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Guiding Your Independent Living Organization

*A Workbook for
Active Decision Makers
in the Independent
Living Movement*

Tom Seekins, Roger Keffer, and James Budde
The Research and Training Center
on Independent Living

Foreward to Orientation Coordinators

**An Introduction to the Purpose,
Organization, and Use of
“Guiding Your
Independent Living Organization”**

**Tom Seekins, Roger Keffer, and James Budde
The Research and Training Center on Independent Living
The University of Kansas
Lawrence, Kansas**

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The Problem of Orientation and Organizational Renewal

Many people have pointed out the difficulty of orienting new participants to the independent living (IL) movement. Executive directors, board members of consumer groups, and state advisory council staff have all expressed their concern. They have found it frustrating to try to communicate a sense of their organization's common goals and the roles its members play.

In response to this problem, the Research and Training Center on Independent Living has developed a workbook entitled Guiding Your Independent Living Organization. It offers a systematic approach to presenting basic ideas about independent living. It provides information about a particular organization and demonstrates how to conduct periodic reviews.

This pamphlet describes how an organization can use the workbook.

Intended Readers

This workbook is primarily a tool for orienting new participants into the IL movement. Some may have had more experience with a disability and less with community organizations, while it may be the opposite for others. The workbook is divided into sections that introduce the basic ideas of independent living and community organization to those who lack experience in these areas. It can also be useful to experienced members of newer or developing organizations. We hope that the workbook will be useful to all

those who are involved in independent living organizations, including those who have been in the field for a long time.

Benefits

The workbook has several benefits. First, it is designed specifically for independent living (IL) organizations. Other tools for organizational development are often too general or designed for other populations. Second, the workbook presents standard information concerning independent living. This information will help participants in your organization gain a broader understanding of the movement, even if there are points about which you may disagree. Third, the workbook is designed specifically to encourage debate about basic ideas involved in the IL movement and the operation of IL organizations. Fourth, we recognize that each organization is unique. The workbook provides a number of places to describe the characteristics of your local center. Fifth, the workbook and this pamphlet are designed to help conduct organizational development sessions. In short, both provide IL organizations with a simple package for orienting new members and maintaining a common understanding of the organization's goals and the roles its members play.

An Overview of the Workbook

The workbook is designed to help decision makers of local IL organizations orient new members to the organization and maintain a common understanding of both the organization and the roles its members play.

Anyone making decisions that affect how one or more persons with disabilities can share in human society needs to review--and often redefine--both what one is trying to do and how one goes about doing it. Further, any group organized to promote independent living--whether local, regional, national, passive monitoring group, support group, advocacy group, or active service program, publicly or privately supported--must pause from time to time to ensure that its efforts are effective and its goals worthwhile. We have tried to fashion a tool to make frequent organizational renewal easier and more meaningful to you, whether you have recently joined an IL organization or you have served long and hard throughout its development.

Each workbook section clarifies basic ideas about tasks facing organizations. It is followed by Topics for Reflection and Discussion. Topics are designed to encourage discussion about the basic ideas presented in the section. In addition, several uncompleted TABLES will help you define--and redefine--important policy decisions of your organization. Active consideration of these topics and completion of the TABLES--the "work" in this workbook--will amount to a thorough review of your organization.

We hope the workbook will fill important needs for guidance in operating IL organizations. The first chapter starts with a look at what is meant by independent living. Organizations that have been developed to foster independent living are reviewed, and methods for determining needs and setting priorities are discussed. How persons with disabilities can take part in society at large, and especially in independent living organizations, is also examined.

Chapter II goes into organization in more detail. First, it shows what forms IL organizations may take, how each might best fit different levels of community awareness and support, and how these forms may lead from one to another. Next, it looks closer to see how authority and responsibility may be shared by governing and advisory boards, full-time staff, and committees. The chapter also explains how the progress of an IL organization can be evaluated.

A third chapter talks about available resources--the tools, materials, and collaboration networks you use to promote independent living in your community. It begins with a review of current national laws directly affecting independent living and independent living organizations. Next, it considers funding sources and how funds are used.

