considered unacceptable. This awakening within the independent living movement was exemplified by another leading disability rights activist, Wade Blank.

ADAPT

Wade Blank began his lifelong struggle in civil rights activism with Dr. Martin Luther King, Jr. to Selma, Alabama. It was during this period that he learned about the stark oppression which occurred against people considered to be outside the "mainstream" of our "civilized" society. By 1971, Wade was working in a nursing facility, Heritage House, trying to improve the quality of life of some of the younger residents. These efforts, including taking some of the residents to a Grateful Dead concert, ultimately failed. Institutional services and living arrangements were at odds with the pursuit of personal liberties and life with dignity.

In 1974, Wade founded the Atlantis Community, a model for community-based, consumer-controlled, independent living. The Atlantis Community provided personal assistance services primarily under the control of the consumer within a community setting. The first consumers of the Atlantis Community were some of the young residents "freed" from Heritage House by Wade (after he had been fired). Initially, Wade provided personal assistance services to nine people by himself for no pay so that these individuals could integrate into society and live lives of liberty and dignity.

In 1978, Wade and Atlantis realized that access to public transportation was a necessity if people with disabilities were to live independently in the community. This was the year that American Disabled for Accessible Public Transit (ADAPT) was founded.

On July 5-6, 1978, Wade and nineteen disabled activists held a public transit bus “hostage” on the corner of Broadway and Colfax in Denver, Colorado. ADAPT eventually mushroomed into the nation’s first grassroots, disability rights, activist organization.

In the spring of 1990, the Secretary of Transportation, Sam Skinner, finally issued regulations mandating lifts on buses. These regulations implemented a law passed in 1970—the Urban Mass Transit Act—which required lifts on new buses. The transit industry had successfully blocked implementation of this part of the law for twenty years, until ADAPT changed their minds and the minds of the nation.

In 1990, after passage of the Americans With Disabilities Act (ADA), ADAPT shifted its vision toward a national system of community-based personal assistance services and the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The acronym ADAPT became “American Disabled for Attendant Programs Today.” The fight for a national policy of attendant services and the end of institutionalization continues to this day.

Wade Blank died on February 15, 1993, while unsuccessfully attempting to rescue his son from drowning in the ocean. Wade and Ed Roberts live on in many hearts and in the continuing struggle for the rights of people with disabilities. The lives of these two leaders in the disability rights movement, Ed Roberts and Wade Blank, provide poignant examples of the modern history, philosophy, and evolution of independent living in the United States. To complete this rough sketch of the history of independent living, a look must be taken at the various pieces of legislation concerning the rights of people with disabilities, with a particular emphasis on the original “bible” of civil rights for people with disabilities, the Rehabilitation Act of 1973.

Civil Rights Laws

Before turning to the Rehabilitation Act, a chronological listing and brief description of important federal civil rights laws affecting people with disabilities is in order.

1964--Civil Rights Act: prohibits discrimination on the basis of race, religion, ethnicity, national origin, and creed; later, gender was added as a protected class.

1968--Architectural Barriers Act: prohibits architectural barriers in all federally owned or leased buildings.

1970--Urban Mass Transit Act: requires that all new mass transit vehicles be equipped with wheelchair lifts. As mentioned earlier, it was twenty years, primarily because of machinations of the American Public Transit Association (APTA), before the part of the law requiring wheelchair lifts was implemented.

1973--Rehabilitation Act: particularly Title V, Sections 501, 503, and 504, prohibits discrimination in federal programs and services and all other programs or services receiving federal funding.

1975--Developmental Disabilities Bill of Rights Act: among other things, establishes Protection and Advocacy services (P & A).

1975--Education of All Handicapped Children Act (PL 94-142): requires free, appropriate public education in the least restrictive environment possible for children

with disabilities. This law is now called the Individuals with Disabilities Education Act (IDEA).

1978--Amendments to the Rehabilitation Act: provides for consumer-controlled centers for independent living.

1983--Amendments to the Rehabilitation Act: provides for the Client Assistance Program (CAP), an advocacy program for consumers of rehabilitation and independent living services.

1985--Mental Illness Bill of Rights Act: requires protection and advocacy services (P & A) for people with mental illness.

1988--Civil Rights Restoration Act: counteracts bad case law by clarifying Congress' original intention that under the Rehabilitation Act, discrimination in ANY program or service that is a part of an entity receiving federal funding--not just the part which actually and directly receives the funding--is illegal.

1988--Air Carrier Access Act: prohibits discrimination on the basis of disability in air travel and provides for equal access to air transportation services.

1988--Fair Housing Amendments Act: prohibits discrimination in housing against people with disabilities and families with children. Also provides for architectural accessibility of certain new housing units, renovation of existing units, and accessibility modifications at the renter's expense.

1990--Americans with Disabilities Act: provides comprehensive civil rights protection for people with disabilities; closely modeled after the Civil Rights Act and the Section 504 of Title V of the Rehabilitation Act and its regulations.

The modern history of civil rights for people with disabilities is three decades old. A key piece of this decades-long process is the story of how the Rehabilitation Act of 1973 was finally passed and then implemented. It is the story of the first organized disability rights protest.

The Rehabilitation Act of 1973

In 1972, Congress passed a rehabilitation bill that independent living activists cheered. President Richard Nixon's veto prevented this bill from becoming law. During the era of political activity at the end of the Vietnam War, Nixon's veto was not taken lying down by disability activists who launched fierce protests across the country. In New York City, early leader for disability rights, Judy Heumann, staged a sit-in on Madison Avenue with eighty other activists. Traffic was stopped. After a flood of angry letters and protests, in September 1973, Congress overrode Nixon's veto and the Rehabilitation Act of 1973 finally became law. Passage of this pivotal law was the beginning of the ongoing fight for implementation and revision of the law according to the vision of independent living advocates and disability rights activists.

Key language in the Rehabilitation Act, found in Section 504 of Title V, states that:

No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Advocates realized that this new law would need regulations in order to be implemented and enforced. By 1977, Presidents Nixon and Ford had come and gone. Jimmy Carter had become president and had appointed Joseph Califano his Secretary of Health, Education and Welfare (HEW). Califano refused to issue regulations and was given an ultimatum and deadline of April 4, 1977. April 4 went by with no regulations and no word from Califano.

On April 5, demonstrations by people with disabilities took place in ten cities across the country. By the end of the day, demonstrations in nine cities were over. In one city—San Francisco—protesters refused to disband.

Demonstrators, more than 150 people with disabilities, had taken over the federal office building and refused to leave. They stayed until May 1. Califano had issued regulations by April 28, but the protesters stayed until they had reviewed the regulations and approved of them.

The lesson is a fairly simple one. As Martin Luther King said,

It is an historical fact that the privileged groups seldom give up their privileges voluntarily. Individuals may see the moral light and voluntarily give up their unjust posture, but, as we are reminded, groups tend to be more immoral than individuals. We know, through painful experience that freedom is never voluntarily given by the oppressor, it must be demanded by the oppressed.

Leaders in the Independent Living Movement

The history of the independent living movement is not complete without mention of some other leaders who continue to make substantial contributions to the movement and to the rights and empowerment of people with disabilities.

- Max Starkloff, Charlie Carr, and Marca Bristo founded the National Council on Independent Living (NCIL) in 1983. NCIL is one of the only national organizations that is consumer-controlled and promotes the rights and empowerment of people with disabilities.
- Justin Dart played a prominent role in the fight for passage of the Americans with Disabilities Act, and is seen by many as the spiritual leader of the movement today.
- Lex Frieden is co-founder of ILRU Program. As director of the National Council on Disability, he directed preparation of the original ADA legislation and its introduction in Congress.
- Liz Savage and Pat Wright are considered to be the “mothers of the ADA.” They led the consumer fight for the passage of the ADA.

There are countless other people who have and continue to make substantial contributions to the independent living movement.

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Consumer Control Principles in Independent Living¹

In matters of principle, stand like a rock... Thomas Jefferson

In many organizations, the consideration of principles, values, and mission is a rare occurrence seldom connected to planning and action. In independent living centers, however, such considerations need to occur on a continual basis. These discussions are necessary for the formation of a collective consciousness that connects daily operations, successes, and dilemmas to the principle of consumer control. However, in developing a common understanding of the principle of consumer control, centers must also arrive at a common definition for the term “consumer.”

Within the independent living field, precisely defining “consumer” and developing policies that address the role of consumers in governance, administration, staffing, service delivery, and advocacy proved to be a complex task. Early definitions focused on the participant in services, but ignored other individuals who are intended beneficiaries of independent living activities--both direct and indirect.

A broader definition of consumer has evolved and is now commonly used in the independent living field:

A consumer is any individual with a disability who may be a past, present, or future participant in independent living services or one who may indirectly benefit from independent living advocacy efforts.

This definition, which is reflected in this monograph, addresses the pivotal interaction of the independent living center with the larger community and the center’s need to respond to a broad array of issues facing citizens with varying disabilities and ethnic, economic, and cultural differences. It addresses the need for broad-based representation of persons from cross-disability and demographic categories and lays the foundation for an organization that can serve as “a source of support and pride to [all] disabled people in the community and as a symbol of productivity and self-reliance for the broader social and economic community” (Challenge of Emerging Leadership, Mott Foundation Report, 1983). With this broader definition, organizations are charged with creating policies and establishing practices that emphasize the principle of consumer control as representing the cross-disability and social/cultural diversity that exists within their communities.

Defining Consumer Control

“Consumer control” is defined as: significant representation, power, authority, and influence of individuals with varying disabilities in all aspects of an organization that provides services to enhance independence and that seeks to change the political,

¹ This article is excerpted and reprinted with permission from Shreve, Spiller, Griffen, Waldron, and Stolzman. (1988). *Consumer Control in Independent Living*, Chapter 2, Center for Resource Management, Inc., South Hampton, NH.

social, and economic environment and quality of life possible for all disabled persons.

Translating consumer control principles into consumer control practices requires the exercise of authority by consumers over the organization itself, the exercise of choice by consumers over the services they receive, and the exercise of influence by the organization in overcoming the community barriers that inhibit its consumer population.

Consumer control practices apply to:

- organizational decision-making,
- policy development,
- planning,
- staffing patterns,
- service approaches,
- volunteer involvement,
- approach to the community,
- definition of target population, and
- community advocacy priorities.

Consumer control is achieved and sustained by an organization that maintains the ability to be molded by its constituency. To implement consumer control principles, four areas comprising the full range of center functions and operations need attention: policy making; staffing; services; and community advocacy.

In the remainder of this chapter, the principle of consumer control is defined in the context of major functional areas of an independent living center's operations.

Consumer Control at the Policy Level

In non-profit corporations, the board of directors is the legal entity empowered to establish the value base of the organization, develop policies, and oversee the affairs of the corporation. The board of directors assumes an important "stewardship" function in ensuring that the mission is fulfilled and that public funds are efficiently and appropriately expended. Since independent living centers are a product of consumer self-advocacy, it follows that the board of directors is defined as a majority of individuals with disabilities who are knowledgeable about the desires and needs of consumers and who possess a critical range of other specialized knowledge and expertise relevant to governance in non-profit organizations. Indeed, the standards issued by the National Council on the Handicapped in 1985, with broad approval from leaders in the field, state that the board of directors of independent living centers should be comprised of at least 51 percent representation by persons with disabilities.

A board of directors comprised of a majority of persons with disabilities is an important way of enacting the principle of consumer control. But it is not enough. The board must

ensure that the sovereignty of consumers pervades the mission, long range goals and plans, and policies that govern staffing, financial, and service delivery decisions. More than any other group or individual, the board influences the integrity and strength of the organization's commitment to consumer control and other core values of the independent living movement.

Consumer Control at the Staffing Level

Consumer control at the staffing level means ensuring that the management and staff positions are held by people with disabilities. These employment opportunities ensure significant influence by people with disabilities in administrative decision-making, service design and delivery, and community advocacy activities.

At the staffing level, consumer control can be viewed as a chain of management events and decisions. The executive director, who is a critical link in the chain, serves as the interface between the policy-making function at the board level and the implementation of policy at the staff level. The director is responsible for maintaining consistency between policy and practices and fulfilling the mission through achieving operational goals. As chief executive officer, the director is responsible for planning, staffing, resource development and allocation, and monitoring service quality. Thus, the executive director's perspective on consumer control is a critical variable in translating principles into appropriate and effective center practices.

