

More than a Motto: SILC Member Orientation to IL History and Philosophy

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IL-NET

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Table of Contents

Session 1: Orientation, Expectations, and Introductions	1
Plan for Session 1	1
Introduction.....	1
Course Objectives	1
Online Course Approach, Expectations, Guidelines, and Tips	2
Schedule of Class Sessions	4
Participant Achievement Documentation	4
Follow-up Survey and Evaluation	4
Assignment.....	5
Session 2: IL Philosophy and the Role of SILCs	6
Plan for Session 2	6
Unique Role of SILCs	6
Purpose and Defined Duties of the SILC	7
Assignment.....	8
Session 3: Disability History and the Development of SILCs	9
Plan for Session 3	9
Independent Living History and Its Meaning for SILCs.....	9
Assignment.....	10
Session 4: Taking Control	11
Plan for Session 4	11
The Independent Living Model	11
Assignment.....	12
Session 5: Terms You Need to Know.....	13
Plan for Session 5	13
The Language of Independent Living	13
Key Definitions.....	13
The Workforce Investment Act (WIA)	14
The Rehabilitation Act.....	14
Title VII--Independent Living Services and Centers for Independent Living	14
Regulations Implementing the Law.....	15
Assignment.....	15
Session 6: Stand Like a Rock	17
Plan for Session 6	17
Independent Living Principles.....	17
Assignment.....	18
Sessions 7 and 8: Applying IL Principles in IL Planning.....	19
Plan for Sessions 7 and 8.....	19
Hypothetical Scenarios in This and Subsequent Sessions.....	19
Scenario: Justifying Your Methods	19
Assignment.....	20
Session 9: Applying IL Principles When Working with Policymakers	21

Plan for Session 9	21
Working with Policymakers.....	21
A Few Words About What SILCs Can and Cannot Do with Federal Funds.....	21
Scenarios for This Session	22
Assignment.....	23
Sessions 10 and 11: Applying IL Principles When Assessing Statewide Needs	24
Plan for Sessions 10 and 11.....	24
The SILC Planning Role	24
Example Philosophical Situation.....	24
Assignment.....	26
Sessions 12 and 13: Applying IL Principles as a Tool for Collaboration with the DSU..	27
Plan for Sessions 12 and 13.....	27
Scenario	27
Assignment.....	28
Sessions 14 and 15: Final Assignment—Set Some Personal Goals.....	29
Plan for Sessions 14 and 15.....	29
Closing Sessions	29
Assignment.....	29
Examples of Outcome-Oriented Statements for Assignment.....	29
Appendix: IL History and Philosophy Resources.....	30
Independent Living History	30
The Emergence of Independent Living.....	32
Codification of Independent Living.....	33
Disability Policy Framework and Advocacy	35
Advocacy Organizations and Information Networks	38

More than a Motto: SILC Member Orientation to IL History and Philosophy

Session 1: Orientation, Expectations, and Introductions

Plan for Session 1

- Review course objectives, structure and requirements.
- Meet course participants.
- Assess knowledge of information to be covered.
- Share personal information about your involvement in independent living and, specifically, your experience as a member of a statewide independent living council (SILC).

Introduction

Welcome to **More than a Motto: SILC Member Orientation to IL History and Philosophy**. Our purpose will be to enable course participants to gain a deeper understanding of the history of independent living and the philosophy on which it is based. We titled this course *More than a Motto* to signify our intent to deepen the discussion beyond the abbreviated statements we often use to express the principles, goals, or ideals of independent living.

As an advocate in the field of independent living, you may serve, or are considering serving, on a SILC. Serving on a SILC is a unique experience; it's not quite like volunteering at any other organization.

SILCs are different because they must be consumer controlled, and as such, the majority of the members must be people with disabilities. While most of us believe that this is a commendable requirement, it also presents many distinct challenges. In addition to disability considerations, SILC members are required to be "knowledgeable about centers and IL services."¹ As we all know, just having personal experience with a disability doesn't mean a person automatically understands the Independent Living (IL) Movement.

Course Objectives

This course will address IL history and philosophy, both of which are central to the unique approach of the movement. The knowledge you gain through this course will assist you in becoming a more effective SILC member. It is our hope that by the end of this course you will be able to

¹ Code of Federal Regulations 364.21.

1. describe how the Independent Living philosophy provides the foundation for the purpose and duties of a SILC;
2. explain the history and philosophy of Independent Living;
3. identify approaches to integrate the principles of IL philosophy into daily SILC activities and practice; and
4. define terms that are frequently used by SILC members and staff.

This course does not address the duties of a SILC in depth but does address the philosophy that underlies SILC duties. Participants who complete the course should be able to understand—even embrace—IL philosophy and ensure that the philosophy is in the forefront of all decisions of the SILC. You will review and react to materials that the instructor will provide regarding IL history and philosophy. All assignments are designed to promote penetrating discussion—to make you think about the impact of your actions on the network of IL services in your state.

The assignment for each session (or sessions) is included in this manual. The assignment will also be posted as the first message of the day for each session in the discussion area of the online learning platform. As a student, it is your responsibility to respond to all assignments so others in the training may benefit from your observations.

Your greatest learning opportunities in this interactive course will come from your direct communication with your classmates. This course works best if you comment on the responses of other students. Be liberal with your kudos, criticize constructively, and offer supportive suggestions. In turn, you will receive the same kind of support from your classmates.

Your instructor will visit the course website several times daily throughout the training. He will comment now and then, guiding and focusing the class discussion. The instructor cannot respond to every posting because of the sheer number of entries. The lack of response to a specific posting should not be taken personally. If you need to communicate with the instructor privately, feel free to send an email message. You will receive a swift response.

Online Course Approach, Expectations, Guidelines, and Tips

Here are a few key aspects of online courses. Understanding how online courses work and following a few simple guidelines and tips will enhance your learning and enjoyment of the course.

Flexibility and discipline

You can log on to the course website any hour of the day or night, taking part at times that best fit your schedule. While this “anytime, anywhere” flexibility is convenient, it requires greater than average discipline and does not allow one to “coast.” Make the most of your course experience by completing each daily assignment on the day the

class is covering that assignment. Daily posting of your comments will benefit you and your colleagues. This interaction is a major part of the course and is one of the ways that online courses differ from self-study courses. Students are expected to participate in each assignment in order to receive a certificate of completion.

An important feature of online courses is that you can reread and review course material or instructor and participant comments as often as you like. You will be able to evaluate course material at your own pace and then respond thoughtfully and constructively. Participants have a greater responsibility for their own learning than they would have in a traditional learning environment.

Communication and learning

Online courses are most effective when there is lively class “discussion.” Participants, therefore, are expected to take initiative in communication and interaction. Within the unique online environment, the responsibility is on the participant to maintain an open communication link, request clarification, and direct interaction in a way that will serve to increase his or her personal understanding. Even though face-to-face communication is absent, the written discussion of online classes creates entirely new ways of learning—sometimes just different, sometimes even better.

Participants contribute as much to the learning environment as the instructor, whose role becomes one of a colleague and facilitator rather than the director and sole source of knowledge.