Chapter IV discusses the details of your organization. The important documents of the organization, such as the bylaws, should be inserted in this section. Three Appendices are included. Appendix 1 lists and defines

services and activities of independent living centers. This is intended to offer a quick overview of the range of potential center activities.

Appendix 2 provides a glossary of terms frequently encountered by those active in the IL movement. A number of orientation coordinators have commented on its usefulness in the orientation process.

Finally, a list of suggested readings is offered. These readings are selected to provide a more comprehensive understanding of independent living and to provide approaches to solving particular problems.

A systematic review of ends and means is needed time and again throughout an IL organization's life. It becomes, of course, the main focus when founding your IL organization. In addition, each new member, director, or staffperson must be "ORIENTED"--made familiar with the basics of your operation. Further, many funding sources require thorough analysis of your overall program and purposes. Finally, everyone active in your organization should have periodic chances to help renew your organization and his or her personal commitment to it.

Using the Workbook

We recommend that a committee (if you choose to call it such) of one or more of your members be assigned responsibility for organizational orientation and development (OD) activities. This OD committee should plan and develop enough OD activities to keep your IL organization current and

every member fully informed. It should decide, among other things, how to make best use of material in this workbook. Here are a few suggestions:

The TABLES must be completed to tailor this workbook to your organization. You can do this in several ways.

If you are forming a new organization, you can give each member a copy to read, asking him or her to complete each TABLE. As members debate the issues and return completed TABLES, you can prepare and hand out a tentative, and later an operating, set of TABLES based on these discussions. We have three-hole-punched and carefully arranged these pages to make loose-leaf handling simpler.

If you are just beginning to form an IL organization, you may be able to use these operating TABLES as guides to writing your formal documents. After your IL organization begins operating its OD committee, it should see that every member, new and old, has a current copy of what has now become your organization's individualized workbook. Un-completed TABLES may be replaced by completed ones. Alternatively, they may be used as exercises to help focus group discussions during organizational renewal sessions.

If your IL organization has been established, the "Topics for Reflection and Discussion" become your most active tool. Many topics are already frequently discussed, but periodic

open discussion may improve everyone's understanding of your organization. Your OD committee should, therefore, prompt and arrange OD activities. You can do it by reserving parts of regularly scheduled meetings to discuss these important, often decisive, organizational issues.

Or, you can set up annual OD workshops or weekend retreats to study them in depth. In any case, you must tailor your OD activities to needs and capabilities of your organization.

Tailoring the Workbook to Your Organization

A number of the workbook chapters require you to provide information about your center. These chapters and the information needed are listed below. Forms for presenting this information are provided in each of the sections:

In Chapter I, Section 4, you will need to indicate the purpose of your organization and its major goals.

In Chapter II, Section 2, you will need to indicate who has responsibility for performing various organizational tasks.

In Chapter II, Section 3, you will need to list the committees that operate within your organization.

In Chapter I, Section 3, you will need to list and describe the services your organization provides.

Appendix 1, A Services Compendium for Independent Living, is designed to help you complete this task. It lists typical services and their common definitions.

In Chapter I, Section 4, you must describe the information your organization has collected about the number of disabled residents in your community and the needs they have expressed.

In Chapter III, Section 1, you are to describe the cooperative relationships you have developed with other organizations. You are also asked to describe how your organization is unique.

In Chapter III, Section 3, you will need to list the amounts of money your organization has received, receives, or plans to receive from different sources. You are asked to present a budget of how organizational funds are spent.

In Chapter IV, you will be asked to identify staff and board members and briefly describe their responsibilities. In addition, this section asks you to provide a number of important organizational documents such as its bylaws.

Discussion Sessions for Orientation and Development

There are eight discussion sessions that can be organized around the workbook. The Discussion Guide that follows lists the topic of each session and the sections of the workbook that provide basic information about the topic.

You may want to supplement the information contained in the workbook with information about your organization. You may also provide other information you have found useful in considering the topic.

You should schedule each session in advance. For example, you may have a discussion session announced in the agenda for a future meeting. You might also refer members to appropriate sections of their workbooks, so they can have an opportunity to review material and prepare for discussion.