Service delivery and support staff also constitute important links in the staffing chain. Adhering to the principles of consumer control assumes that center staff reflect disability representation and have opportunities for substantive participation and input. Staff with disabilities who are grounded in the philosophy of the movement, able to operationalize its values, and share in the experience of disability with consumers are critical to enacting principles of consumer control. By hiring people with disabilities, centers demonstrate an understanding of the need for consumer trust and acceptance and the importance of staff credibility. A unique and critically valuable feature of independent living center staffing is an emphasis on hiring persons with disabilities to provide consumer-defined services to their peers. Independent living centers committed to consumer controlled service delivery have staffing plans that build upon shared life experiences as a means of enhancing communication about life options.

It is also important to recruit and hire people with disabilities in support staff and clerical positions. This demonstrates the center's commitment to consumer representation. Finally, another means of broadening consumer control within a center is to recruit and involve people with disabilities in volunteer positions. Volunteers can perform countless functions within a center. By promoting people with disabilities in these capacities, the center can be strengthened and the individuals volunteering can increase their skills and confidence.

Consumer Control over Services

While there is rich diversity in service delivery methods in centers across the country, the over-riding commonality and central characteristic of the independent living service

delivery model is consumer control over the design and direction of services. Consumer control over services means that it is the consumer who has the primary responsibility for identifying needs, setting goals, developing plans and strategies, and achieving independent living objectives. Consumers in this model are active participants in the service process rather than passive recipients, as in the traditional medical or rehabilitation model of service delivery. Staff function as resource identifiers, support providers, facilitators, and peer tutors.

The language commonly used in centers is itself consistent with this general theme: “consumer” of services, rather than “client” is the term of choice because it assumes an active role based on equality and mutuality of experience and a participatory process.

Peer relationships are one of the key features of services organized around the principle of consumer control. In peer relationships, the two parties meet as equals. They share a common life experience with disability and have faced many of the same issues and barriers in their pursuit of independence. Services delivered by peers provide an effective avenue for dealing with a variety of issues within the context of a service relationship based on an understanding of common life experiences and barriers to independence.

Consumer control over services is, to borrow a phrase from the private sector, “a market driven economy” in which the consumer has primacy in the process.

Consumer Control over the Advocacy Agenda

Advocacy is an essential element in a center’s programmatic design. Indeed, advocacy has been seen by many leaders in the field as the “cornerstone” of the movement in that its efforts and activities are designed to amplify the individual consumer’s voice in order to change the political, social, and economic environment that prevents achieving independence and maximum quality of life. Operationalizing the principle of consumer control in advocacy requires that all key players - board, staff, and consumers - be provided with opportunities to share perspectives, knowledge, and information about needed changes in the environment and participate in activities designed to affect the desired changes.

Community advocacy activities involve knowledge of the external environment, a commitment to providing opportunities to participate in the development of the advocacy agenda, and the experience and skills necessary to achieve the desired results. Through individual and collective advocacy efforts, people with disabilities acquire skills, abilities, and a greater understanding of how to affect the world in which they live. The involvement and control of people with disabilities in an independent living center’s advocacy efforts is fundamental to the independent living mission of creating change and empowering people with disabilities to expand individual and community options and enhance the quality of their lives.

Summary

Consumer control in independent living centers means having a governing body comprised of at least 51 percent of its membership with people with disabilities. It means having people with disabilities in key management roles. It means having direct service staff with disabilities who work with consumers to define their own needs, on their own terms, and with their own solutions. It means having people with disabilities in support and clerical staff positions. It means involving volunteers with disabilities in the center's daily operations. It means that stakeholders in the process -- people with disabilities -- play significant roles in deciding the issues and methods for advocacy efforts.

The principle of consumer control recognizes that people with disabilities should control their own destiny. It ensures their full control over the direction, composition, and operation of the organization that serves them. The principle of consumer control is translated into organizational policies by the board of directors and operationalized into practice by the management and staff of the center. This translation of consumer control principles into consistent, effective organizational practices results in the exercise of power by consumers over the center and its services, and contributes to its influence in the community it serves.

The practical applications of the consumer control principle must be flexible if services and advocacy efforts are to represent and respond to the varying interests and diversity among consumers in the communities served by the ILC. Across the country, independent living centers reflect wide diversity in practice while adhering to the principle of consumer control.

Developing the Independent Living Service Model -- Essential Features¹

The essence of the independent living movement and its core values became the foundation for a consumer-oriented service model that emphasized individual choice, personal control, and the need for self-determination. In commenting upon the evolution of this model, DeJong (1983) stated, "The dignity of risk is the heart of the independent living movement. Without the possibility of failure, the disabled person lacks true independence and the ultimate mark of humanity, the right to choose." As leaders in the movement translated philosophical principles into actual service programs and community advocacy efforts, they recognized that there would be a rich and necessary diversity in service approaches across centers. However, it was also clear that as centers evolved, certain key elements were essential to designing and maintaining effective community-based independent living services. These included:

Consumer control over policy and management decisions. Persons with disabilities would control decisions governing organizational policies and procedures, the provision of services, and community activities. In this sense, the term "consumer" is defined broadly to mean persons with disabilities who may be direct recipients of services as well as those who are not but who are secondary beneficiaries of advocacy efforts. Consumer control in decision-making is intended to ensure that policies, procedures, services, and activities are responsive to the needs and respectful of the rights of the disability population.

Consumer control over service objectives and methods. This aspect of independent living services places primary responsibility for identifying service needs, setting independent living goals and objectives and making decisions about service participation with the consumer who is receiving services. This means that the service provider role shifts from that of controlling and providing the services to one that consciously seeks to promote the independence and self-sufficiency of the consumer within the context of service participation selected by the consumer.

Cross-disability emphasis. Independent living emphasizes responsiveness to the needs of all persons with disabilities. At the national level, this separates the independent living program from programs that emphasize services to a particular disability group.

Community based and community responsive. Independent living centers are designed to be responsive and accessible to the disability community in their service locale, and to involve the community significantly in setting program priorities.

Peer role modeling. The emphasis on peer role modeling in independent living reflects a belief that people with disabilities can greatly benefit from the perspectives and support of others with disabilities who have successfully struggled to lead productive and meaningful lives in their communities. Peers serve as strong role models and facilitators to consumers in their efforts to achieve designed level of independence.

¹ This article is excerpted and reprinted with permission from Lachat, M.A., The Independent Living Service Model, Center for Resource Management, Inc., South Hampton, NH, 1988, p. 11-13.

Provision of a range of services. Because independent living is responsive to the varied dimensions of knowledge, skills, options, and support associated with achieving personal independence, a range of services is provided. These include such core services as information and referral, skills training, advocacy, and peer counseling as well as others such as attendant care services, housing services, transportation services, educational services, vocational services, equipment services, communication services, legal services, and social/recreational services.

A community advocacy thrust. Independent living recognizes that in order for consumers to achieve independent lifestyles, environmental and social barriers in the community must be eliminated. There is thus a dual commitment to both individual services and community advocacy—activities conducted to enhance opportunities for people with disabilities to have equal access to all aspects of community life and to achieve meaningful integration into society.

Open and ongoing access to services. Independent living is not a closure-oriented program. Services are open and available to consumers on an ongoing basis, reflecting consumers' evolving and continuing needs and interests.

These key features of the independent living service model underscore the importance of constituency control, the power of peer support, and the fact that independent living centers were established to meet the needs of specific disability populations that had been underserved and segregated by traditional rehabilitation services. Also, the independent living service model has been characterized by the dual thrusts of individualized support services to promote self-determination and community advocacy to promote integration in the social and economic mainstream.

Appendix C: Examples of Membership Recruitment and Orientation

Membership Recruitment and Orientation in Rhode Island

By Darrell Lynn Jones, August 2008

Executive Director's Point of View

The Rhode Island Statewide Independent Living Council executive director, Camille Pansa, says that she has a professional background in recruiting, but that she began to experience a “revolving door” syndrome with the members of her Council. She took the problem to the Council itself and one of the members recommended a more rigorous process for recruiting and orienting members that includes three steps. The Council subsequently initiated these steps as their new process for recruitment, nomination, and appointment:

- Instead of immediately bringing people onto the Council who have been recommended/appointed the Council now requires a nominee to join a committee of the Council for a year as a volunteer first. This gives the nominee and the Council members an opportunity to learn more about each other and make sure the membership makes a good match. The Council is especially interested to see if the nominee's enthusiasm for the work continues over time.
- During the time the nominee is serving on a committee, he or she is required to participate in a six-session orientation program. If an individual misses a session, they are asked to make up for the absence at another time. The sixth session is to visit one of the two Centers for Independent Living in Rhode Island.
- If the nominee follows through with these requirements, i.e., participates authentically in the committee's work, and attends the six orientation sessions, the Council then makes the recommendation for the individual's appointment to the governor.

Camille conducts the orientation sessions herself and covers IL philosophy, consumer control/choice, the make up of SILCs, regulations governing SILCs, acronyms, the SPIL, 704 Reports, business procedures, reimbursement forms, by-laws, the ILRU Web site resources, and the *IL History and Philosophy* DVD produced by ILRU. Camille does not consider herself an educator but rather uses an interactive approach that engages the participant(s) in discussion.

Camille says that she is still refining the process and it's too early to tell if the changes will result in the outcomes they hope for, but she has seen a definite improvement in several characteristics of her Council members. These include more knowledge about independent living and the work of the SILC, which has resulted in an increased comfort level that Council members have reported with their participation. On the flip side, she says they are reporting feeling less intimidated by their roles and responsibilities.

A Council Member's Point of View

Camille gave permission for us to interview one of her Council members who had successfully completed the committee/orientation process, to learn what her experience had been and whether she felt that the process had more effectively prepared her for participation than an immediate appointment would have.

Anna Liebenow had just received her formal appointment by the governor after volunteering with the Council for approximately a year when she was interviewed. She had actively participated in one of the Council's standing committees, meeting monthly, and attending other meetings as needed. She had also completed the six-session orientation.

Anna's interest in independent living had come from her own experience with disability and subsequent visit to both of Rhode Island's CILs to request services. She subsequently attended an annual conference on IL sponsored by one of the CILs. At that conference, Camille Pansa had a table where she was providing information about the Rhode Island SILC and looking for individuals who might be interested in becoming a member. Camille and Anna struck up a conversation that led to Anna's very passionate commitment to the independent living movement in Rhode Island.

When asked what her year-long volunteer involvement gave her, Anna said that it increased her connections with the key IL players in the state which gave her a broader context for the disability issues that SILC members need to understand. As an example, she said that her committee had just started working on a paper about accessible transportation in the state. She certainly felt that her personal experiences with transportation had prepared her to give input. However, it was being able to attend a public hearing and to actually meet an official from the public transportation system at a party (both through her committee participation) that allowed her to maximize her knowledge base and skills.

Additionally, Anna says that the orientation sessions grounded her in the independent living history and philosophy in a way that her personal experiences never could have. And finally, the orientation exposed her to CIL and SILC jargon she was unfamiliar with and provided her a setting in which she could ask all her remaining questions—a luxury she may not have had during formal Council meetings.

In summary, Anna wanted us to share that she believes starting as a volunteer with the SILC makes a lot of sense. She thinks it was the *gradual* familiarization with what the SILC is all about that made the difference for her.

New York State Independent Living Council New Member Orientation

Individual Council Member Responsibilities

- Attend all council and committee meetings and functions, such as special events.
- Be informed about the council's mission, structure, policies, and projects.
- Review agenda and supporting materials prior to board and committee meetings.
- Serve on committees or task forces and offer to take on special assignments.
- Make a personal financial contribution to the organization (when relevant).
- Inform others about the organization.
- Suggest possible nominees to the board who can make significant contributions to the work of the board and the organization
- Keep up-to-date on developments in field related information.
- Follow conflict of interest and confidentiality policies.
- Refrain from making special requests of the staff.
- Respect the Executive Director's role to supervise staff (Do not attempt to intervene or micromanage).
- Assist the board in carrying out its fiduciary responsibilities, such as reviewing the organization's annual financial statements.

Personal characteristics to consider

- Ability to: listen, analyze, think clearly and creatively, work well with people individually and in a group.
- Willing to: prepare for and attend board and committee meetings, ask questions, take responsibility and follow through on a given assignment, contribute personal and financial (when relevant), open doors in the community, evaluate oneself.
- Develop certain skills if you do not already possess them, such as to: cultivate and solicit funds, cultivate and recruit board members and other volunteers, read and understand financial statements, learn more about the council and its state plan.
- Possess: honesty, sensitivity to and tolerance of differing views, a friendly, responsive, and patient approach, community-building skills, personal integrity, a developed sense of values, concern for your nonprofit's development, a sense of humor.