IL-NET online courses have been specifically designed to take advantage of technology. We have not attempted to replicate a model that works well in a face-to-face traditional environment. The online delivery method can provide the same kind of outstanding learning opportunity you would have in a traditional course—but in a far more efficient manner. Also remember that in physical classrooms, some participants sit without participating. In the online environment, it’s a little harder to remain uninvolved.

Time needed

Plan to devote an average of one hour per day to your assignments and activities. This includes accessing lectures, participating in course discussion, completing and submitting assignments, and reading supplementary workshop materials. Once the course begins, you are encouraged to log on every day.

About the speed of this workshop

This workshop moves along surprisingly quickly. We have found that students who devote at least an hour every day to the course get the most out of it. Those who fall behind may not receive feedback from the instructor and their peers because the class has moved on to other assignments. If you do fall behind, you should complete the assignments, but be aware that you may not get the same quality of feedback.

IL-related assignments

Discussion at your own organization or work site will enhance the learning experience. Participants are encouraged, but not required, to discuss the questions and scenarios presented in this course with colleagues prior to completing the assignments.

Schedule of Class Sessions

March 10	SESSION 1: Orientation, Expectations, and Introductions
March 11	SESSION 2: IL Philosophy and the Role of SILCs
March 12	SESSION 3: Disability History and the Development of SILCs
March 13	SESSION 4: Taking Control
March 14	SESSION 5: Terms You Need to Know
March 17	SESSION 6: Stand Like a Rock
March 18-19	SESSIONS 7 & 8: Applying IL Principles in IL Planning
March 20	SESSION 9: Applying IL Principles When Working with Policymakers
March 21 & 24	SESSIONS 10 & 11: Applying IL Principles When Assessing Statewide Needs
March 25-26	SESSIONS 12 & 13: Applying IL Principles as a Tool for Collaboration with the DSU
March 27-28	SESSIONS 14 & 15: Final Assignment—Set Some Personal Goals

Participant Achievement Documentation

A certificate is available from ILRU for those students who log in to class regularly, keep current with assigned readings, complete assignments, participate in the discussions, fill out the evaluations and complete the final assignment on time.

Follow-up Survey and Evaluation

An evaluator may contact you to complete a brief survey designed to assess if you are applying what you learned in this course to the work that you do. The results of this survey will be used to assess the longer-term outcomes of the training.

Assignment

1. Read the Introduction and Course Objectives above.
2. Review “Online Course Expectations, Guidelines, and Tips” above.
3. Go to the discussion area and tell us a little about yourself. For example:
 - Do you currently serve on a SILC? If so, how long have you been on it and what positions have you assumed (committee assignments, offices, etc.)?
 - Where do you work? What is your job?
 - What experience do you have with online trainings?
 - What equipment do you use?
 - What do you do in your spare time?
4. After you have written a little about yourself, read what others in this class have written. Don’t be afraid to comment or ask questions of your classmates.

Session 2: IL Philosophy and the Role of SILCs

Plan for Session 2

- Review the purpose and duties of a SILC.
- Understand the relationship between IL history and philosophy and SILC purpose and duties.

Unique Role of SILCs

One of the first steps each new member of a SILC needs to take is to understand how the SILC fits into the big picture of disability concerns. Until you understand the unique role SILCs play, you will be at a distinct disadvantage as a SILC member in fulfilling your duties.

In order to understand the evolution of SILCs, you need to understand the role that consumer control plays in the IL 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.

Naturally, as centers began cropping up across the country, the federal government looked for a way to coordinate activity with the states. 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. So in 1992 when Congress reauthorized the Rehabilitation Act of 1973, it greatly strengthened the responsibilities and authority of SILCs.

Purpose and Defined Duties of the SILC

The purpose of the SILC is set out in Chapter 1 (Individuals with Significant Disabilities), Section 701 of Title VII of the Rehabilitation Act (the Act), as amended. It says that—

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....

Also in Title VII (Section 705) is a list of duties that frame SILC operations. These duties include the following:

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 (SRC) 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 of the federal Rehabilitation Services Administration 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.²

All activities of the SILC must fall within these five duties. The Act does, however, require that the SILC follow specific guidelines in carrying out these five duties. Among these are: formation of partnerships, outreach efforts, preparing and submitting a plan, coordinating services, and expanding the center for independent living network. The law does not allow the SILC to become a service provider.

The first line of the Purpose above is to promote a philosophy of independent living. This course is designed to help you meet that challenge. As a SILC member, it is critical that you understand and practice IL philosophy without regard to the duty you are addressing.

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

Assignment

1. Review the above reading assignment for this session, Unique Role of SILCs.
2. Post your answer to the following question on the discussion board: How prominent is IL philosophy at your SILC? Please give one example.
3. Read the posts of your classmates.

Session 3: Disability History and the Development of SILCs

Plan for Session 3

- Watch or listen to Video Clip #1: *A Brief History of Disability*.
- Review materials related to disability history and segregation.
- Consider the impact of disability history on the work of the SILC.

Independent Living History and Its Meaning for SILCs

The video provides an interesting historical perspective on independent living and its importance in shaping societal attitudes. The treatment and perceptions of people with disabilities in Western culture have varied greatly throughout the centuries and this video does a nice job of pointing out those variations. Some of the issues raised in the video have implications for people served by your state's independent living network today.

For example, you may be surprised to learn how much the Supreme Court's *Brown v. Board of Education* decision influenced the disability rights movement. However, you are probably aware that even after all the progress that has been made in the arena of integrated and equal education, there are still parents who have to advocate strongly with their school boards to get an appropriate education for their children with disabilities.

Another population that SILCs might be concerned with is veterans with disabilities. Often when veterans speak of services, they complain about a slow, bureaucratic system that seems designed to confuse and aggravate them. Yet, ironically, following each war, services have expanded for all people with disabilities as a result of doors that were opened for vets.

Eugenics is a practice that we don't think much about these days since it has gone out of favor with most people. It is hard to imagine a society that accepted forced sterilization, yet there are men and women alive today who were unknowingly sterilized as teens or young adults to prevent parenthood. (Still today, there are those who advocate for euthanasia, including prominent Princeton University philosopher Peter Singer.) What did you think of the contrast between those who supported eugenics and others who practiced "benign paternalism?"

Many of the segregated programs discussed were started by people who meant well, but assumed that people with disabilities are "more comfortable with their own" and prefer to work and/or live in segregated environments. Even today, there are practitioners who perpetuate this stereotype by creating segregated environments for their consumers.

SILCs have a unique role in the lives of people with disabilities. As we assess the needs of individuals in our state, for the purpose of informing the IL planning process, we must

know and understand how disability history continues to impact services. When we make recommendations to policymakers, we need to be free of the biases that influence others.

Assignment

Please answer the following questions and post your answers to the discussion area:

1. What “segregated” programs for people with disabilities are in your community or state?
2. Are these perceived as discriminatory or appropriate?
3. The *Brown v. Board of Education* decision by the Supreme Court applied to racial discrimination. How did this decision impact the disability rights movement?