The Discussion Guide lists each session, a challenge related to the topic, and pertinent questions to prompt discussion. At the beginning of each session, you might remind participants of the topic being discussed, read the challenge, and ask the discussion question you feel would provide the most interesting and fruitful discussion.

If the discussion around the topic and question seems slow or seems to come to an end, you might ask another question. Alternatively, you might ask participants if they have any questions about the topic.

Finally, you may find it worthwhile to keep a log of the discussion sessions. This involves summarizing the basic points made during the

discussion. Such a log can help orient new members and may prompt action relative to your discussion.

BRIEF DISCUSSION GUIDE

Session Topic and Challenge

Consumerism: Consumers should be involved in our center to the maximum extent possible. (Chapter I: Sections 1, 2, and 5. Chapter II: Section 1.)

Recruiting: The ideal board or committee is a balance of talent, experience, and action. (Chapter III: Section 4.)

Determining Needs and Setting Priorities: The organization must continually adapt to changing requirements of independent living in the community (Chapter I: Section 4.)

Task Roles and Responsibilities
Responsibilities for the operations of an organization must be shared in a manner that promotes effectiveness. (Chapter II: Sections 2 and 3.)

Questions to Prompt Discussion

Who are the consumers of the organization? How are they involved in the organization? What obstacles exist to greater consumer involvement? How can consumer participation be made more meaningful?

Are there enough members? How many members have experience as consumers? Do members represent a diverse background? If you were to add a new member, what characteristics should the member have?

How are priority concerns of consumers determined? Do these methods present a complete picture of need? What is left out? What other informational methods might add to your understanding of your community's independent living needs and priorities.

Are the separate tasks of the governing board, etc. understood by everyone? Are the tasks performed effectively? Are there areas of tension over responsibility or authority? What are the criteria for different groups taking action? How are the agendas of meetings determined? Does everyone have access to the agenda and other important information?

Resources: Money is important, but it is not the only important resource. (Chapter III: Sections 1, 2, and 3.)

Programs and Services: Independent living organizations should provide only those services not provided by others. (Chapter I: Sections 3, Appendix 1.)

Networking: One responsibility of independent living organizations is to act as advocates to improve community life so independent living becomes more possible. (Chapter III: Section 1. Chapter I: Section 2.)

What organizations are not doing something for independent living in the community? How can seemingly unrelated programs/organizations be linked together in a way that facilitates independent living? What laws has the organization used for funding or advocacy? Has the organization created any laws or local ordinances that facilitate independent living? What current services are at risk because of lack of funding? What new services or programs need to be funded? How can funds for these programs be raised?

Does your organization focus on commonly shared needs of many disability groups or just one? What role do consumers play in providing services? How does the organization encourage other agencies to serve citizens with disabilities? How is the organization trying to "work itself out of a job?"

How does the organization work with human services agencies in the community? How does it work with private business? Local government units? Who else should you know from these sectors? What other organizations in the area are engaged in similar activities? How might you cooperate? How can you contribute to the success of other organizations working to facilitate independent living? How do you honor those who have done something to promote independent living? How are consumers involved?

Policy Review: The organization must adapt to changes in the community and changes in the priorities of citizens with disabilities. (Organizational bylaws, policies and procedures.)

What politics are outdated or need clarification? What policies have worked well? What new policies are needed? How are consumers involved in organizational policy and review?

Guiding Your Independent Living Organization

**A Workbook for
Active Decision Makers
in the
Independent Living Movement**

**Tom Seekins, Roger Keffer, and James Budde
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The University of Kansas
Lawrence, Kansas**

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PREFACE

Many people have pointed out the difficulty of orienting new participants to the independent living (IL) movement. Executive directors, board members of consumer groups, and state advisory council staff have all expressed their concern. They have found it frustrating to try to communicate a sense of their organization's goals and the roles its members play.

This workbook was designed to meet those needs. First, it helps orient new participants to IL goals, in general, and to their local organization and its operations. Second, it will help boards and committees do periodic reviews of their organization's structure and operation.