Adapted from BoardSource materials online at
<http://www.boardsource.org/FullAnswer.asp?ID=104>.

Organizational Chart

NYSILC
(See council member list at
www.nysilc.org.)

Consultants

Bookkeeping Service
Micki Mauger
25th Hour Accounting

Policy/Downstate Liaison
Thomas Small, Attorney

Webmaster
Kathy Raeihle
Accessible Website Des.

SSAN/SPIL Projects
Melanie Shaw, NYAIL

Media Advocacy
Tim Cronin
Communication Concepts

Families Together NYS/Youth
Leadership
*Stephanie Orlando & Paige
Pierce*

NYSILC Executive Committee

Executive Director
Brad Williams

Office Manager
Joseph Adler

Administrative Assistant
Patty Black

Project Coordinator
Susan Cohen

NYSILC Committee Structure
(See chart.)

Committee Structure

Executive
Committee

Public Policy
Committee

Finance
Committee

Personnel
Committee

Recruitment Committee

State Plan Committee

Emergency
Preparedness
& Evacuation
Subcommittee

Audit
Subcommittee

New Member
Orientation
Subcommittee

Disability Voter Education
Subcommittee

Consumer Satisfaction
Subcommittee

Needs Assessment Subcommittee

Youth Leadership Subcommittee

Travel Subcommittee

I. Background

A. Authority.

Chapter 1 of Title VII of the Rehabilitation Act of 1973, as amended, provides financial assistance to States for providing, expanding, and improving the provision of Independent Living (IL) services; to develop and support statewide networks of Centers for Independent Living (CILs); and to improve working relationships among State IL Services (SILS) programs, CILs, Statewide IL Councils (SILCs), programs funded under other titles of the Act, and other programs that address the needs of individuals with significant disabilities funded by Federal and non-Federal authorities. The purpose of Chapter 1 of Title VII of the Act (Chapter 1) is to promote a philosophy of independent living, which includes consumer control; peer support; self-help; self-determination; equal access; and individual and system advocacy in order to maximize the leadership; empowerment; independence and productivity of individuals with significant disabilities; and the integration and full inclusion of individuals with significant disabilities into the mainstream of American society.

For a State to participate in the programs under Chapter 1, it must submit to the Rehabilitation Services Administration (RSA) an approvable State Plan for Independent Living (SPIL). No Federal funds or other benefits can be made available under this Chapter unless the SPIL conforms to applicable statutory and regulatory requirements. This SPIL reflects the State's commitment to carry out the programs in compliance with the provisions in the plan, the application for funds under the part B, Chapter 1 program, and also the State's planning and implementation activities related to various administrative and operational considerations associated with the plan. As such, the approved SPIL will serve as one of the key elements in RSA's monitoring of the State's performance in carrying out the assurances to which the State commits itself in submitting the State plan.

B. Composition of the SILC.

- (1) State the total number of persons on the SILC. [30]
- (2) State the number of SILC members with disabilities, as defined in 34 CFR 364.4 (b), and not employed by a State agency or a CIL. [11]
- (3) Is a representative of the DSU an ex-officio, member of the SILC? [Yes]
- (4) State the number of voting members on the SILC. [24]
- (5) State the number of different disability groups (physical, mental, cognitive, sensory, or multiple) represented by members of the SILC (up to five). [5]
- (6) Is a CIL director chosen by CIL directors within the State appointed to the SILC? [Yes]
- (7) Does the SILC include representatives from other State agencies that provide services to individuals with disabilities? [Yes]

(8) Does the council have a voting membership that is knowledgeable about CILs and IL services? [Yes]

(9) Do Council members provide statewide representation? [Yes]

(10) Is the Council Chairperson elected from among the voting members of the Council by the voting members of the Council or the Governor, pursuant to section 705(b)(5) of the Act? [Yes]

C. Placement of the SILC.

The SILC is not established as an entity within any State agency, including the Designated State Unit (DSU), and is independent of the DSU and all other State agencies. Following is a brief description of the legal status and placement of the SILC: "NYSILC is a non-profit corporation that operates separately from any New York State agency. The FY 2007 contract with NYSED/VESID has been approved so that NYSILC can conduct its activities and State business per the Statewide Plan for Independent Living (SPIL)."

II. Mission, Goals, and Objectives

The mission of the New York State Independent Living Council, Inc. (NYSILC) is "to support the Centers for Independent Living (CILs) and increase resources for the independence of people with disabilities in New York State." NYSILC's vision is "to achieve a world where people with disabilities experience equal rights and opportunities in all aspects of society." The new mission and vision statements were developed during a visioning session in March 1999. NYSILC also prioritized the following goal areas related to the new mission and vision statements:

- (1) To increase funding and resources;
- (2) To increase public awareness about CILs, Independent Living philosophy and people with disabilities;
- (3) To provide technical assistance and training; and
- (4) To develop and pursue a public policy agenda that results in systemic change.

The mission of the New York State Education Department's Office of Vocational and Educational Services for Individuals with Disabilities (VESID) is "to promote educational equity and excellence for students with disabilities while ensuring that they receive the rights and protections to which they are entitled; assure appropriate continuity between the child and adult services systems; and provide the highest quality vocational rehabilitation and independent living services to all eligible persons as quickly as those services are required to enable them to work and to live independent, self-directed lives." VESID is the Designated State Unit (DSU) for vocational rehabilitation in New York State.

The mission of the Office of Children and Family Services' Commission for the Blind and Visually Handicapped (CBVH) is "to enhance employability, to maximize

independence, and to assist in the development of the capacities and strengths of people who are legally blind.” CBVH is the DSU responsible for the administration of vocational rehabilitation and other related services to legally blind residents of New York State.

NYSILC, VESID, and CBVH are authorized by the Rehabilitation Act as amended to jointly develop the State Plan for Independent Living (SPIL). NYSILC is responsible to monitor and evaluate the implementation of the SPIL. Further, NYSILC is authorized to coordinate activities with the CILs, VESID and CBVH State Rehabilitation Councils and other State agencies and councils that address the needs of people with disabilities. NYSILC supports RSA’s role to monitor and evaluate the IL programs in New York State to assure that people with significant disabilities have equal access to services and programs under Title VII of the Rehabilitation Act as amended.

III. Statewide Plan for Independent Living (SPIL) 2008-2010

A. Cooperation, Coordination, & Working Relationships

First, since the SPIL formulation process included the DSU, SILC, CILs, consumers, other providers and stakeholders, it helped to develop objectives that will sustain the interests of these parties during the next 3-year plan. This provides the opportunity to define, work cooperatively, and implement clear cut deliverables.

Second, NYSILC and the DSU have developed a cooperative recruitment and appointment process for the SILC. It strategically looks to form a diverse council that balances IL participation with members from related disability networks. Thus, full council meetings become a forum to convene numerous stakeholders to address important disability issues. It also ensures open communication between those present. The following link provides a listing of NYSILC’s current council members, www.nysilc.org/council.htm which verifies the various affiliations of council members.

Third, as verified on the link noted above, NYSILC has five ex officio members from state agencies. They include representatives from the State Plan Partners (VESID and CBVH), NYS Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD), NYS Office of Mental Retardation and Developmental Disabilities (OMRDD), and NYS Office of Mental Health (OMH) (vacant). In the next year, NYSILC is considering the expansion of its ex officio members to other state agencies or councils that it conducts business with on a regular basis. Some of the entities being considered are the NYS Department of Health (DOH), NYS Office for Aging (SOFA), and the NYS Developmental Disabilities Planning Council (DDPC), and NYAIL. Additional ex officio members will help to further enhance working relationships, cooperation, and coordination.

B. SPIL Objectives

[NYSILC incorporates its current SPIL objectives into this section.]

C. Outreach

NYSILC, VESID and CBVH are committed to promoting the participation and needs of minority individuals and groups in all aspects of independent living programs and services. The NYSILC Needs Assessment Subcommittee is currently working to complete an existing analysis of U.S. Census and center service data (which includes demographic diversity) to help assess the varied and changing needs of Independent Living (IL) in the state. A summary of the analysis and findings will be reported with subsequent recommendations. It will lead to a full statewide needs assessment. The final results will help to define the future growth of the network, as well as recognize and recommend effective outreach strategies to designated targeted populations, the geographic areas where they reside, and how the needs of these minority groups with significant disabilities will be addressed.

The initial analysis is expected to be completed by June 2007. The needs assessment should be substantively completed by the end of September 2007. The final assessment, with recommendations and strategies, should be completed and distributed by the end of December 2007. The NYSILC Needs Assessment Subcommittee will look to share the findings with the DSU, NYAIL, and the statewide network of centers. Decisions will be made regarding the best way to develop product and/or provide training that will enhance outreach to unserved and underserved populations, including minority groups. If needed, the IL training academy can focus resources toward this end.

During the SPIL formulation process, it was recognized that there is a need to reach out to veterans wounded and disabled as a result of their service in the wars in Iraq and Afghanistan. As these individuals move from rehabilitation to life back in the community, they will need to be made aware about Independent Living services and Centers for Independent Living (CIL's) as potential resources to help them with their transition. Another huge population identified for the near future is the aging of the "baby boomer" population. This need has been documented in a study conducted by the New York State Office for the Aging (SOFA) entitled, *Project 2015: Shaping Public Policy Preparing for Demographic Change*, <http://aging.state.ny.us/explore/project2015/P2015status05.pdf>

The comprehensive report notes several significant demographic shifts:

- The state's population will drop from the third largest (1995) to the fourth largest (2025).
- Rapid growth of younger and older minority populations – Black, Hispanic, Native American and Asian/Pacific Islanders.
- By 2025, minority New Yorkers will comprise 47 percent of all residents in comparison to 33 percent (1995).
- Major growth in the older worker population due to the aging of the "baby boomer" population (born 1946 to 1964) and increasing life expectancy.
- The 60 and older population is expected to increase by 40 percent over 30 years

(1995-2025).

- Many of the projected shifts noted above will also increase the number of New Yorkers with disabilities.

D. Network Design

New York State's federally-funded network has not changed over the past few years. There are still twenty-one grants. Five of the CILs are operated as satellites sponsored by CILs with preexisting Title VII, Part C funds. The satellites share the same governing boards as their host CILs. They are noted below with an asterisk. For clarity, the federally funded CILs in the New York State network include:

1. Capital District Center for Independence (Albany)
2. Bronx Independent Living Services (Bronx)
3. Western New York Independent Living Project (Buffalo)
4. Native American Independent Living Services (Buffalo/Native American)*
5. Access to Independence and Mobility (Corning)
6. Southern Adirondack Independent Living (Glens Falls/Saratoga County)
7. Harlem Independent Living Center (Harlem)
8. Center for Independence of the Disabled in New York (Manhattan)
9. Action Toward Independence (Middletown/Sullivan County)
10. Tri-Lakes Center for Independent Living (Raybrook/Tri-Lakes Region)
11. Regional Center for Independent Living (Rochester)
12. Center for Disability Rights (Rochester/Inner-City)
13. ARISE Children and Family Services (Syracuse)
14. ARISE Children and Family Services (Syracuse/Oswego County)*
15. Independent Living Center of the Hudson Valley (Troy/Columbia County)
16. Resource Center for Independent Living (Utica)
17. Resource Center for Independent Living (Utica/Herkimer)*
18. Northern Regional Center for Independent Living (Watertown)
19. Westchester Independent Living Center (White Plains)
20. Westchester Independent Living Center (White Plains/Minority Outreach)*
21. Westchester Independent Living Center (White Plains/Putnam County)*

The contact information for these federally-funded sites can be found on the NYSILC website at, <http://www.nysilc.org/directory.htm>. They are listed in alphabetical order with other state funded centers.

The chart below provides some preliminary data for each federally funded grant. It

identifies the county where they are seated, the county's total population and % disabled (based on U.S. Census Bureau data), and whether or not each site receives federal and/or state IL funding. NYSILC will have more information to examine regarding the network when it completes its Needs Assessment by the end of 2007.