Session 4: Taking Control

Plan for Session 4

- Watch or listen to Video Clip #2: *The Emergence of Independent Living*.
- Review materials related to “taking control.”
- Examine the differences between the Medical Model and the Independent Living Model.

The Independent Living Model

In order to understand the impact that independent living has had on the entire disability movement, it is important to appreciate that for individuals with disabilities to achieve independence, equality, access, and self-determination, our society needed to move from a “medical model” to an “independent living model.” When discussing the Medical Model, we are not just talking about the attitudes and actions of physicians. Historically, many different types of professionals employed the paternalistic, “I know what’s best for you” attitude, including physical therapists, school administrators, and vocational rehabilitation counselors. The transition to the IL Model was central to the growth of all other aspects of the IL Movement.

The transition from the Medical Model to an IL Model was not easy. The Women’s Movement made inroads in the sixties when women started demanding that doctors ask their opinion and then actually listen to what they had to say. When the IL Movement emerged, such concepts as consumer control and consumer direction also evolved. Populations of people that had previously acceded authority to professionals were learning to speak up.

Gerben DeJong was one of the early writers and researchers on independent living. In 1978, he created a paradigm that contrasted the Independent Living Model with the rehabilitation model, which followed the Medical Model. This comparison is illustrated in the chart that was shown in Video Clip #2. Below is a revision and updating of that chart that gives a clearer comparison of the Medical and IL Models.

In this chart you will discover that the entire thought process around service provision to people with disabilities needed to change. Prior to this transition, a disability was seen as “the problem,” rather than society’s unwillingness to address barriers that people with disabilities face. The person with the disability needed to be “fixed” rather than the environment in which he or she lived.

In the Medical Model, the professional “knows best.” He or she identifies the problem and sets the goal, and if the client or patient “cooperates,” hopefully the goal will be met. In the IL Model, the person with a disability is in charge, setting goals in which he or she is invested.

Medical Model vs. Independent Living Model³		
	MEDICAL MODEL	INDEPENDENT LIVING MODEL
Problem	Disability	Personal, familial, and societal barriers
Locus of problem	Individual who needs to be “fixed”	An environment that nurtures barriers
Solution	Professional intervention; treatment	Self-directed approaches and remedies
Service recipient	Patient or Client	Consumer or Participant
Who controls?	Professional	Consumer or Participant
Desired outcome	Cure; attain professional’s goal(s)	Greater independence

Why is embracing the IL model important for you as a SILC member or staff person? You cannot look at any facet of independent living without finding examples of consumer control or choice. Not only is consumer control the basis upon which all programs and services are presented, but the systems designed to assist people with disabilities are staffed and administered by people with disabilities. This is especially true of centers for independent living (CILs) and statewide independent living councils (SILCs).

Assignment

1. Review Assignment materials.
2. Answer the following question on the class discussion board: How does the transition from the Medical Model to the Independent Living Model impact how IL services such as advocacy, information and referral, and skills training are provided?
3. Read and comment on the posts of your classmates.

³ Originally developed by Gerben DeJong (1978) and adapted by Bob Michaels (2012).

Session 5: Terms You Need to Know

Plan for Session 5

- Watch or listen to Video Clips #3 and 4: *Codification of Independent Living and Disability Policy Framework and Advocacy*, respectively.
- Review materials related to terms and definitions.
- Visit IL-NET's website.

The Language of Independent Living

You may be overwhelmed with confusing language, references, and buzzwords that plague most of us who are newly appointed to the SILC: "Title VII," "Title I," "EDGAR," "121s," "I&E," "26s," and so forth. . . .

Let's not kid ourselves—reading and understanding legislation is neither easy nor enjoyable for most people, but being an effective SILC member requires that you at least know where to find the answers. This segment is designed to give you that information.

Key Definitions

Following are a few pertinent definitions and descriptions that will begin to orient you to the terms you will need to know.

- *Bill*: A proposed law that has been introduced in either house of the U. S. Congress or state 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 of a state.
- *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 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 Rehabilitation Act was absorbed into the Workforce Investment Act, a comprehensive piece of legislation intended to pull

together dozens of vocationally-related programs. The Rehabilitation Act became Title IV of the Workforce Investment Act (WIA).

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.

The Rehabilitation Act

When the Rehabilitation Act is looked at separately, we often still break it down by titles. The Rehabilitation 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.

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

This Title, like others, includes chapters, parts, and sections as follows:

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.

Regulations Implementing the Law

When Congress passed and President Clinton signed the Workforce Investment Act of 1998 into law, Title IV (the Rehabilitation 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.

Assignment

1. Review the material for this session below.
2. Visit <http://www.ilru.org>, the website of Independent Living Research Utilization.
 - o Click on *Projects*, then *IL-NET: CIL-NET and SILC-NET National Training & Technical Assistance Project*. You might want to bookmark this page and put a shortcut on your desktop.
 - o Next, click on *Information You Asked For*. This opens a page containing information that you can use throughout your time on the SILC.
 - o You will see bulleted links to The Rehabilitation Act and Statewide Independent Living Councils. These subtopics will be of particular interest to you. If you click on The Rehabilitation Act, you will find complete copies of the Workforce Investment Act and the Rehabilitation Act, as well as comprehensive information on Independent Living Services and Centers for Independent Living, the State Plan for Independent Living, and the Statewide Independent Living Council.

Regulations and other pertinent documents disseminated by RSA are available there.

3. Explore the website.
4. Write about your experience on the class discussion board.
5. Review the posts of your classmates.

Session 6: Stand Like a Rock

Plan for Session 6

- Understand the principles that provide the foundation for Independent Living.
- Consider the importance of values and principles in the work of the SILC.

Independent Living Principles

“In matters of principle, stand like a rock.”

—Thomas Jefferson

Those who have a strong IL Philosophy also have a strong set of values. They generally believe that all people should have the same rights. They believe in the dignity and worth of all people. Independent living principles evolve from these values. A principle is a basic truth, or assumption, or even just a standard of behavior.

A list of principles that guide the independent living field might include the following:⁴

- A commitment to civil rights, with no discrimination on the basis of disability.
- A consumer or customer is the best authority when purchasing a service or product and his or her wishes must be respected.
- All communities must assure that there is **equal access** and that activities must be fully accessible to all people with disabilities.
- All programs and services that are community-based must be physically located in a non-institutional setting in their community and be responsive to the needs identified by people with disabilities in that community.
- Individuals with disabilities are **not always “sick”** and may not require help from certified medical professionals for daily living.
- People learn and grow through **self-help**, discussing their needs, concerns, and issues with people who have had similar experiences
- Community-wide change activities, such as systemic **advocacy**, are needed to ensure that people with disabilities benefit from all that society has to offer.
- Programs and services must be **cross-disability** and stress the full equality and participation of all persons with disabilities, regardless of type or extent of disability.
- Architectural, communication and attitudinal **barrier removal** must occur to ensure that people are able to fully participate in their communities.

⁴ Developed by Bob Michaels with the assistance of the Illinois SILC and the European Network on Independent Living (2012).