One way to learn more about the IL movement is to review the growing number of excellent publications, many of which are listed as suggested readings at the end of the workbook. We hope these materials, in combination with the workbook, will be helpful.

Because the IL movement includes people of varied backgrounds and experiences, we have tried to be aware of our broad audience. Some may have had more experience with a disability and less with community organizations, while it may be the opposite for others. The workbook has been set up to cover as many aspects of the IL movement as possible.

Each section of the workbook introduces an important aspect of how an independent living organization operates. It is followed by a section called Topics for Reflection and Discussion. These questions are intended to prompt careful consideration of how an organization can apply the ideas presented in the main chapter. There are also several sections and tables dealing with the structure of your organization.

The independent living movement is setting new directions, expanding into new communities, and gaining new participants. Since much of the work is conducted by independent living centers (ILCs), located in approximately 300 communities around the country, this workbook focuses on them. However, there are many more communities without such centers. Other organizations have sprung up to address the problems of independent living in those communities. We hope that this workbook, and other similar products from the Research and Training Center on Independent Living, will be helpful to all those working to achieve independent living.

The Authors

ACKNOWLEDGEMENTS

We would like to express our appreciation to Pat Weaver who prepared an early draft of the workbook. If Pat had remained with the Center, she surely would have been the primary force behind the project. We would also like to express our deep appreciation to June Keffer who acted as translator and collaborator. Finally, Sue Elkins provided magical editorial assistance, Pam Willits handled the mystery of wordprocessing, and Chris Boles completed the graphics. Finally, the RTC/IL staff is a collaborative group. The contributions of its other members to this project are many.

CHAPTER I - DEFINITIONS/GOALS

Every organized group shares some set of common ideas. This chapter deals with the ideas and values of the independent living (IL) movement. It answers the following questions: What is meant by independent living? What roles should individuals with disabilities play in the IL movement? What are IL organizations? What is the mission of your organization? What are the needs and priorities in your community? How is the mission of your organization achieved?

Section 1. Defining Independent Living and the IL Movement

Rice, Roessler, Greenwood, and Frieden (1983) define independent living as the ability of disabled persons to participate actively in society: to work, own a home, raise a family, participate to the fullest extent possible in normal activities, and exercise freedom of choice.

The IL movement consists of a number of efforts at the personal, community, state, and national levels to make this definition a reality for all disabled people. Rice et al. (1983) trace the origins of the movement back to 1959. The movement did not catch fire until the late 1970s, however, when Congress appropriated funds to start independent living centers (ILCs) in communities across the country. Now, there are as many as 300 ILCs and many other community organizations whose goal is to promote the independence of persons with disabilities.

Four themes dominate the philosophy of the movement: environmental handicaps, civil rights, deinstitutionalization, and consumer control. An environmental handicap is when a physical or social environment is responsible for limiting the independence of someone with a disability. This suggests that environmental conditions, rather than individuals, are a productive target for intervention or change. For example, a great many IL organizations have focused on attempts to eliminate architectural barriers in communities.

The civil rights of disabled people are at risk when they do not have access to education, employment, housing, transportation, community events, and public places. Many IL activities have been aimed at securing or protecting the civil rights of persons with disabilities. For example, many advocates have lobbied heavily to extend the coverage of local ordinances, state laws, and national legislation that prohibit discrimination against those with disabilities.

Deinstitutionalization refers to the effort to move away from the "care of persons with disabilities" in institutions and toward developing communities and providing generic services to facilitate independent living. A prime example involves establishing ILCs.

Finally, consumer control involves the right of community residents who are disabled to decide the type of services (e.g., medical, transportation, housing, etc.) they will receive and how the services will be provided. For example, many ILCs are governed by boards of directors with a majority of members having a disability.

These four themes will be explored in many of the following chapters. We urge you pursue them in more depth by reviewing some of the materials listed as suggested readings (See Appendix 3).