CIL/Satellite	County/Seated	Total County Population	Disabled %	Federal Funds	State Funds
1. Albany	Albany	297,414	16.4	Y	Y
2. Bronx	Bronx	1,357,589	25.1	Y	Y
3. Buffalo	Erie	930,703	18.1	Y	Y
4. Buffalo/NAILS	Erie	930,703	18.1	Y	N
5. Corning	Steuben	98,632	19.3	Y	Y
6. Glens Falls/Saratoga	Warren	65,548	16.8	N	Y
	Saratoga	214,859	12.7	Y	N
7. Harlem	New York	1,593,200	19.0	Y	Y
8. Manhattan	New York	1,593,200	19.0	Y	Y
9. Middletown/Sullivan	Orange	372,893	15.2	N	Y
	Sullivan	76,539	20.3	Y	N
10. Tri-Lakes/Raybrook	Essex	38,676	20.2	Y	N
11. Rochester/RCIL	Monroe	733,366	16.3	Y	Y
12. Rochester/CDR	Monroe	733,366	16.3	Y	N
13. Syracuse	Onondaga	458,053	16.3	Y	Y
14. Oswego (Syracuse # 13)	Oswego	123,373	17.4	Y	N
15. Troy/Hudson	Rensselaer	155,251	16.5	N	Y
	Columbia	63,622	17.0	Y	N
16. Utica	Oneida	234,105	18.8	Y	Y
17. Herkimer (Utica # 16)	Herkimer	63,780	18.3	Y	N
18. Watertown	Jefferson	116,384	14.8	Y	Y
19. White Plains	Westchester	940,807	15.6	Y	Y
20. Minority Outreach (White Plains # 19)	Westchester	940,807	15.6	Y	N
21. Putnum (White Plains # 19)	Putnum	100,507	12.8	Y	N

E. Identification of Unserved/Underserved Needs

Section 1.2B details how the NYSILC Needs Assessment Subcommittee is currently working to complete an analysis of existing Census and center demographic data to help assess the varied and changing needs of Independent Living (IL) in the state. A summary of the analysis and findings will be reported with subsequent recommendations. It will lead to a full statewide needs assessment. The final results will help to define the future growth of the network, including an identification of unserved and underserved populations. It will also recognize and recommend effective outreach strategies to designated targeted populations, the geographic areas where they reside, and how the needs of these minority groups with significant disabilities will be addressed.

The initial analysis is expected to be completed by June 2007. The needs assessment should be substantively completed by the end of September 2007. The final assessment, with recommendations and strategies, should be completed and distributed by the end of December 2007. The NYSILC Needs Assessment

Subcommittee will share the findings with the DSU, NYAIL, and the statewide network of centers.

Funding Priorities and Decision Making Criteria

The NYSILC Needs Assessment Subcommittee will rely on the results of the needs assessment to help state specific funding priorities to RSA. Until that time, it should be noted that the SPIL formulation process recognized a need to reach out to veterans wounded and disabled as a result of their service in the wars in Iraq and Afghanistan. As these individuals move from rehabilitation to life back in the community, they will need to be made aware about Independent Living services and Centers for Independent Living (CILs) as potential resources to help them with their transition. See Section 1.2B. Another vast population identified for the near future is the aging of the “baby boomer” population by 2015, leading to an increase in the number of senior citizens and people with disabilities, as well as a major growth in the cultural/ethnic diversity of the State’s population by 2025.

The following decision-making criteria will be utilized to address annual changes to the level of Title VII, Part C funding for New York:

1. Funding Decrease: If RSA informs NYSILC and the DSU (VESID) of a funding decrease to the Title VII Part C grants, the amount of the decrease will be calculated in proportion to the grant amounts (based on a fixed percentage). Since the grants are varied in amounts, it was pointed out that dividing a decrease in equal shares is not fair to the grants with lower funding levels.
2. Level Funding: If RSA informs NYSILC and the DSU (VESID) that the Title VII, Part C grants will receive level funding (no change), then each grant will continue to get the same amount from the previous year.
3. COLA: If RSA informs NYSILC and the DSU (VESID) that the Title VII, Part C grants will receive a Cost Of Living Adjustment (COLA), then RSA will verify the COLA amount and the percentage (usually determined by the Consumer Price Index). This percentage will then be multiplied by the funding level for each grant from the previous year to calculate their new grant amount.
4. Additional Funds Above the COLA (\$50,000 or Less): If RSA informs NYSILC and the DSU (VESID) that the Title VII, Part C grants will receive additional funds above the COLA, but in the amount of \$50,000 or less, then it will be divided into equal shares amongst the existing federally-funded network (See Section 3.1).
5. Additional Funds Above the COLA (More Than \$50,000): If RSA informs NYSILC and the DSU (VESID) that the Title VII, Part C grants will receive additional funds above the COLA in the amount more than \$50,000, then it will be used for the expansion of new CILs through a competitive RFP process. New CILs can focus on the provision of IL services in unserved areas, as well as to specific underserved populations.

Process to Communicate

RSA will notify NYSILC and the DSU (VESID) about annual changes to the level of Title VII, Part C funding for New York by the start of each calendar year. The state plan partners will confirm action based on the decision-making criteria above, as well as communicate preferences for any funding priorities through correspondence to RSA. The funding priorities will be relevant to the funding level changes. They will be further defined by the results from the statewide needs assessment, when available.

F. Monitoring/Review Activities

A summary of the statewide consumer satisfaction findings are provided below:

Demographics: All New York State CILs 2006

1. The staff helped me understand my choices and options (Strongly agree/agree – 91%).
2. The staff encouraged me to make my own decisions (Strongly agree/agree – 94%).
3. Overall, I was satisfied with the Center's staff (Strongly agree/agree – 91%).
4. I benefited from the information I received (Strongly agree/agree – 90%).
5. I benefited from the services I used (Strongly agree/agree – 90%).
6. I would recommend the Center to others (Strongly agree/agree – 93%).
7. Overall, I was satisfied with the Center (Strongly agree/agree – 91%).

Questions # 1 and 7 equaled their score from the previous survey, while questions # 2-6 all increased.

G. Technical Assistance and Training Needs

A summary of the statewide networks technical assistance and training needs is prioritized below:

1. Development of the SPIL.
2. Monitoring & review of implementation of SPIL.
3. Consumer Satisfaction Surveys.
4. Best Practice Surveys.
5. Computer Skills.
6. 704 Reports.
7. Community Needs Assessments.
8. Outreach to Unserved/Underserved Populations (General Overview).
9. Collaboration with In-State Stakeholders.
10. Marketing & Public Relations/Community Awareness.

H. SPIL Evaluation Findings

This was the first year of the new three-year SPIL for 2008-2010. The evaluation plan for the SPIL has been provided below.

SPIL 2008-2010 Evaluation Plan

NYSILC, and the State Plan Partners, are responsible for the development and monitoring of implementation of the SPIL. NYSILC will utilize six evaluation components to satisfy requirements for Section 7. They include:

COMPLETION DATES

1. Submit an Annual 704 Report to RSA in Conjunction with State Plan Partners. NYSILC will prepare information for Part I of the report and submit it to DSU (VESID). VESID will include the information in the full report that it submits to RSA not more than 120 days after the end of the Federal Fiscal Year (January 30th). NYSILC's 704 Report will be emailed out to council members. Target date: March NYSILC full council meeting.

<u>2008</u>	<u>2009</u>	<u>2010</u>

2. Completion of Condensed Annual Report. The Annual Report will review council activities and progress on the SPIL over the previous year in a condensed format. The report will consist of narrative, statistical, and fiscal information. NYSILC's condensed Annual Report will be emailed out to council members. Target date: May NYSILC full council meeting.

<u>2008</u>	<u>2009</u>	<u>2010</u>

3. Full Council Review of the Progress on the SPIL. The NYSILC SPIL Committee will convene each summer and review the contents of the 704 and Annual Reports to evaluate the council's progress on SPIL objectives (1.2 Objectives). The SPIL Committee will report their results for ratification by the full council. Target date: September NYSILC full council meeting.

<u>2008</u>	<u>2009</u>	<u>2010</u>

4. Annual Review of Audited Financial Statement. NYSILC's executive committee will review the audited financial statement and report the results to the full council. A copy of the audit will be sent to the DSU (VESID). Target date: November NYSILC full council meeting.

<u>2008</u>	<u>2009</u>	<u>2010</u>

5. Statewide Consumer Satisfaction Survey. A Statewide Consumer Satisfaction Survey will be conducted in year two (2009) of the plan. The statewide results of the consumer satisfaction survey will be shared with the council and incorporated into relevant 704 and Annual Reports, as well as posted on the NYSILC website. VESID will share the consumer satisfaction survey results with individual CILs per the agreement made in their contract. Target date: September 2009 NYSILC full council meeting.

<u>2008</u>	<u>2009</u>	<u>2010</u>

6. Conduct and Report Results of Statewide Assessments Defined in the SPIL.

- The Statewide Needs Assessment will be completed at the end of 2007 and referenced during the upcoming SPIL 2008-2010.
- A Statewide Travel Assessment will be performed in year one (2008).
- A follow up Statewide Technology Needs Assessment will be conducted in year three (2010) to help define the network's technology and equipment gaps entering the next three-year state plan.

<u>2008</u>	<u>2009</u>	<u>2010</u>

The results of these assessments will be incorporated into relevant 704 and Annual Reports, as well as posted on the NYSILC website (As completed). Target dates: September 2007, September 2008, and September 2010.

7. Participation at Site Reviews of Federally Funded CILs. Since New York is a 722 State, NYSILC will send a representative to participate in the federal site reviews when invited. However, it is important to distinguish that NYSILC does not monitor the CILs, it monitors the implementation and progress of the SPIL. Therefore, NYSILC will use the information gained from each site review to promote model practices and identify potential technical assistance or training needs (As scheduled).

<u>2008</u>	<u>2009</u>	<u>2010</u>

Appendix D: RSA Responses to NCIL

January 25, 2008

Background

Title VII of the Act and its implementing regulations describe how the three major entities responsible for the implementation of Title VII and the SPIL -- the DSU, SILC and the network of CILs – are to use the Federal funds provided in order to fulfill the purpose of the independent living program.¹ Each entity has important and distinct statutory roles and responsibilities in fulfilling the purpose and engaging in the activities described in the SPIL. Each entity is not authorized to use Federal funds to engage in every activity envisioned in the law. Rather, the DSU, SILC or CILs engage in these activities with Federal funds only if, and only to the extent that, they conform with each of their roles and responsibilities as outlined in the Act. The DSU, SILC and CILs all work to fulfill the purpose of the independent living program, but they must do so using their Federal funds through the activities authorized for each of them under the Act. Therefore, the SILC may engage in a given activity with Federal funds only if, and only to the extent that, it directly relates to one or more of the SILC duties and authorized activities outlined in sections 705(c), (d) and (e) of the Act.

This is not intended to minimize the role of the SILC. On the contrary, RSA believes that the SILC is critical to the success of the independent living program and each State's SPIL. The SILC's duties encompass many important activities that have a broad impact on individuals with disabilities throughout the state. Although the Act lists a limited number of SILC duties, there is a variety of creative, meaningful and allowable ways in which the SILC may fulfill each of the duties. A SILC's involvement in the SPIL can be active, substantial and comprehensive within the guidelines established by federal law and regulations.

¹ Section 701 of the Act provides:

The purpose of this chapter is to promote a philosophy of independent living, including a philosophy of consumer control, peer support, self help, self determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society, by

- (1) providing financial assistance to States for providing, expanding, and improving the provision of independent living services;
- (2) providing financial assistance to develop and support statewide networks of centers for independent living; and
- (3) providing financial assistance to States for improving working relationships among State independent living rehabilitation service programs, centers for independent living, Statewide Independent Living Councils established under section 705, State vocational rehabilitation programs receiving assistance under title I, State programs of supported employment services receiving assistance under part B of title VI, client assistance programs receiving assistance under section 112, programs funded under other titles of this Act, programs funded under other Federal law, and programs funded through non Federal sources.

RSA's Responses to Specific NCIL Questions

1. Authorized Use of Funds

NCIL Comment/Question:

The uses for Part B funds are apparently not something SILCs are supposed to do even when Part B is how they are funded?"

RSA Response:

The DSU receives Part B funds on behalf of the State. The authorized uses for Part B funds are set forth in section 713 of the Act.² At the outset, section 713 provides, "The State may use funds received under this part to provide the resources described in section 705(e), relating to the Statewide Independent Living Council." Section 713 goes on to provide that the State may use funds received under this part for seven other activities related to providing or improving IL services, gathering data on IL services, providing outreach to unserved and underserved populations, training, and supporting CILs.