- The organizations best suited to support and assist individuals with disabilities must be **consumer controlled**.
- All persons must have access to **community-based living** and no person should be institutionalized on the basis of a disability.
- Peer supporters (people with disabilities) are the individuals best suited to support, assist, and guide people with disabilities.
- All people have a right to confidentiality and the right to receive assistance without sacrificing their privacy.

Assignment

Think about the idea that “those who have a strong IL Philosophy also have a strong set of values” and answer the following questions on the class discussion board:

1. Do you think it’s possible to hold onto the principles of consumer control and equal access without valuing human rights? Why or why not?
2. Why is it important that your SILC have a strong philosophical base?
3. What is your responsibility as a member of the SILC to point out a philosophical inconsistency if you think you see one?

Sessions 7 and 8: Applying IL Principles in IL Planning

Plan for Sessions 7 and 8

- Examine a typical scenario that might face a SILC.
- Apply IL principles to a real life situation.

Hypothetical Scenarios in This and Subsequent Sessions

The following assignment involves the first scenario in this course. The scenarios will present you with dilemmas that test the application of the IL philosophy in real life situations faced every day by SILCs around the country. These scenarios are meant to challenge your thinking, asking you to make choices between the IL Movement's goals, your own values, and real-world challenges.

There are a couple of steps that you can take to make processing these scenarios more meaningful for you.

- First, visit the discussion group as often as possible. Don't restrict yourself to your initial response. You will benefit from reading and reacting to the views of others and they will gain from reading and reacting to yours, but the greatest benefit will be from the debate that ensues. Again, these scenarios work best if each of you feels free to comment on the responses of other students. Be liberal with your kudos, criticize constructively, and offer supportive suggestions.
- Second, enhance the experience by inviting your colleagues to discuss the scenario. Set up your own small group session. Form a circle, give everyone a copy of the scenario, have one participant read the scenario aloud, and answer the questions at the end. If you have more than one small group, add an extra 30 minutes for the large group to discuss and debate your respective answers.

Scenario: Justifying Your Methods

Peggy Ray is the recently-elected chair of the Statewide Independent Living Council. She has been a member of the SILC for three years and is excited about her chance to make an impact in the state on behalf of the disability community.

One of the biggest problems faced by the disability community is that people with disabilities just don't vote. This had become painfully evident when the head of the local union literally laughed at them when leaders in the disability community asked for support for the Medicaid Buy-In legislation. Peggy will never forget the look on the faces of the leaders as they realized that their legislation was finished.

Peggy smiled at what was about to happen. The first order of business that day was introducing Rita Watters from Voteget, Inc. Rita excitedly set out her plan to the members of the SILC so that it could be incorporated into the next State Plan for Independent Living (SPIL).

Each of the fifteen centers for independent living in the state would submit electronically the names and addresses of all of their consumers to Voteget, Inc. Voteget would then run the names and addresses through a database to determine who is registered to vote and who is not. In addition, Voteget would tell the CILs how often those that have registered actually vote.

“Think of what you will have,” Rita continued, “You’ll know who is not registered so you can send each of them an application—and even have volunteers make follow-up calls.” This was exciting to Peggy and many of the SILC members. The previous year, the centers in the state served almost 21,000 consumers in the state. “Just think of the impact we can have!” Peggy exclaimed.

Rita was even more convincing as she went on to explain how the more sophisticated people’s movements went a step further—they targeted people who had a track record of voting in every election. Finally, the SILC would be able to get policymakers to pay attention to its issues.

When asked about confidentiality, Rita assured them that the only ones who would have access to the information were Voteget and the CIL where the consumers received services.

Peggy went on to explain that Voteget will charge a flat rate of \$5000, or less than \$.25 per name submitted. The SILC would need to include the project in the SPIL they were about to complete. “I think the SILC should include this project in the SPIL and underwrite its cost. I will entertain a motion to that effect,” Peggy said.

“Just a minute,” interrupted Will Christopher, the CIL representative on the SILC. “Are you sure this is a good idea?” he asked.

Assignment

1. Read the above scenario, “Justifying your Methods;” answer the following questions; and post your answers to the discussion area.
 - Is the proposed project a good idea?
 - Would any IL principles be violated? If so, which ones?
 - What trade-offs would have to be made and are they worth it? Why or why not?
2. Respond to the comments of at least two of your peers.

Session 9: Applying IL Principles When Working with Policymakers

Plan for Session 9

- Consider how to integrate IL philosophy into the work SILCs do with policymakers.

Working with Policymakers

During the last few sessions, we explored the role that IL principles had in the development of IL philosophy. Now we are going to see how SILCs apply that philosophy when interacting with other leaders in the state or community. What do you do when you believe a policymaker is violating an IL principle? What if an agency's entire program is inconsistent with IL philosophy?

In considering situations that may occur within your state, let's explore some approaches to dealing with policymakers and how to work with them from an IL perspective. Then we will take a look at a program that violates IL philosophy on many levels.

When preparing to work with policymakers, it is important to remember that we need to first take a look at our own attitudes. If we enter into a discussion thinking that the other person is too dense to ever "get it," we set ourselves up for failure. Our chances for productive dialogue improve considerably if we stay open and assume that if policymakers were just exposed to our philosophy, they would understand.

A Few Words About What SILCs Can and Cannot Do with Federal Funds

The SILC may have numerous opportunities to observe the application of IL principles within the state and utilize that information when carrying out its statutory duties. Although this is not a course targeted to address the specific roles and responsibilities of the SILC, it will be helpful for you to know a little more about the range of possibilities for SILC action using federal funds; federal funding is the primary funding resource for SILCs.

The role of the SILC is outlined in *Purpose and Defined Duties of the SILC* on page 7 of this course manual. SILC actions must be consistent with these statutory duties.

Examples of how the SILC could influence larger state issues are shown in a TECHNICAL ASSISTANCE CIRCULAR issued by the Rehabilitation Services Administration.⁵ "For example, the SILC may fulfill an important role in demonstrating ways to expand and improve IL services through ongoing coordination with 'councils that address the needs of specific disability populations and issues' pursuant to Section 705(c)(3), or it may conduct studies and gather information as described in Section 705(c)(2) as a means to 'monitor, review, and evaluate the implementation of the [SPIL].'"

⁵ RSA-TAC-13-01.

Another example comes from federal regulations at 34 CFR 365.1, which sets out how Part B, the primary funding source for the SILC, may be used. Among the eight uses is:

- (f) 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 policy makers in order to enhance IL services for individuals with significant disabilities.

In the Technical Assistance Circular noted above, RSA stated, “The appropriateness of the SILC’s role in any of the activities identified in Section 713 must be evaluated on a case-by-case basis, depending on the nature and scope of the SILC involvement in a particular activity, to ensure the SILC is acting in accordance with duties described in Section 705 of the Rehabilitation Act.”

Over time, you’ll become much more familiar with regulations. For now, for the following exercises, it will be sufficient to understand that even within the SILC’s statutory duties, there are important opportunities for the SILC to have a powerful influence on the lives of people in your state.

Scenarios for This Session

These are typical situations that may occur within a state’s policy-making processes. As you respond, give special consideration to how the SILC might address issues such as this in its role of developing the Statewide Plan for Independent Living (SPIL) and in fulfilling its coordination responsibilities with other councils.