TOPICS FOR REFLECTION AND DISCUSSION

How do you define independent living? Do you believe it is possible for everyone to achieve independent living? Are there limitations? Who is responsible for facilitating independent living in your community? What is your role? What aspects of the physical and social environment might handicap individuals with disabilities in your community? Are there ways your community might be more integrated? How much community/consumer involvement is there in your organization?

Section 2: Consumerism

Freedom of choice is a key concept in defining independent living. The notion of consumerism helps put this ideal into practice.

Individuals with disabilities are consumers on three levels. First, each individual is a consumer of services provided by public and private agencies. This includes services provided by grocery stores, realtors, department stores, schools, helping agencies, and health care providers. Second, each individual is, as all citizens are, a consumer of public affairs. This includes local business practices, such as employment policies, and governmental policies, such as local ordinances on handicapped parking. Finally, an individual with a disability is a consumer of the services offered by local IL organizations.

One goal of the IL movement is to help individuals with disabilities become more effective consumers on all three levels. First, individuals who are effective consumers of public and private services are more likely to achieve their independent living goals. To enhance an individual consumer's effectiveness, an IL organization might provide information about available options, information about their rights, and training in how to advocate for the options they choose.

Second, public affairs can influence the extent to which all consumers in a community can achieve independent living. Presumably, the more individuals with disabilities who participate effectively in public

affairs, the more likely decisions will be made about community conditions that will facilitate independent living for everyone. To enhance consumer effectiveness in public affairs, an organization might support and train self-advocacy groups, monitor public affairs, and propose programs designed to facilitate independent living.

Finally, to be considered an IL organization, a substantial number of individuals with disabilities must be directly involved in decisions affecting the organization's operation. For example, federal legislation that established ILCs (discussed in more detail in Chapter II) calls for centers to be "administered and staffed primarily by handicapped individuals themselves." To enhance consumer involvement, individuals with disabilities can be appointed to the organization's board of directors, hired as staff, or organized into consumer advisory and advocacy groups.

The way in which consumerism is expressed in any community or IL organization will depend on a number of factors. After all, not all consumers want to be active at all three levels of consumerism.

The theme of consumerism is implicit in each of the following chapters. The questions asked below should be asked about topics in each chapter.

TOPICS FOR REFLECTION AND DISCUSSION

Who are the consumers in your organization? What obstacles exist to greater consumer involvement?

How can consumer participation be made more meaningful? How do you help consumers become more knowledgeable and articulate?

Section 3: What Are Independent Living Organizations?

Any organization whose mission is to facilitate the goal of independent living for individuals having physically disabling conditions may be considered an IL organization. Generally, there are two types, IL groups and IL programs.

IL groups include organizations that work to achieve independent living goals but provide no direct services. Examples include: (1) Local community advisory commissions (e.g., a mayor's commission) on the needs of persons with disabilities which engage in community-level advocacy and educational activities, (2) Local self-help support groups composed of disabled individuals and/or their families, (3) State government advisory committees composed of disabled individuals appointed to advise government agencies about the role of a state department in facilitating independent living, and (4) Local, state, and national coalitions of IL organizations.

Independent living programs are nonprofit corporations based in a community. They provide direct and support services to persons with severe physical disabilities, enabling them to live as independently as possible in their communities. Custodial care facilities or programs operating on a medical model are specifically excluded from being IL programs. In addition, IL programs must demonstrate substantial consumer involvement. Their ideal form is policy and administrative control by consumers.

Examples of IL programs include: (1) Nonresidential ILCs that provide or

coordinate programs, attendant care, peer counseling, housing, financial and legal advocacy, community awareness, barrier removal, and other services, (2) IL residential programs that provide long-term residential options for individuals, (3) IL transitional programs that provide skill training and other temporary services to help an individual move from relative dependence to relative independence.

TOPICS FOR REFLECTION AND DISCUSSION

Which form of IL organization do you have? What type of members does your organization have? How are you connected to other IL organizations locally? Statewide? Nationally? Has your organization ever taken a different form? Is it planning to change form?

Section 4: The Mission of Your Organization

Every organization shares a set of common ideas and has a mission to achieve. The ideas your organization shares and its mission focus on the ability of residents in your community to live independently.