Section 713 requires that the Part B funds received by the SILC be used to provide the resources described in section 705(e). The resources described in section 705(e) are "such resources, including such staff and personnel, as may be necessary and sufficient to carry out the functions of the Council under this section. . . ." The functions of the SILC are described in sections 705(c),³ (d),⁴(e),⁵ and (f).⁶ Therefore, the SILC may use

² Section 713 of the Act provides:

The State may use funds received under this part to provide the resources described in section 705(e), relating to the Statewide Independent Living Council, and may use funds received under this part

- (1) to provide independent living services to individuals with significant disabilities;
- (2) to demonstrate ways to expand and improve independent living services;
- (3) to support the operation of centers for independent living that are in compliance with the standards and assurances set forth in subsections (b) and (c) of section 725;
- (4) to support activities to increase the capacities of public or nonprofit agencies and organizations and other entities to develop comprehensive approaches or systems for providing independent living services;
- (5) to conduct studies and analyses, gather information, develop model policies and procedures, and present information, approaches, strategies, findings, conclusions, and recommendations to Federal, State, and local policymakers in order to enhance independent living services for individuals with disabilities;
- (6) to train individuals with disabilities and individuals providing services to individuals with disabilities and other persons regarding the independent living philosophy; and
- (7) to provide outreach to populations that are unserved or underserved by programs under this title, including minority groups and urban and rural populations."

³ Section 705(c) of the Act provides:

The Council shall:

- (1) jointly develop and sign (in conjunction with the designated State unit) the State plan required in section 704;
- (2) monitor, review, and evaluate the implementation of the State plan;

its Part B funding only to carry out its section 705 functions. There is no such prohibition, however, on funding the SILC may receive from sources other than Part B or State match funding. The SILC may use other such funding to engage in activities beyond those listed in section 705 as long as it does not impair or interfere with the SILC's ability to perform its statutory duties.

In carrying out its section 705 functions, the SILC may engage in some of the activities listed in section 713 to the extent that its involvement in those activities is consistent with and does not exceed the SILC's section 705 statutory duties. For example, the SILC may fulfill an important role in demonstrating ways to expand and improve IL services through section 705(c)(3)'s ongoing coordination with "councils that address the needs of specific disability populations and issues" or it may conduct studies and gather information through section 705(c)(2)'s responsibility to "monitor, review, and evaluate the implementation of the State plan." The appropriateness of the SILC's role in any of the activities listed in section 713 must be evaluated on a case-by-case basis, depending on the nature and scope of the SILC involvement in the particular activity, to ensure the SILC is acting within its section 705 duties.

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- (3) coordinate activities with the State Rehabilitation Council established under section 105, if the State has such a Council, or the commission described in section 101(a)(21)(A), if the State has such a commission, and councils that address the needs of specific disability populations and issues under other Federal law;
 - (4) ensure that all regularly scheduled meetings of the Statewide Independent Living Council are open to the public and sufficient advance notice is provided; and
 - (5) submit to the Commissioner such periodic reports as the Commissioner may reasonably request, and keep such records, and afford such access to such records, as the Commissioner finds necessary to verify such reports.

⁴ Section 705(d) of the Act provides: "The Council is authorized to hold such hearings and forums as the Council may determine to be necessary to carry out the duties of the Council.

⁵ Section 705(e) of the Act provides:

- (1) The council shall prepare, in conjunction with the designated State unit, a plan for the use of such resources, including such staff and personnel, as may be necessary and sufficient to carry out the functions of the Council under this section with funds made available under this chapter, and under section 110 (consistent with section 101(a)(18)), and from other public and private sources. The resource plan shall, to the maximum extent possible, rely on the use of resources in existence during the period of implementation of the plan.
- (2) Each Council shall consistent with State law, supervise and evaluate such staff and other personnel as may be necessary to carry out the functions of the Council under this section.
- (3) While assisting the Council in carrying out its duties, staff and other personnel shall not be assigned duties by the designated State agency or any other agency or office of the State, that would create a conflict of interest.

⁶ Section 705(f) of the Act provides: "The Council may use such resources to reimburse members of the Council for reasonable and necessary expenses of attending Council meetings and performing Council duties (including child care and personal assistance services), and to pay compensation to a member of the Council, if such member is not employed or must forfeit wages from other employment, for each day the member is engaged in performing Council duties.

2. SILC Duties and Responsibilities

NCIL Comment/Question:

“Several SILCs have been told that they may only conduct the duties identified in Sec. 705 (c). SILCs have been under the impression that their responsibilities go beyond preparing a SPIL and monitoring its implementation.”

“Likewise, the law requires that the SPIL includes provisions “for public hearings regarding the contents of the plan during both the formulation and review of the plan. Again there are expectations that the SILC will not only identify the duties, but perform them throughout the year.”

“Section 705(c) was intended to be a floor (minimum standard), not a ceiling (maximum). . . . Where does the Act or the Regulations limit the SILCs duties to those identified in section 705(c)?”

RSA Response:

Federal funding is given directly to States and CILs to support them in achieving the purposes of the Act. The States are required to establish and fund SILCs as a condition of receiving the federal funding, and all three entities – the DSU, on behalf of the State, the SILC, and the CILs – are required to maximize the cooperation, coordination, and working relationships among themselves and other organizations that address the needs of individuals with disabilities.⁷ As noted above, the SILC has a particular statutory role to play in meeting the purpose of the Act in cooperation with the DSU and the CILs, and that role definitely goes beyond developing and signing the SPIL. The SILC is responsible for fulfilling its statutory duties in section 705 on an ongoing, year-round basis.

The SILC’s duties are, however, limited to those identified in section 705. Just as the DSU is authorized to use its Part B funding only for the purposes listed in section 713, the SILC may use its Title VII funding only for fulfilling the authorized functions of the Council under Section 705. Section 705(c) sets forth five specific duties of the SILC, and other authorized activities, including conducting hearings and forums as necessary, are found in sections 705 (d), (e), and (f). No language such as “including, but not limited to . . .” is associated with the list of SILC duties, nor is there any general authority to engage in any activity that furthers the purpose of Title VII if the SILC deems it appropriate.

Because Congress provided funds under the Act to enable SILCs to carry out the requirements in section 705, these funds may be used only for reimbursement of expenses related to the duties and functions authorized by the Act. Therefore, if a SILC chooses to engage in other activities, these other activities must be funded through other public or private sources and must not impair or interfere with its Federally mandated functions.

⁷ Section 704(i) of the Act requires the State plan to set forth the steps that will be taken “to maximize the cooperation, coordination, and working relationships among the independent living rehabilitation service program, the Statewide Independent Living Council, and centers for independent living. . . .”

3. SILC Resource Development

NCIL Comments/Questions:

How do SILCs obtain funds from other public and private sources if they aren't allowed to do resource development? How can SILCs secure these funds if they are not able to conduct resource development activities?

CFR 364.5 and 364.6 specifically provides guidance on handling program income. If resource development is not permitted, why is there guidance on how program income should be handled?

RSA Response:

In preparing its resource plan, the SILC may use Part B funds, Innovation and Expansion Funds, and other public and private sources, to the extent allowable by those other sources.⁸ However, SILCs may not use federal funding to conduct resource development activities. The cost principles at OMB Circular A-87, Attachment B, Item 17 (applicable to SILCs who are part of State government) and OMB Circular A-122, Attachment B, Item 17 (applicable to nonprofits) prohibit charging federal grants for the cost of fundraising.⁹ Centers for independent living are permitted to charge their federal grants for resource development activities because section 725(b)(7) of the Act provides explicit authority to engage in an activity – conducting resource development activities -- that would otherwise be prohibited by the OMB cost principles. The Act does not give SILCs similar explicit resource development authority.

The SILC still has opportunities, other than using Federal funds, to obtain other public and private sources of funding. For example, SILC members or staff may pursue resource development opportunities on their own time, or the SILC may use another source of funding such as private funds or non-match state government funds that do not prohibit the recovery of resource development costs, to pursue additional funding. Other non-Federal resources may also become available as a direct result of the SILC's fulfillment of its section 705(c) statutory duties. For instance, a council or commission with which the SILC

⁸ Section 705 (e)(1) provides:

The Council shall prepare, in conjunction with the designated State unit, a plan for the provision of such resources, including such staff and personnel, as may be necessary and sufficient to carry out the functions of the Council under this section, with funds made available under this chapter, and under section 110 (consistent with section 101(a)(18)), and from other public and private sources. The resource plan shall, to the maximum extent possible, rely on the use of resources in existence during the period of implementation of the plan.

⁹ OMB Circular A-87, Attachment B, Item 17 and OMB Circular A-122, Attachment B, Item 17 provide:

- a. Costs of organized fund raising, including financial campaigns, endowment drives, solicitation of gifts and bequests, and similar expenses incurred solely to raise capital or obtain contributions are unallowable.
- b. Costs of investment counsel and staff and similar expenses incurred solely to enhance income from investments are unallowable.
- c. Fund raising and investment activities shall be allocated an appropriate share of indirect costs under the conditions described in subparagraph B.3 of Attachment A.

is coordinating activities in accordance with section 705(c)(3) may offer funding for a collaborative initiative in support of a SPIL objective.

Regarding the issue of IL program income, it is clear from the language in 34 CFR 364.5 and 364.6¹⁰ that the regulations apply to income generated from the provision of IL services by the designated state unit and or the CILs. These sections do not apply to the SILC.

4. SILC Advocacy

NCIL Comments/Questions:

Many SILCs have reported that there is a prohibition of SILC advocacy activities within the SPIL. Section 701 sets out the purpose of chapter 1 of Title VII by stating, “The purpose of this chapter is to promote a philosophy of independent living, including . . . individual and system advocacy.” How do SILCs address the purpose of Title VII if they cannot advocate?

¹⁰ 34 CFR 364.5 provides:

- (a) Program income means gross income received **by a grantee** under Title VII of the Act that is directly generated by an activity supported under 34 CFR part 365, 366, or 367;
- (b) Sources of program income include, but are not limited to, payments received from workers' compensation funds or fees for services to defray part or all of the costs of services provided to particular consumers;
- (c) (1) Program income, whenever earned, must be used for the provision of IL services or the administration of the State plan, as appropriate.
(2) A service provider is authorized to treat program income as
 - (i) A deduction from total allowable costs charged to a Federal grant, in accordance with 34 CFR 80.25(g)(1); or
 - (ii) An addition to the grant funds to be used for additional allowable program expenditures, in accordance with 34 CFR 80.25(g)(2).
(3) Program income may not be used to meet the non-Federal share requirement under 34 CFR 365.12(b). (emphasis added)

34 CFR 364.6 provides:

- (a) Except as provided in paragraph (b) of this section, any Federal funds, including reallocated funds, that are appropriated for a fiscal year to carry out a program under 34 CFR part 365, 366, or 367 that are not obligated or expended **by the DSU or center** prior to the beginning of the succeeding fiscal year, and any program income received during a fiscal year that is not obligated or expended **by the DSU or center** prior to the beginning of the succeeding fiscal year in which the program income was received, remain available for obligation and expenditure **by the DSU or center** during that succeeding fiscal year.
- (b) Federal funds appropriated for a fiscal year under part B of chapter 1 and under chapter 2 of Title VII of the Act remain available for obligation in the succeeding fiscal year only to the extent that the DSU complied with any matching requirement by obligating, in accordance with 34 CFR 76.707, the non-Federal share in the fiscal year for which the funds were appropriated. (emphasis added).

RSA Response:

According to section 705(c) of the Act and 34 CFR 364.4, the SILC is not among the service providers authorized to provide the four IL core services, including individual and systems advocacy.¹¹ However, Federal law and regulations do not preclude the SILC from using its Federal funds to engage in some forms of advocacy that flow directly from the SILC's fulfillment of its statutory duties.

There are many ways in which the SILC may engage in advocacy in the normal course of fulfilling its statutory duties. In accordance with 705(c)(1) and (4), for example, the SILC listens to and advocates for individuals with significant disabilities in the process of developing the SPIL in conjunction with the DSU. Through this process, the SILC identifies the individual and systems needs of individuals with significant disabilities and ensures that those needs are adequately addressed in the goals and objectives of the approved SPIL.

In accordance with 705(c)(2), the SILC monitors the SPIL and ensures that the SPIL strategies being implemented are effectively addressing the individual and systems needs of individuals with significant disabilities. Based on its evaluation of the SPIL, the SILC may recommend or advocate for new approaches in the next SPIL or SPIL amendments to better serve the needs of individuals with significant disabilities.