Scenario 1

Your state’s Department of Health is about to submit a waiver to set up personal assistance service (PAS) for people who are developmentally disabled and is asking for public input.

A parent suggests a “responsible party” should be involved, that supervision of the personal assistant be handled by the PAS agency, and that all training be completed prior to the first day of employment, without input from the consumer.

The executive director of the state’s nurses association suggests that a physician must prescribe the service at least annually and a nurse must oversee it.

A representative from a center for independent living points out that consumer-directed PAS (wherein the recipient of services plays a significant role in hiring, training, and supervising the personal assistant) is a proven option for people with developmental disabilities, often stated as a preference by consumers of CIL services. The advocate also recommends that the Department of Health review this option thoroughly before a new waiver is adopted.

Scenario 2

The governor has notified the state's Labor Department that the state will not build, as previously planned, the one-stop Workforce Development Center in a rural area of the state.

Because of the intense reaction from the community, the governor's staff has called a meeting of interested parties.

The Veterans Affairs representative complains that veterans now have to travel 200 miles to the nearest center.

The mayor of the small town protests that the loss of the new center means the loss of 25 jobs in his community.

The SILC representative reminds the governor's staff that the SILC, by law, must assess the needs of people with disabilities in the state and share the information with decision-makers such as the governor. The greatest need identified in the most recent assessment was employment. In addition, the SILC has identified that the current facility that must be used is inaccessible for many people with disabilities.

Assignment

1. Identify all of the IL principles that you believe have a role in an assessment of the two scenarios in this exercise and post your list on the discussion area.
2. Respond to the comments of at least two of your peers.

Sessions 10 and 11: Applying IL Principles When Assessing Statewide Needs

Plan for Sessions 10 and 11

- Analyze an example of philosophical differences that impact the IL planning process.
- Watch or listen to the video at <http://www.mnddc.org/parallels2/four/video/video44-tryanotherway.html>.

The SILC Planning Role

Statewide Independent Living Councils have an important role within their states to develop a State Plan for Independent Living. Before planning can begin, it is necessary to identify the needs of the independent living community for which the planning is undertaken. The SPIL's purpose is then to respond to those needs.

Understanding the needs of the disability community from an independent living perspective involves an ongoing analysis of individual preferences and goals, barriers, resources, laws, policies, and community practices. Being able to examine an issue in this multifaceted way is an important skill for all IL leaders to have. As a SILC member, you can maximize your effectiveness by staying current on the issues that affect the ability of people with disabilities to achieve leadership, empowerment, independence, productivity, and full integration into the mainstream of American society.

In this session we are going to examine one example of a policy and community practice that is at odds with independent living philosophy. After you read it and watch the video, give thoughtful consideration to how your SILC might address this in your state within the designated duties and purpose of the Council.

Example Philosophical Situation

In March 2011, Samuel R. Bagenstos, the Principal Deputy Assistant Attorney General in the Civil Rights Division of the U.S. Department of Justice, cited a National Disability Rights Network report that explicitly criticized sheltered workshops. Citing *Olmstead v. L.C.*, he argued that “a full and equal life in the community—the ultimate goal of *Olmstead*—cannot be achieved without a meaningful, integrated way to spend the day, including integrated ‘work options.’” Bagenstos further stated:

When individuals with disabilities spend years—indeed, decades—in congregate programs doing so-called jobs like these, yet do not learn any real vocational skills, we should not lightly conclude that it is the disability that is the problem. Rather, the programs’ failure to teach any significant, job-market-relevant skills leaves their clients stuck. As a recent review of the literature concludes, “[t]he ineffectiveness of sheltered workshops for helping individuals progress to competitive employment is well established.”

It is generally the position of the IL Movement that people with disabilities do not need segregated environments of any kind. In the case of employment, they need real jobs with real wages.

Sheltered workshops exist today because certain leaders in habilitation continue to perpetuate the idea that employment in segregated settings at sub-minimum wages is appropriate. They believe that “certain” people with disabilities will never be employable in the traditional sense and, therefore, need this protected, artificial environment.

Advocates of integrated work point out that the operators of these sheltered workshops could, in fact, pay a higher wage since they usually receive funding from the state for each of the participants in addition to the dollars they get for their contracts. Unfortunately, the philosophical position of sheltered workshop operators often influences family members to make choices out of fear rather than rational assessment of the needs, abilities, and choices of program participants. Family members may thus make decisions out of “relief” that the family member has any program at all.

Forty years ago, the late Marc Gold created a method for training people who were labeled profoundly retarded called *Try Another Way*. Essentially, Marc felt that if tasks were broken down to their smallest steps, anybody can learn anything. Marc demonstrated how to do this by teaching a person with profound retardation that he had never met before how to assemble a bicycle brake. His students became so adept at this that Bendix used to hire them.

The vast majority of those in the disability community are employable and eager to work, and by allowing this exception, society perpetuates the negative stereotype that people with disabilities are less capable than the rest of civilization.

When we discover segregated facilities in third-world countries where the workers earn a pittance and have no hope of advancement, we call them “sweatshops,” yet we have a lower standard for some of our own citizens.

If the private and government entities that are contracting with the sheltered workshops needed to look elsewhere for this work to be done, would they be able to bypass our minimum wage law? Maybe it’s time to renegotiate their contracts and start giving these employees with disabilities a respectable wage. One goal of the IL Movement might be to ensure that every worker is given real pay that is commensurate with the work they do and to ensure that it is done in an integrated environment. Of course, there are individuals who lack the skills necessary to compete in the workforce, but unless people are given opportunities to learn skills and have access to other options, they may never have any choice in the matter.

It is important to acknowledge that the people who run these sheltered workshops aren’t bad people any more than the family members who desperately want six hours of day care for their relative. However, the IL Movement can shine a light on this inequitable practice by offering IL Principles as an alternative.

Assignment

1. Review the example (above) for this session.
2. Which IL Principles are being violated when we put someone in a sheltered workshop?
3. Do you agree with Mr. Bagenstos (who is quoted in the example) that the ultimate goal of Olmstead cannot be achieved without a meaningful, integrated way to spend the day, including integrated “work options?” Why or why not?
4. If the elimination of sheltered employment were a priority in your state, what might the SILC do to address this in the SPIL?

Sessions 12 and 13: Applying IL Principles as a Tool for Collaboration with the DSU

Plan for Sessions 12 and 13

- Examine a typical scenario involving collaboration with the DSU that a SILC might face.
- Apply IL Principles to a real-life situation.

Scenario

The following is another scenario, presenting a real-life situation with the DSU, which could provide an opportunity to consider the application of the IL philosophy. As you read it, keep in mind the IL Principles presented in Session Five. Also keep in mind the importance of learning how to frame the message of IL so that collaboration between the SILC and the DSU can be most effective.

Maryanne has been on the SILC for 15 months. She is the executive director of a moderately-sized CIL and is the CIL representative on the SILC.

The Council conducted several surveys and focus groups as part of their needs assessment effort and followed that up with many hours of discussion as a prelude to developing their next SPIL. The SILC concluded that its top priority should be the development of a new center in an unserved area in the northwest part of the state.

It is unlikely that there will be increases in federal funds (Part C) large enough to start a new center. Plus, because of a fiscal crisis in the state, no state general funds will be available. After considerable deliberation, the SILC decided to set aside \$250,000 in Part B dollars in each of the next three years. The balance of the Part B funds would help defray SILC's operation expenses.

When this plan was presented at the next meeting, Jim Myers, the head of the designated state unit (DSU), objected. For years, the DSU had been using 75% of these funds for specialized rehabilitation counselors to buy wheelchairs for people who were not considered eligible for vocational rehabilitation services. Jim wanted to continue using the funds as they had in the past and cited the fact that last year they served almost 400 clients.

Maryanne became upset. Jim had been present at the previous meetings and had plenty of time to object. "If this center is successful," she explained, "they will serve at least that number, plus they will be able to provide ongoing services that promote community-based living. If we continue to put money into the DSU's wheelchair program, instead of learning about self-help, consumers will only learn how to rely on government programs."

Assignment

1. Review the scenario for this session.
2. Using the list of principles in Session Six on page 17, what other arguments might Maryanne make in favor of a new center?
3. Using that same set of principles, what other arguments might Maryanne make against Jim's proposal?
4. Why is it important for SILCs to have a process for identifying needs?
5. What steps could the SILC take to enhance communication and collaboration with the DSU?
6. Respond to the comments of your peers.

Sessions 14 and 15: Final Assignment—Set Some Personal Goals

Plan for Sessions 14 and 15

- Consider your personal goals for developing your knowledge of IL history and philosophy.
- Identify and share two objectives toward increasing your knowledge of IL history and philosophy.

Closing Sessions

These two sessions contain the final requirement for this course and must be finished in order to receive a certificate of completion. Using information covered in this course, you will create a plan that describes what you will do to increase your knowledge of IL history and philosophy. The Appendix includes a list of resources to help you with the assignment. You may also want to refer back to the list of resources in the future whenever you want a refresher. The education never stops.

Assignment

Increasing My Knowledge of IL History and Philosophy

1. Write two clear, measurable, outcome-oriented statements with target dates that describe what you will do to increase your knowledge of both IL history and IL philosophy. See the examples below.
2. Post your plan in the discussion area. The instructor will respond to each plan that is posted before the end of the course. Provide constructive feedback to your classmates. Please respect confidentiality.
3. Complete and submit the post-course survey and End of Course satisfaction survey.

Examples of Outcome-Oriented Statements for Assignment

Here are two examples of outcome-oriented statements that describe what you might do to increase your knowledge of both IL history and IL philosophy.

1. IL History: I will read “History of Independent Living,” written by Gina McDonald and Mike Oxford, by Feb. 28.
2. IL Philosophy: I will attend the Association of Programs for Rural Independent Living (APRIL) Conference by Dec. 1.

Appendix: IL History and Philosophy Resources

The following is a list of resources developed by Independent Living Research Utilization and Utah State University Center for Persons with Disabilities as part of the Study Guide that accompanies the four videos on Independent Living History and Philosophy.

Independent Living History

Beyond Affliction: The Disability History Project

This four-hour documentary radio series describes the shared experiences of people with disabilities and their families since the beginning of the 19th century. This website includes excerpts from the series as well as many of the primary source documents—extended interviews, images, and texts—from which the on-air programs were developed: <http://www.npr.org/programs/disability/>.

Disability History Museum

Disability, like race and gender, is a central part of the human experience. The museum's goal is to create a theme-based, searchable collection of primary source materials that will help expand knowledge and understanding about the historical experience of people with disabilities in the United States. The Disability History Museum's Library is a digital archive that only exists online. It contains digital versions of images, texts, and other artifacts related to disability history that have been gathered from libraries and private collections across the country: <http://www.disabilitymuseum.org/lib/>.

The Disability History Dateline

A project of San Francisco State University's Institute on Disability, this ever-expanding chronology encompasses all aspects of the history of disability: major events, issues and themes, prominent individuals and organizations, cultural expressions and images, laws and public policies, activist and advocacy efforts, and more. The entries cover all historical eras and every geographical region, as well as referring to both disability-specific and cross-disability historical occurrences. Although many of the current entries have a U.S. focus, the dateline is and increasingly will become world historical in scope: <http://www.sfsu.edu/~dprc/chronology/chron70s.html>.

About the Brown v. Board of Education Case

Five legal cases, under the heading of *Brown v. Board of Education*, sought the same solution—to tear down the legal basis for racial segregation in schools and other public places. The Supreme Court's decision in 1954 drastically altered the future policies of human rights and changed the course of history: <http://brownvboard.org/summary>.

Challenging Views on Euthanasia and Other Ethical Issues

This book contains writings from Peter Singer, a philosopher of bioethics at Princeton University's Center for Human Values. It discusses his challenging views on animal rights, environmental accountability, abortion, euthanasia, and other ethical issues including the killing of unwanted neonates born with severe disabilities. Singer, Peter (2000). *Writings on an Ethical Life*. New York: Ecco Press.

Unspeakable Conversations: Harriet McBryde Johnson

Reflections by a disability activist and attorney from South Carolina who participated in a debate with Peter Singer, professor at Princeton University, on issues of ethics and disabilities: <http://www.racematters.org/harrietmcbrydejohnson.htm>.

Getting Life: A Novel

Getting Life offers a rare glimpse behind the closed doors of long-term care. This fictional story draws readers into the wheelchair of Emily Mason, a 35-year-old nonverbal woman with cerebral palsy, and allows you to share each of her experiences—painful, thrilling, or confusing as she struggles to leave the nursing home behind and join the community. Cole, Julie Shaw (2000). *Getting Life*. Louisville: Avocado Press.

Not Dead Yet

Many people are unaware that Hitler's extermination policies began with the large-scale elimination of people with disabilities. Proponents of physician-assisted suicide are offended by references to this piece of disability history in the course of debate over the so-called "right to die." The fact is that Hitler stole most of his ideas on eugenics from publications originating in the U.S. Not Dead Yet is an organization that opposes legalized assisted suicide: <http://www.notdeadyet.org/>.

A Disability History of the U.S.

This new book proclaims to be the first to cover disability history from before 1492 to the present. Compelling stories from primary documents retell disability history through the people who lived it. The author writes, "Disability is our story, the story of someone we love, the story of whom we may become, and it is undoubtedly the story of our nation." Nielsen, Kim (2012). *A Disability History of the U.S.* Boston, MA: Beacon.

What Have We Done: An Oral History of the Disability Rights Movement

Author Fred Pelka, an independent scholar, documents the disability rights movement in this 592-page book through the words and stories of activists and leaders. The book begins with stories of people who grew up with disabilities in the 1940s and '50s. It includes how activists transformed the way that people with disabilities are viewed and how various streams came together to push through the Americans with Disabilities Act.

Pelka, Fred (2012). *What Have We Done: An Oral History of the Disability Rights Movement*. Amherst: University of Massachusetts Press.