The SILC may also be able to support the CILs' systems advocacy activities through exercising its statutory duties. For example, the SILC may be able to work with a public transportation agency to address the CIL-identified transportation needs of individuals with significant disabilities.

The SILC also advocates for independent living on a year-round basis through its interaction with a variety of disability-related councils, commissions and organizations at the state, local and federal levels, in accordance with 705(c)(3). Such interaction

¹¹ 34 CFR 364.4 provides:

Service provider means (1) A designated State unit (DSU) that directly provides IL services to individuals with significant disabilities; (2) A center that receives financial assistance under part B or C of chapter 1 of Title VII of the Act; or (3) Any other entity or individual that meets the requirements of Sec. 364.43(e) and provides IL services under a grant or contract from the DSU pursuant to Sec. 364.43(b).

Advocacy is defined in 34 CFR 364.4: as "pleading an individual's cause or speaking or writing in support of an individual. To the extent permitted by State law or the rules of the agency before which an individual is appearing, a non-lawyer may engage in advocacy on behalf of another individual. Advocacy may

- (1) Involve representing an individual
 - (i) Before private entities or organizations, government agencies (whether State, local, or Federal), or in a court of law (whether State or Federal); or
 - (ii) In negotiations or mediation, in formal or informal administrative proceedings before government agencies (whether State, local, or Federal), or in legal proceedings in a court of law; and
- (2) Be on behalf of
 - (i) A single individual, in which case it is individual advocacy;
 - (ii) A group or class of individuals, in which case it is systems (or systemic) advocacy; or
 - (iii) Oneself, in which case it is self advocacy.

enables the SILC to promote a better understanding of the independent living philosophy; encourage new collaborative initiatives in support of the SPIL goals and objectives; and influence the state's disability policies and practices in this way. It is important to note, however, that although the SILC may interact with the State and Federal legislatures by, for example, being invited by a state legislative committee to provide testimony on an IL-related issue or proposal, the Federal government identifies certain interactions as lobbying, and while lobbying may be a form of advocacy, all grantees and subgrantees are prohibited from using federal funds to engage in lobbying.¹²

¹² OMB Circular A-122, Attachment B, Item 25 provides the following on Lobbying. OMB Circular A-87 has almost identical language at Attachment B, Item 24.

25. Lobbying.

Notwithstanding other provisions of this Circular, costs associated with the following activities are unallowable:

(1) Attempts to influence the outcomes of any Federal, State, or local election, referendum, initiative, or similar procedure, through in kind or cash contributions, endorsements, publicity, or similar activity;

(2) Establishing, administering, contributing to, or paying the expenses of a political party, campaign, political action committee, or other organization established for the purpose of influencing the outcomes of elections;

(3) Any attempt to influence: (i) The introduction of Federal or State legislation; or (ii) the enactment or modification of any pending Federal or State legislation through communication with any member or employee of the Congress or State legislature (including efforts to influence State or local officials to engage in similar lobbying activity), or with any Government official or employee in connection with a decision to sign or veto enrolled legislation;

(4) Any attempt to influence: (i) The introduction of Federal or State legislation; or (ii) the enactment or modification of any pending Federal or State legislation by preparing, distributing or using publicity or propaganda, or by urging members of the general public or any segment thereof to contribute to or participate in any mass demonstration, march, rally, fundraising drive, lobbying campaign or letter writing or telephone campaign; or

(5) Legislative liaison activities, including attendance at legislative sessions or committee hearings, gathering information regarding legislation, and analyzing the effect of legislation, when such activities are carried on in support of or in knowing preparation for an effort to engage in unallowable lobbying. The following activities are excepted from the coverage of subparagraph a:

(1) Providing a technical and factual presentation of information on a topic directly related to the performance of a grant, contract or other agreement through hearing testimony, statements or letters to the Congress or a State legislature, or subdivision, member, or cognizant staff member thereof, in response to a documented request (including a Congressional Record notice requesting testimony or statements for the record at a regularly scheduled hearing) made by the recipient member, legislative body or subdivision, or a cognizant staff member thereof; provided such information is readily obtainable and can be readily put in deliverable form; and further provided that costs under this section for travel, lodging or meals are unallowable unless incurred to offer testimony at a regularly scheduled Congressional hearing pursuant to a written request for such presentation made by the Chairman or Ranking Minority Member of the Committee or Subcommittee conducting such hearing.

(2) Any lobbying made unallowable by subparagraph a(3) to influence State legislation in order to directly

Whether a particular SILC advocacy activity results from the fulfillment of its duties in section 705 depends on the scope and nature of the SILC's involvement in the activity in question.

NCIL Comments/Questions:

A SILC must have the ability to advocate if it is to establish an effective network of CILs as well as expand the network into unserved/underserved areas of the state as required by CFR 364.25, which states that: (a) The State plan must include a design for the establishment of a statewide network of centers that comply with the standards and assurances in section 725 (b) and (c) of the Act and subparts F and G of 34 CFR part 366. (b) The design required by paragraph (a) of this section must identify unserved and underserved areas and must provide an order of priority for serving these areas.

reduce the cost, or to avoid material impairment of the organization's authority to perform the grant, contract, or other agreement.

(3) Any activity specifically authorized by statute to be undertaken with funds from the grant, contract, or other agreement.

(1) When an organization seeks reimbursement for indirect costs, total lobbying costs shall be separately identified in the indirect cost rate proposal, and thereafter treated as other unallowable activity costs in accordance with the procedures of subparagraph B.3 of Attachment A.

(2) Organizations shall submit, as part of the annual indirect cost rate proposal, a certification that the requirements and standards of this paragraph have been complied with.

(3) Organizations shall maintain adequate records to demonstrate that the determination of costs as being allowable or unallowable pursuant to paragraph 25 complies with the requirements of this Circular.

(4) Time logs, calendars, or similar records shall not be required to be created for purposes of complying with this paragraph during any particular calendar month when: (1) the employee engages in lobbying (as defined in subparagraphs (a) and (b)) 25 percent or less of the employee's compensated hours of employment during that calendar month, and (2) within the preceding five-year period, the organization has not materially misstated allowable or unallowable costs of any nature, including legislative lobbying costs. When conditions (1) and (2) are met, organizations are not required to establish records to support the allowability of claimed costs in addition to records already required or maintained. Also, when conditions (1) and (2) are met, the absence of time logs, calendars, or similar records will not serve as a basis for disallowing costs by contesting estimates of lobbying time spent by employees during a calendar month.

(5) Agencies shall establish procedures for resolving in advance, in consultation with OMB, any significant questions or disagreements concerning the interpretation or application of paragraph 25. Any such advance resolution shall be binding in any subsequent settlements, audits or investigations with respect to that grant or contract for purposes of interpretation of this Circular; provided, however, that this shall not be construed to prevent a contractor or grantee from contesting the lawfulness of such a determination.

d. Executive lobbying costs. Costs incurred in attempting to improperly influence either directly or indirectly, an employee or officer of the Executive Branch of the Federal Government to give consideration or to act regarding a sponsored agreement or a regulatory matter are unallowable. Improper influence means any influence that induces or tends to induce a Federal employee or officer to give consideration or to act regarding a federally sponsored agreement or regulatory matter on any basis other than the merits of the matter.

RSA Response:

The DSU, SILC and the CILs have distinct roles in fulfilling the purposes of Title VII and the SPIL, including expansion of the statewide network of centers. The distinct roles of the SILC are delineated in the Act. Though section 705(c) includes a limited number of duties, each of those duties encompasses a multitude of avenues and approaches in which the SILC may engage in those duties to assist in the establishment and expansion of the network of centers.

5. Administration of funding

NCIL Comments/Questions:

Sec. 704 (c)(1) obliges the DSUs to “receive, account for, and disburse funds” based on the plan. The DSU has clear fiduciary responsibilities in accounting for Title VII funds; however, States have the ability to subcontract with organizations to provide a myriad of services as reflected in CFR 34 364.57. Why can’t the DSU disburse the funds to the SILC? Where in the law or regulations are the DSUs prohibited from subcontracting with the State’s SILC?

CFR 34 364.21 (i) (4) states that “The SILC is responsible for the proper expenditure of funds and use of resources that it receives under the resource plan,” which seems to imply that the administration of funding is permissible as long as its accounted for in the resource plan. States have reported that only statutory requirements go in the resource plan, and that the authorized use of funds activities must be paid directly by the DSU. Where in the Act or Regulations does it specifically state that only the SILC’s statutory requirements are included in the SILC’s resource plan?

RSA Response:

Under Section 704(c)(1),¹³ the DSU is responsible for receiving, accounting for, and disbursing funds. The regulations at 34 CFR 364.57 list the duties of the DSU that are delegable and receiving, accounting for, and disbursing funds are not a delegable duty of the DSU.¹⁴ Therefore the DSU remains the entity responsible for this function. In addition, the SILC is authorized by section 705(e) to manage its own resource plan, but section 705(e) specifically provides that the SILC resource plan only includes the funding that is necessary for the SILC to carry out its functions under section 705. The SILC is not authorized to use its federal funds to receive, account for, or disburse Part B funding or any funding other than the funding it receives to fulfill its own duties.

¹³ Section 704(c)(1) provides: “The plan shall designate the designated State unit of such State as the agency that, on behalf of the State, shall (1) receive, account for, and disburse funds received by the State under this chapter based on the plan.”

¹⁴ A DSU may carry out the functions and responsibilities described in §§ 364.50, 364.51 (subject to 364.43(d)), 364.52, 364.53, and 364.56 or, except as otherwise provided, may delegate these functions and responsibilities to the appropriate service provider with which the DSU subgrants or contracts to provide IL services.

6. Allocation of Title I, section 110 (Innovation and Expansion – I&E) funds

NCIL Comments/Questions:

The law states that “The State plan shall . . . include an assurance that the State will reserve and use a portion of the funds allotted to the State under section 110 . . . to support the funding of . . . the Statewide Independent Living Council, consistent with the plan prepared under section 705(e)(1). The law does not contain an exception for those states, which fail, for whatever reason, to include I&E in the plan. It just says that you spend the money according to what is in the SPIL. Why are some states not required to allocate funds to the SILCs?

RSA Response:

Section 101(a)(18) of the Rehab Act requires that the VR State plan assure that the State VR agencies will reserve a portion of Title I funds to support I&E activities, including supporting the funding of the SILC.¹⁵ However, section 101(a)(18)(A)(ii)(II) says that the funding support should be consistent with the SILC's resource plan prepared under section 705(e). Because section 705(e) lists several available resources the SILC can use to fund its duties under Title VII, a SILC may have sufficient funding from other sources and not need any or all of the funds that the VR agency can set aside for it. In such a case, the SILC's resource plan prepared under 705(e) would fund the SILC without using I&E funds. The SILC's use of I&E funds (no use) would be consistent with its resource plan and thus, with section 101(a)(18).

Because I&E funds, Part B IL funds, State IL funds, and the other public and private sources available to fund the SILC are limited and can all be used for other purposes as well as funding the SILC, the SILC and the DSU (the agency that manages both VR and IL funds) must reach agreement on how best to fund the SILC using the available resources.

¹⁵ Section 101(a)(18) of the Act provides:

The State plan shall

- (A) include an assurance that the State will reserve and use a portion of the funds allotted to the State under section 110
 - (i) for the development and implementation of innovative approaches to expand and improve the provision of vocational rehabilitation services to individuals with disabilities under this title, particularly individuals with the most significant disabilities, consistent with the findings of the statewide assessment and goals and priorities of the State as described in paragraph (15); and
 - (ii) to support the funding of
 - (I) the State Rehabilitation Council, of the State has such a Council, consistent with the plan prepared under section 105(d)(1); and
 - (II) the Statewide Independent Living Council, consistent with the plan prepared under section 705(e)(1);
- (B) include a description of how the reserved funds will be utilized; and
- (C) provide that the State shall submit to the Commissioner an annual report containing a description of how the reserved funds were utilized during the preceding year.

7. Public Hearings

NCIL Comments/Questions:

Several states have reported that they are being told that public hearings must be held by the DSU and the SILC. CFR 34 364.21 (h) says that “the SILC is authorized to hold any hearings and forums that the SILC determines to be necessary to carry out its duties.” Why are SILCs being told otherwise?

RSA response:

There are two different types of public hearings contemplated by Title VII. Both the DSU and the SILC must conduct public hearings on the contents of the State plan prior to its submission to the Secretary and on any revisions to the approved State plan. See 34 CFR 364.20(g).¹⁶ The SILC is also “authorized to hold such hearings and forums as the Council may determine to be necessary to carry out the duties of the Council.” See section 705(d) and its implementing regulation at 34 CFR 364.21(h). It is not required, although it is permitted, that the SILC hearings authorized under section 705(d) be held jointly with the DSU.

8. Monitoring

NCIL Comments/Questions:

Many states have commented that Section 6 of the SPIL is setting up SILCs (or even DSUs) to monitor CIL’s compliance with Sect. 725 of the Act - when that is clearly RSA’s responsibility. Neither SILCs nor DSUs have the responsibility of monitoring CILs.

RSA Response:

The questions in the SPIL in section 6 requiring a description of how certain service provider requirements will be met is based directly on the requirement of 34 CFR 364.20(i): “The State plan also must address how the specific requirements in §§ 364.21 through 364.43 and in §§ 364.56 and 364.59 will be met.” This provision refers to the state plan, and does not require the DSU or the SILC to monitor CILs to ensure the requirements are met. The DSU and the SILC must determine, however, how to ensure that service providers meet these specific requirements.

The SILC does not have the authority to monitor CILs and therefore would not have that responsibility. Because the DSUs must account for funds received under Part B under section 704(c)(1), DSUs must have procedures in place to ensure

¹⁶ 34 CFR 364.20(g)(1) provides: “The State plan must assure that the DSU and the SILC conduct public meetings to provide all segments of the public, including interested groups, organizations, and individuals, an opportunity to comment on the State plan prior to its submission to the Secretary and on any revisions to the approved State plan.”

that service providers spend their Part B funds in compliance with federal requirements. See 34 CFR 76.770.¹⁷

¹⁷ 34 CFR 76.770 provides: “Each State shall have procedures for reviewing and approving applications for subgrants and amendments to those applications, for providing technical assistance, for evaluating projects, and for performing other administrative responsibilities the State has determined are necessary to ensure compliance with applicable statutes and regulations.”

Appendix E: Involving the Community in Decisions Data Gathering for SILCs¹

Community Input – Why Bother?

Should SILCs bother to involve their communities and gather input prior to developing their state plan? Absolutely! It's a good way to involve people and create investment as well as good business practice that creates buy-in. This is very important because SILCs should want and need a legitimate state plan which should be a high priority. It affirms or denies assumptions and allows SILCs to make more informed and better decisions. While it takes more time up front, it speeds up the process down the line, promoting two-way communication and collaboration, a high priority for state plans.

Commonly Used Methods for Gathering Input

The most useful and commonly used methods for SILCs are interviews, surveys, community forums, focus groups and e-mail comments. This isn't an exhaustive list of methods, but rather are the ones that most people think of when they want to involve the community and gather data or gather input.

Interviews

Interviews can be conducted face-to-face, by telephone, or videoconference; they can be informal or formal. Interviewers record information stated verbally by the interviewee. One of the most common ways to collect information, good interviews are the outcome of complete, fair, and perceptive questioning by the interviewer.

Interviews can be very useful when you're planning, when you're trying to gather ideas for program design, and when you want some upfront advice. One SILC director, when revamping a training program, interviewed people who conducted other training programs nationally in order to identify best practices. Sometimes interviews are conducted after a program for assessment, summarizing or reaction. An example would be that you have an all day staff retreat and you want to interview key management regarding their perceptions of the effectiveness of the event.

Most Important Things to Remember about Interviews

- Interviews are good for in-depth conversation because obviously in an interview you can probe by asking, "What do you mean by that? Could you give me an example?" Interviews often yield "quotes" and rich examples of successes or

¹ Excerpted from the transcript of Webcast/teleconference *Involving the Community in Decisions: Data Gathering for SILCs* sponsored by the SILC-NET (a program of Independent Living Research Utilization in partnership with the National Council on Independent Living and Association of Programs for Rural Independent Living) on June 12, 2008. Presenters were Judy Sharken Simon (Management Assistance Program) and Brad Williams (New York SILC). The archive can be accessed at <http://www.ilru.org/html/training/webcasts/archive/2008/06-12-SILC-NET.html>

challenges.

- Interviews allow you to build rapport and solicit additional detail to support the interviewee's perceptions. You can read facial expressions so you can see their reaction and ask, "You seem a little uncomfortable with that. Can you tell me what might be going on?" Interviews can yield more in-depth information.

The Downside of Interviews

- Interviews are time-consuming. It's very difficult to do an interview, either a phone interview or a face-to-face interview, in less than 1 hour or 1.5 hours. Interviews are particularly important when key relationships are at stake, for example, when you really want to find out what funders think about something -- a major donor or a political leader. The face time or at least that one-on-one time with that particular individual can help build that relationship.
- It is often difficult to summarize results quantitatively and the analyses are typically time-consuming because it deals with people's perceptions and thoughts. How the notes are taken and key words that people use can make it more difficult to standardize the responses and come up with something that says, for example, 30% of the people that we interviewed felt this way. This is much easier to do with some of the other methodologies.
- Interviews lack the synergy obtained through other group data gathering methods such as focus groups or community forums. Because interviews are generally conducted one-on-one, people aren't influencing each other and bouncing ideas off of each other. You're only getting one person's perspective most often.
- Interviewers can bias outcomes by the choice of questions or attitude displayed, compromising objectivity.
- In terms of cost issues, comparing interviews to surveys that can be mass mailed to hundreds of people, you simply can't and usually don't have the resources to interview many people.

Surveys

Surveys are structured questionnaires. They allow you to ask many people exactly the same questions, phrased in the same way. They often have questions with numeric responses, but can include write-in questions or "comments" sections. Most often, responses are analyzed quantitatively (e.g., percent of respondents indicating agreement on each question).

Typically surveys are used before embarking on something such as market research - how many people value your service as it is now might be one example. Sometimes surveys are used ongoing when you're looking, for example, at doing a name change or recruiting new clients. You may ask people's opinion about a program that's currently in progress. Surveys can be used at the end of a program or service as a postmortem look at things.

Most Important Things to Remember about Surveys

- The design of the survey is critically important. How the questions are configured can determine whether you get accurate information or not. If it is a poorly designed survey, there might be a lot of confusion as people go to answer those questions, possibly compromising your data.
- Quantitative analysis of the results is one of the benefits of surveys, but it also means you need people who can do that quantitative analysis. So you need the skill set to do that analysis, otherwise, the value of doing it as a survey instrument is lost.
- Surveys are particularly helpful in reaching a broad audience because you can cover large quantities of people, and few other methodologies can do that in a way that a written or an electronic survey can.

The Downside of Surveys

- Response rate is one of the most cited reasons people don't use surveys; a two percent response rate is considered good by industry standards.
- There is very little opportunity for probing. Most often it is an electronic or a written survey and people answer yes/no. You can't determine what was behind their yes or no. Why did they answer that? Maybe they were confused by the question. Maybe their interpretation of a particular term was different than what you had intended. So you don't have that opportunity to delve further into their responses.
- They can be costly to administer. Typical costs include: survey development time, printed/copied surveys, postage, data entry, time required to analyze and summarize data. But, they can also be more cost effective than interviews and focus groups if there are a large number of respondents.

Online Surveys

Online surveys have extreme benefit, but costs can vary greatly. You might find one product that could be along the lines of around three dollars a month or some other ones that are far more expensive

- There is a training curve involved. Unless you have someone who is very savvy with these types of products, you are probably not just going to be able to jump online and to be able to utilize these products. You're going to have to invest time to learn the software, develop the survey instruments, publish the surveys, and manipulate the data as it comes in.
- Accessibility. You cannot assume that the product conforms to accessibility standards for both the instrument designer and the end user. One SILC utilizes Survey Monkey and found that people had varying experiences. What they did was have three testers who, upon finishing the survey, were willing to test the final product to see if they liked the speech readers. Two were able to navigate

through it successfully, while a third had difficulty with the dialogue boxes for the open-ended questions. Be aware that many of these online survey instruments do have trade-offs and to be aware of them.

Community Forums

Community forums are usually used for large groups in a public setting where there are 30 or more stakeholders. Typically community forums are used to collect opinions, beliefs, and attitudes about issues of interest to people in the public, such as your stakeholders. Here is what one consultant said, “I worked for an organization in St. Paul, Minneapolis, who was very interested in getting involved in neighborhood development efforts. They wanted to go out into the community and hear from neighborhoods about what their role should be as a human service agency in terms of neighborhood development. So they undertook creating community forums in many of the neighborhoods around St. Paul where they felt they wanted to get service in those neighborhoods or provide service in those neighborhoods. So they were really undertaking a process of collecting beliefs and ideas - things that were of interest to people in those communities. It is certainly about building energy, ideas, excitement about a topic because in a community forum versus surveys, you have an ability to tap into that emotional context in the setting. You have a group of people that can build off each other and you as facilitator can create a sense of energy and excitement by how you set up a room, how you decorate the space that you're in, the kind of speakers you have there, and the energy of the participants themselves”.

Another area where community forums are often used is about providing an opportunity to learn more about a topic because in that kind of setting you can have an expert or an educational speaker. You can give written materials or have other vehicles for people to pick up information. There is an exchange that can happen that isn't really as available in some of the other methodologies.

Most Important Things to Remember about Community Forums

- Logistics - there are many details to consider when you're talking about a group of 30 or more in a public setting.
- There are many facets of it that you need to be prepared to address. The orchestration of that event can really make a difference.
- You need good facilitation. The same consultant referenced above said, “In Minneapolis there was a situation a couple of years ago where Minneapolis was closing a number of public schools and they were having community forums to hear the community's reactions to that. Emotions were high, as you can imagine in that kind of public setting, the rules for engagement were unclear, and pretty quickly things got out of hand and so they didn't get the information that they wanted because they hadn't really orchestrated those events or thought ahead about how to orchestrate them well”.
- They are a great opportunity for P. R. because you have an opportunity for good two-way exchange. Community forums in particular are good vehicles for getting

the word out about your program, service or agency.

The Downside of Community Forums

- You must have good staffing, with people who are prepared to be there and have the skills to get the facility set up properly.
- The group can take on a life of its own, just as the example referred to above illustrated. Perhaps they had planned to orchestrate it very well, but the group took over because emotions were so high. That can happen in a community forum versus some of the other methodologies where you have more control over the setting and the group reaction.
- Capturing the data can be challenging. There are often a lot of people present so how are they sharing information? How does that information get written down or captured, either through audio taping or videotaping? This can be a challenge in terms of gathering the data in a way that you can utilize it later.

Focus Groups

A focus group is a group of 7 to 10 people who are together in a facilitated discussion to share beliefs, opinions, and ideas, selected for their ability to answer questions on a certain topic.

Common uses of a focus group include summarizing, postmortem, or gathering people's ideas about your image, or your organization's customer service.

Most Important Things to Remember about Focus Groups

Focus groups are useful when you want detailed "case studies". They are not very useful for gathering information where you want to quantify the responses. They are particularly helpful in combination with other methods. Focus groups are great at creating opportunities for fun, engagement, interaction and are useful for gathering answers to "why" questions and capturing ideas, beliefs and feelings.

The Downside of Focus Groups

- Requires a leader with good group facilitation skills. Remember, it's a group of people that can take on a life of their own if not well facilitated.
- Time is limited generally to about 1.5 hours. That's usually enough time for five or six questions. So the number of questions that you're able to ask in a focus group is compromised versus, again, with a survey or an interview where you can go down different paths and ask different questions. You can cover a hundred questions in a survey, and in a focus group, you have fewer opportunities to ask questions because part of what you need to do is take some of that time to set up the environment.

E-mail Comments

Typically this method is used for collecting opinions, beliefs, and attitudes. You know people have strong opinions about issues and sending their comments via e-mail is a very quick, efficient way to get that information. A great time to use an e-mail data gathering mechanism is during the course of a public comment period because it's quick and immediate.

Most Important Things to Remember about E-mail Comments

Be prepared for large volume. You must set up your process beforehand; it is important to be accessible and have a controlled medium. One SILC director says, "Two state plans ago we set up the process to be able to receive e-mail comments for our state plan. We only received a few comments, but the process was set up and we had the ability to receive those comments nonetheless".

The Downside of E-mail Comments

- It is difficult to analyze the data. You lack an ability to probe or bounce ideas off of one another. The responses tend to come from those who are most passionate, pro or con.
- They are coming in randomly and it's not interactive.
- Be aware that some responses come from targeted or organized efforts to support popular initiatives as opposed to individual, random comments.

The Process for Any Method

There are eight steps to effectively implement any of these methods.