The Emergence of Independent Living

Disability Rights Movement

More than a history, *The Disability Rights Movement* documents the wrenching evolution of attitudes: from isolation and charity to confrontation and rights; from sheltered workshops to independent living; from telethons of pity to technology's power; from "cripples" and "invalids" to People with disabilities! Fleischer and Zames capture the substance and spirit of the disability rights movement and bring it to life. Fleischer, D., & Zames, F. (2001). *The Disability Rights Movement: From Charity to Confrontation*. Philadelphia: Temple University.

The History of the ADA: A Movement Perspective

This brief history of the ADA and the Disability Rights movement, written by Arlene Mayerson, explains the barriers faced politically and socially. Disability advocates fighting for the rights of those with disabilities faced many challenges in passage of the ADA: http://www.dredf.org/publications/ada_history.shtml.

History of the Disability Rights Movement through Stories

Shapiro, a *U.S. News & World Report* journalist, explores in depth the thoughts, fears, and facts behind the disability rights movement. The premise throughout this compelling historical account is that there is no pity or tragedy in disability—it is society's myths, fears, and stereotypes that make being disabled difficult. Shapiro's coverage is thorough, ranging from the movement's beginnings in Berkeley in the 1960s to the issues that will emerge in the future. Shapiro, Joseph (1993). *No Pity*, Temple University Press.

Origins of IL Model

DeJong proposed a shift from the medical model to the independent living model. This theory located problems or "deficiencies" in the society, not the individual. The answers were to be found in changing society, not people with disabilities. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional. DeJong, Gerben (2007). "Defining and Implementing the Independent Living Concept." A chapter in *Major Themes on Health and Social Welfare*. Nicholas Watson, ed. Oxford: Routledge, Taylor & Francis Group. Reprinted from lead chapter in *Independent Living in America*, Nancy M. Crewe and Irving K. Zola, eds., San Francisco: Jossey-Bass, Inc., 4-27 (1983) which was reprinted from article published in *Archives of Physical Medicine and Rehabilitation*, 60 (October 1979), 435-446.

Emergence of the Independent Living Movement

As with most major social changes or phenomena, the IL movement did not happen overnight in the U.S. There were many significant events in the 1960s and the 1970s that led to its rise and continue to shape its ongoing transition and growth:
http://www.disabilityworld.org/09-10_03/il/ilhistory.shtml.

Impact of Polio

This page from the Smithsonian National Museum of American History site indicates polio was the most notorious disease of the 20th century until AIDS appeared. On April 12, 1955, it was announced that Jonas Salk, using March of Dimes donations from millions of people, had developed a vaccine to prevent polio:
<http://americanhistory.si.edu/polio/howpolio/disability.htm>.

A Remembrance of Justin Dart

This obituary of Justin Dart, considered by many to be the disability rights community's greatest leader, was written by Fred Faye and Fred Pelka. Among his many accomplishments, contributions, and honors, Dart gave life to Justice for All and personally funded its development from 1995 to July 2001. His role in the conceptualization and writing of the ADA is discussed as well as tributes from others in the disability community. The obituary ends with an empowering farewell statement to all advocates, written by Dart, who died June 22, 2002:
http://www.disabilityhistory.org/people_dart.html#jdoit.

Concept of "Normalization"

Wolfensberger's critique of human services and his teachings about the way in which people with disabilities are systematically devalued by the culture give us different insights into our role in the way people with disabilities are treated and viewed in society. Wolfensberger, Wolf (1972). *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation.

Codification of Independent Living

A Medicaid Victory

The story of Nick Dupree was broadcast on National Public Radio by Joseph Shapiro. Listen and read about Nick's battle against Alabama Medicaid to get in-home and community supports after he turned 22.
<http://www.npr.org/templates/story/story.php?storyId=974391>.

Useful Guide on Medicare and Medicaid for People with Disabilities

This guide explains the critical role Medicare and Medicaid have in the lives and the futures of children, adults, and seniors with disabilities. It gives people with disabilities useful information to help them get the most from these programs. *Navigating Medicare*

and Medicaid, 2005: A Resource Guide for People with Disabilities, Their Families, and Their Advocates is published by the Kaiser Family Foundation:
<http://www.kff.org/medicare/index.cfm>.

Terms and Leaders in the Independent Living Movement.

This guide defines commonly used acronyms and terms used in discussing disability, such as IDEA, ADAPT, OSERS, and ADAAG, IL philosophy and advocacy. It also has brief bios of disability leaders, such as Ed Roberts, Judy Heumann, Justin Dart, and Kyle Glozier. *IL 101 - Terms and Leaders in the Independent Living Movement* (2002):
http://www.ilru.org/html/publications/training_manuals/IL101.pdf.

Brief History of IL and Comparison Chart of Rehabilitation and Independent Living

An article by Maggie Shreve provides a brief history, the difference in philosophy between rehabilitation and IL, and a simple chart that compares the rehabilitation and the IL paradigms. This chart summarizes the major differences between these perspectives on disability: www.ilru.org/html/publications/infopaks/IL_paradigm.doc.

Disability Studies as a Field of Study

Claiming Disability is the first comprehensive examination of Disability Studies as a field of inquiry. Disability Studies is not simply about the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing, but the meaning we make of those variations. With imagery and examples, Simi Linton explores the divisions society creates—the normal versus the pathological, the competent citizen versus the ward of the state. Linton, Simi (1995). *Claiming Disability: Knowledge and Identity*, New York University Press.

Disability Studies Perspective on Independent Living

Author Paul Longmore was one of the most respected figures in disability studies. In this book he urges establishing disability as a category of social, political, and historical analysis similar to the way that race, gender, and class have been. The essays search for the pattern of systemic prejudice and probe into the institutionalized discrimination that affects Americans with disabilities. His essays on bioethics and public policy examine the conflict of agendas between disability rights activists and policy makers, healthcare professionals, euthanasia advocates, and medical bureaucracies. Longmore, Paul K. (2003) "Chapter 5: The Disability Rights Movement Activism in the 1970s and Beyond." *Why I Burned My Book and Other Essays on Disability*. Temple University Press.

Consumer Control

This journal article examines the empirical evidence for consumer-directed services at home for persons with disabilities. It addresses responsibility for key service decisions, management of home care services, and the impact of consumer direction. Benjamin,

A.E. (December 2001). Consumer-directed Services at Home: A New Model for Persons with Disabilities, *Health Affairs*, 20:6.

Involving Consumers in Quality Improvement

This document was an outgrowth of the Cash and Counseling demonstration projects. It presents specific approaches for assuring and improving quality of consumer-directed services, and provides resources and information for how to involve consumers as active participants in quality improvement. Produced by the Scripps Gerontology Center at Miami University. *A Guide to Quality in Consumer Directed Services* (2004).

<http://www.hcbs.org/files/43/2100/Guidefronts.html> (text)

<http://www.hcbs.org/files/42/2099/Guidefront.pdf> (PDF).

DisabilityInfo.gov

The federal government's one-stop website for information of interest to people with disabilities, their families, employers, service providers and many others. Topics include: employment, education, housing, transportation, health, technology, community life, and civil rights. www.disabilityinfo.gov.