Step 1 – Define the Purpose

- Write it down; be very clear about why you want to gather this input. You need to be very clear about it so that you can communicate it to other people, to participants, why you're doing this, why you're holding a community forum, why you're sending out a survey, why you want to engage in an interview.
- It also helps you develop the questions that you're going to ask, because if you're not clear about the purpose of why you want to gather the information, the kinds of questions will probably lead you down a different road and the answers will not be what you're looking for.
- Get the information you really want. You don't want to spend a lot of time, money, and resources asking questions and then finding out that the information does not tell you what you wanted to know in order to make effective decisions.

Here are two examples of purpose statements –first poorly written, and then rephrased to make them more explicit:

Example One

PURPOSE: To gather input on service needs in the disability community.

Why do you want to know that? To find out if the top priority needs in the state were adequately reflected in the state plan.

CLEARER: To gather community input to ensure that the service needs match with the components outlined in the state plan.

So if your purpose was to gather input on service needs in the disability community, the question you want to ask is why do you want to know that? Well, it's to find out if the top priority needs in the state are adequately addressed in the state plan, or adequately covered. So, looking at the purpose statement as it's originally stated, it may not exactly say that, and the information you get may take you somewhere else. A clearer purpose statement might be to gather input to ensure that the service needs match with the components that are outlined in the state plan.

Example Two

PURPOSE: To hear what our constituents think we do.

Why do we want to know that? Because we need to revise our mission statement.

CLEARER: To hear constituents' ideas about our current mission statement and how to revise.

If your purpose for holding a focus group or doing a community forum is to hear what your constituents think you do, why do you really want to know what your constituents think you do? Well, because we want to rewrite our mission statement. You could get a whole lot of information about what constituents think you do and it might have something to do with your mission statement, but if you were clearer to say “to hear constituents' ideas about our current mission statement and how to revise it,” again, your data gathering, the questions you ask, the invitations you put out to participate in that method will be much more focused and much more effective.

Step 2 – Establish the Timeline

NYSILC Example

[Brad Williams, Executive Director for NY SILC shares his experience regarding the SPIL development timeline]:

We had moved along a seven month timeline and for me, I always found it interesting because I would go to the SILC Congress and there would be some colleagues who might not even start their process until after the SILC Congress, which typically would happen in January, and you could see how busy we would be before we would even get ourselves to the SILC Congress. So it would happen in May where we would start off with a SPIL, a state plan committee to make decisions about the process, and then by August, develop the important outreach materials so that by September we would distribute these outreach materials to the network and post them on the website so that by early October we'd start with the statewide public hearings and late October start the breakout sessions at conferences so we could turn it all around in November, and then meet face to face with the SPIL committee to review all this increased input.

New York SILC SPIL Development Timeline:

1. May 2006 - SPIL committee meets to make decisions about process
2. August 2006 – Develop important outreach materials
3. September 2006 – Distribute outreach materials to the statewide network and post them on website for review and comment
4. Early October 2006 – Conduct three statewide public hearings at CIL sites
5. Late October 2006 – Conduct four additional hearings at breakout sessions of statewide annual conferences to expand feedback beyond the CIL network
6. November 2006 – SPIL committee meets face-to-face to review increased input

So it's really about backtracking. When do you need the information?

What do you need it for? Then give yourself enough time to carry out the method effectively.

Steps 3 & 4 – Identify and invite the participants / Generate the questions to be asked

Identify and invite the participants - where are you going to get the names of people to invite? How are you going to invite them? Thinking through those pieces, and

generating the questions to be asked, one SILC director uses a four-part model for generating questions. She takes time to just brainstorm. What are all the possible questions to ask in this survey or this focus group? Then she prioritizes those questions and incorporates the very important step of testing them. She asks herself the questions, thinks about how she would answer, and then considers whether or not this is going to give her the information needed to accomplish the original goal using the selected data gathering method.

NYSILC Example

We generated a facilitation outline to show the kinds of questions that we were asking in our process. The facilitation outline helped to guide the input and process, no matter what mode or venue was used. What was crucial was that the questions were developed to gain important feedback on key aspects of the state plan. As you read some of the key questions below, you can see right away that they correspond with the use of the Title VII Part B funds or the use of Title VII Part C funds, or independent living -- the scope of independent living services. We asked questions that were going to get relevant feedback to really direct important content toward our state plan.

NYSILC Facilitation Outline

Use of Title VII, Part B Funds: These funds are resource oriented. Approximately \$750,000 is available.

- What is the best way to maintain and/or improve support for the statewide systems advocacy network?
- What do you think are the top technical assistance and training needs of the statewide network?
- What is the best way to increase public awareness about CILs and issues important to people with disabilities?
- What is the best way CILs can conduct outreach to unserved and underserved populations? What has worked in your community?

Use of Title VII, Part C Funds: These funds are for center operations. Sixteen CILs presently receive twenty-one grants totaling \$4 million. The previous SPIL used new funds for the establishment of new CILs. The current plan directs all new funds to the existing Federal network of CILs until they receive a minimum of \$200,000 each.

- How can the statewide network best use new Title VII, Part C funds?
- How can our SILC encourage the maintenance and growth of a statewide network of centers?
- What unserved or underserved areas of the state still exist?

Description of Extent and Scope of Independent Living Services:

- With housing such a priority, and CILs being non-residential, what can be done to increase affordable and accessible housing options?
- What resources do CILs need to effectively divert or transition people with disabilities out of institutional settings?
- What role should CILs play in the transition of students with disabilities?
- What role should CILs play in the implementation of the Help America Vote Act (HAVA)?

Step 5 - Develop a script / Select a facilitator / Choose the location

You may need to develop a script if you're using a focus group or an interview. Select a facilitator, choose the location, making sure that it's accessible, which not only means in terms of the disability piece, but also in terms of transportation and parking. Is it an easy place to find? Is it a comfortable setting?

Steps 6, 7, & 8 - Initiate the method / Interpret and report the results / Translate the results into action

You implement the method: focus group, community forum, survey, or e-mail comments. Then you have to interpret and report the results, reporting back the information to those who participated. People love to hear how the information that they generated was written up, summarized and how it is being used. Lastly, you need to translate those results into action. So whether it's revising the plan, doing follow-up, being clear on what the next steps are, how are you going to put this information into action?

Questions to Ask Yourself for Determining Which Method to Use

- What kind of information am I trying to obtain?
- Is it quantitative information?
- Is it people's feelings, beliefs, and/or perceptions?
- Who would conduct this kind of research if we don't have access to good facilitators?
- Do or don't do a focus group?
- Do or don't do a community forum?
- Who would be participating?

Avoiding “Groupthink”

To avoid groupthink and situations where the whole group gets fixated on one viewpoint, inhibiting other ideas from getting into the conversation, use good facilitation techniques such as a nominal group technique. People are asked to write down their responses, and then the facilitator goes around the room one person at a time, controlling how people are sharing their feedback. If one person goes off on a tangent, the facilitator can say, “that's a great comment, Jerry, we want to make sure we hear from other folks in the room,”, and so it really has to do with some good facilitation, being able to stop a person or redirect the efforts. Sometimes standing physically closer to a participant communicates some of that -- it's time to let somebody else come in, encouraging other responses. “How many of you agree with Jerry? Anybody else have a different opinion”? So you're encouraging the group to think more broadly.

How to Achieve Expanded Input

- Conduct statewide public hearings at centers.
- Conduct breakout sessions at statewide conferences, especially to gain a non-IL perspective.
- Conduct focus group sessions at the local level.
- Get past the transportation barriers or the fact that some people prefer close group settings or the advantage of local control and empowerment.
- Get past the digital divide, taking advantage of e-mail comments submitted by individuals via your SILC website.

Organizing Data and Results

There are different approaches to organizing. If you're successful, you get a lot of community input, and there is some subjectivity in deciding what the categories are and how to divvy up the responses. Generally, you must sift through all of the responses and literally assign a matrix for tallying each response. Each time someone gives comments, they may be commenting on separate issues, so you need to do a raw tally of each comment, continuing on to the next person's comment(s), and keep going through until you finally have a raw score and a correlation of results. This gives a true picture of what the priorities are, giving you legitimacy and confidence with the results. This is a tedious process and can take a long time, but having a very active and involved SPIL committee that engages in this process can yield useful, reliable data.

The Process Works

The process works if there is participation, ownership and legitimacy; it is an investment of time to gather data and input upfront to save confrontation later. One SILC director says, "I can remember having state plan meetings where we would argue endlessly on sections of the SPIL, and it was just a pleasure to have a meeting where, besides minor edits, this state plan went through. That's because the real battles occurred during the committee work; it was beneficial to have all that input through the process and it just felt legitimate".

Recommended Resources

Books

1. *The Public Participation Handbook; Making Better Decisions Through Citizen Involvement*, Creighton, James L., Jossey-Bass, [c]2005.
2. *Nonprofit Guide to Conducting Community Forums: Engaging Citizens, Mobilizing Communities*, Carol Lukas, Linda Hoskins, Fieldstone Alliance.
3. *Nonprofit Guide to Conducting Successful Focus Groups*, Judith Sharken Simon, Publisher: Fieldstone Alliance

Websites

- http://www.ce.communitiesscotland.gov.uk/stellent/groups/public/documents/web_pages/scrcs_006693.hcsp
- <http://www.hcd.ca.gov/hpd/participation.pdf>
- <http://www.communities.gov.uk/localgovernment/360902/constitutionsandethics/constitutionalarrangements/guidanceenhancing/guidanceenhancing/>
- http://www.nysilc.org/spil_plan_2005-7_final/NYSILC%20SPIL%20Development%202008%2020101.htm

Appendix F: What Every SILC Member Should Know

A Self-Administered Test

The list below includes basic information that each member of a statewide independent living council (SILC) should know and understand in order to be an effective voting member of a statewide planning body.

Assess your knowledge of the following issues by placing a check mark beside the items you know and a minus sign beside items you do not know. Be tough-minded.

1. ____ The history of independent living related to and including the Rehabilitation Act Amendments of 1992, particularly Title VII.
2. ____ The history of how centers for independent living developed in the United States.
3. ____ The independent living philosophy--its tenets, principles, values, and how it is practiced.
4. ____ The name, location, size, and executive director of each independent living center in the state.
5. ____ The designated state unit (state vocational rehabilitation agency or blind agency) through which Title VII funding flows, its director, its staff related to Title VII programs, and how to reach these individuals.
6. ____ Agencies in the state providing services to persons with disabilities, their missions, general information about what they provide, and their relationships to each other and within state government.
7. ____ The divisions of the U.S. Department of Education related to people with disabilities and the names of the programs administered by Office of Special Education and Rehabilitative Services (OSERS).
8. ____ The amount of funds allocated to the state under Title VII, Part B and how such funds are being spent.
9. ____ The objectives of the state's plan for independent living.
10. ____ How the state spends its Social Security Reimbursement Funds, particularly if such funding supports centers for independent living or independent living services within the state.
11. ____ Amount of state funds for independent living centers and how they are distributed.
12. ____ Any state laws written for creation, definition, or maintenance of centers for independent living centers.
13. ____ The nature and direction of the state's plan for vocational rehabilitation

and how it relates to the state independent living plan.

14. ____ The definition, assurances, standards, and indicators for centers for independent living.
15. ____ The purpose of the state rehabilitation council and its relationship to the statewide independent living council.
16. ____ The roles, responsibilities, and authority of members of the SILC.
17. ____ The communication system(s) established for effective functioning of the SILC.
18. ____ The articles of incorporation (if appropriate), bylaws, or other tools of governance or policy guidance used by the SILC.
19. ____ The individual members of the SILC, what they represent on the SILC, their offices or responsibilities, if any, and contact information on each.
20. ____ The contents, amounts, and sources of funding of the SILC's resource plan.
21. ____ The budget guiding SILC expenditures and how fiscal matters are managed.
22. ____ The staff of the SILC and how they relate to the SILC as a whole as well as to individual members of the SILC.
23. ____ How staff of the SILC are hired, trained, supervised, and evaluated.
24. ____ The nature and funding for any SILC-approved project funded under Title VII, Part B or any other state funding incorporated into the state's independent living plan.
25. ____ The basic concepts, definitions, and provisions of the Americans with Disabilities Act of 1990.

If you are a SILC member and believe that you do not have sufficient knowledge about these issues, you or your SILC, and perhaps your fellow council members, may need training to learn and to apply this knowledge in your roles as SILC members.

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