Nothing about Us without Us: Disability Oppression and Empowerment

James Charlton weaves stunning oral histories of disability activists from ten different countries across five continents. The author argues that barriers to independent living are embedded in the larger social and economic environment. This political manifesto obtains its energy from the author's commitment, anger, and outrage. Charlton, James (1998). *Nothing about Us without Us: Disability Oppression and Empowerment*. University of California Press.

Guide to Disability Rights Laws.

Concise summaries of all federal disability rights laws, including the Americans with Disabilities Act, Fair Housing Act, Air Carrier Access Act, Telecommunications Act, Architectural Barriers Act, and Individuals with Disabilities Education Act produced by the U.S. Department of Justice. *A Guide to Disability Rights Laws* (September, 2005). <http://www.usdoj.gov/crt/ada/cguide.htm>.

Disability Policy Framework and Advocacy

Original Disability Policy Framework

Read Bobby Silverstein's original article outlining his famous Disability Policy Framework. The framework can be used as a guide to evaluate generic, as well as disability-specific, public policies and programs to ensure meaningful inclusion of people with disabilities in mainstream society. *Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy*. *Iowa Law Review*, August 2000, Volume 85, No 5. http://disability.law.uiowa.edu/csadp_docs/ILR0800.txt (text file)
http://www.communityinclusion.org/article.php?article_id=82 (MS Word file).

Major Disability Legislation

In the appendix of this famous article, Silverstein lists the major disability related legislation from 1956-2000. *Iowa Law Review*, August 2000, Vol. 85/No. 5.
http://disability.law.uiowa.edu/csadp_docs/APPENDIX_2_APR.txt (text file)
http://disability.law.uiowa.edu/csadp_docs/APPENDIX_2_APR.doc (MS Word file).

Controversy over the Use of Statistics and Data

This article connects standard research methodology concepts with the complexities of evaluating disability policy using national data sets. The article provides a practical framework for assessing the adequacy of research regarding the employment rate of persons with disabilities. Silverstein, Robert, Julnes, George, and Nolan, Renee (June 2005). What Policymakers Need and Must Demand from Research Regarding the Employment Rate of Persons with Disabilities. *Behavioral Sciences and the Law*, Volume 23, Issue 3, pages 399-448. John Wiley & Sons, Ltd.
<http://www.disabilitypolicycenter.org/disabpol.htm>.

The Framework and Intellectual Disabilities

This book analyzes human rights and disability rights—the global struggle to realize equality, dignity, and comprehensive human and civil rights for persons with intellectual disabilities. In this chapter Bobby Silverstein applies his framework to an analysis of U.S. legislation. Silverstein, Robert (2003). “Chapter 11: Statutory Changes in Disability Policy: Types of Legislation, Policies, and Goals” in *The Human Rights of Persons with Intellectual Disabilities: Different But Equal*, Stanley S. Herr, Ed. Oxford University Press.

Sound and Fury: Cochlear Implants

A PBS documentary discusses the cochlear implant controversy. Since it was first approved for testing in 1985, the cochlear implant has been engulfed in a storm of controversy. Does the cochlear implant pose a serious threat to Deaf culture? Can people with the implant function effectively as members of the hearing world? Do the results justify the expense of surgery and therapy? Two advocates for people with hearing impairments discuss these issues.
<http://www.pbs.org/wnet/soundandfury/cochlear/debate.html>.

State Work Incentive Initiatives

The site includes descriptions of the numbers and characteristics of persons with significant disabilities; descriptions of federal law (including the Ticket to Work and Work Incentives Improvement Act); model state legislation; descriptions of cross-disability executive and legislative initiatives; initial planning information gathering and program and fiscal estimates; state work incentives policy options (Medicaid Buy-In, Medicaid Waivers, and Income Assistance Demonstrations); and emerging implementation. A Resource Center for Developing and Implementing Medicaid Buy-In and Related

Employment Programs for Persons with Disabilities.
<http://www.uiowa.edu/~lhpdc/work/index.html>.

Nursing Home Transition

This website provides a wealth of resources to help with moving people with disabilities from nursing homes into the community. You can search by topic, type of resource (manual, tool, etc.) or by state. Michigan's "Going Home" is a particularly good resource on this topic. www.hcbs.org.

A Twenty-five Year History of the IDEA

<http://www.ed.gov/policy/speced/leg/idea/history.html>.

History and Current status of the Developmental Disabilities Act

http://www.md-council.org/about/dd_act.html.

Read the Original Supreme Court Olmstead Decision

In the U.S. Supreme Court Decision, *Olmstead v. L.C. and E.W.*, the Court decided that the State of Georgia was discriminating against Lois Curtis and Elaine Wilson by not allowing them to leave the state institution and have supports to live in the community. The full text of the Supreme Court decision is at <http://www.law.cornell.edu/supremecourt/text/98-536>.

Enforcing and Implementing Olmstead

This page provides materials and recordings of IL-NET trainings on *Olmstead* implementation:
http://wiki.ilru.net/index.php?title=Enforcing_and_Implementing_Olmstead.

Personal Assistance Services (PAS) Policy and Practices

The website for the Center for Personal Assistance Services is a good place to find the latest information on personal assistance services (PAS) in the United States. It addresses issues such as the relationship between formal and informal PAS; support for caregivers; the role of assistive technology (AT) in complementing PAS; policies and programs, barriers, and new models for PAS in the home and community; PAS Workforce development, recruitment, retention, and benefits; and workplace models of formal and informal PAS and AT at work. www.pascenter.org/home/index.php.

Advocacy Organizations and Information Networks

ADAPT

American Disabled for Attendant Programs Today (ADAPT) website advocating for people with disabilities to live in the community with supports instead of nursing homes. www.adapt.org/

The Disability Rights Education and Defense Fund

DREDF is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and the education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities. www.dredf.org/

Bazelon Center for Mental Health Law (BCMHL)

The Bazelon Center is a national legal human rights advocate for people with mental disabilities. Through precedent-setting litigation in the public policy arena, the BCMHL works to advance and preserve the rights of people with mental illnesses and developmental disabilities. <http://www.bazelon.org>

Center for Self-Determination

A center that is a highly interactive working collaborative of individuals and organizations committed to the principles of self-determination. The purpose of the collaborative is to change the nature of the support and service system for individuals with disabilities, using the principles of self-determination to help all persons create the lives they want, connected to and with their communities. <http://www.self-determination.com>

National Disability Rights Network

The National Disability Rights Network represents the needs of Protection and Advocacy Agencies (P&As) and Client Assistance Programs (CAPs) to federal agencies and Congress. It also provides training and technical assistance to member agencies, which helps their effectiveness on the state and local level. This is an excellent site for current legislative activities. <http://www.ndrn.org/>

The Ragged Edge

Ragged Edge magazine is successor to the award-winning periodical, *The Disability Rag*. It includes today's writing about society's "ragged edge" issues: medical rationing, genetic discrimination, assisted suicide, long-term care, attendant services. It covers the disability experience in America—what it means to be a "crip" living at the start of the 21st century. <http://www.raggededgemagazine.com/>