A clear statement of your organization's mission serves as a touchstone for all its activities. A mission statement is a short, concise statement of an organization's purpose. It can be as simple as "promoting independent living," or it can be more detailed. In either case, it should help you judge whether your organization's activities are achieving its purpose.

More specific goals may also be written to reflect major activities your organization will pursue to achieve its mission. An example might be, "To involve citizens with disabilities in the development of our community toward independent living." Goals focus activities and help organize projects and tasks. Whereas a mission statement is unlikely to change, goals may change often. In fact, they should be reviewed and reconsidered frequently.

The following table describes the mission and goals of your organization.

Writing a mission statement and specifying goals appears simple at first glance. But it can be very difficult work. Since your community and the needs of your consumers are constantly changing, the mission and goals of your organization should be reviewed periodically. If you need

direction, a number of books listed in the appendix may help. You may also find local business managers or college professors willing to lend a hand.

TOPICS FOR REFLECTION AND DISCUSSION

Is the mission statement clear? Is its wording acceptable? Do the goals reflect the mission? Are there goals that should be added? Deleted?

MISSION STATEMENT

MISSION OF THE ORGANIZATION

--

MAJOR GOALS

1.	
2.	
3.	
4.	
5.	

Section 5: Determining Needs and Setting Priorities

Whether your organization is new or old, it must continually adapt to the changing requirements of independent living in your community. A critical step in facilitating IL goals is to monitor the changing needs of disabled people. How you determine needs will help you make judgments about the types of programs, services, projects, and activities your organization might pursue. This information will also help you focus on what community resources your organization should develop to achieve IL goals.

There are two general ways to determine local need for services provided by IL organizations. The first is to determine how many people with what kinds of disabilities live in the area. This information provides a general impression of the scope of problems people with disabilities might face. Sources include the U.S. census data for your area, motor vehicle registrants possessing disability licenses, service records from a local ILC and social security reports.

The second method is to involve persons with disabilities--consumers of IL programs living in your area--in defining their own needs and concerns. This process is consistent with the philosophy of the IL movement. It is invaluable for setting service priorities and focusing on important community issues (e.g., parking or accessibility obstacles).

One proven method for involving persons with disabilities in setting priorities is the Independent Living Consumers' Concerns Report Method

developed by the Research and Training Center on Independent Living at the University of Kansas. The Concerns Report Method has been used by a wide variety of independent living organizations in both rural and urban areas.

The Concerns Report Method is designed to help citizens with disabilities develop a local IL agenda. The Concerns Report provides information, from the perspective of consumers, about local factors that facilitate IL or pose obstacles to IL in a community. The Concerns Report also lists consumers' suggestions about ways to solve identified problems.

The Concerns Report Method involves consumers in developing a Concerns Survey, conducting communitywide problem-solving discussions, developing a final report, and publicly presenting the final report. A sample of a flier announcing results of the Kansas City Concerns Report and their problem-solving discussions is reproduced below. Information about the use of the Concerns Report Method may be obtained by writing or calling the Research and Training Center on Independent Living, 348 Haworth, University of Kansas, Lawrence, KS 66045 (913-864-4950).

The table on page 17 shows information about your local priorities.

TOPICS FOR REFLECTION AND DISCUSSION

What are good information sources about the number of individuals with disabilities? Do they present a complete picture? What other sources might you add? How were consumers' priority concerns determined? Is the list of priorities believable? Is it complete? What other methods of information gathering might you add? How accurate is the information you have?

A SAMPLE OF THE KANSAS CITY CONCERNS REPORT

A Public Meeting For All Disabled People

**THE SURVEY OF DISABLED CITIZENS' COMMUNITY CONCERNS IS COMPLETE!
Come to the Public Meeting to Share Ideas on Those Issues
That You Identified as Being Important**

Below is a brief list of most important strengths and problems of the Kansas City area that residents of Kansas City, Kansas and Kansas City, Missouri identified:

<u>Relative Strengths</u>	<u>Relative Problems</u>
Support and Help Is Available from Friends and Neighbors	Handicapped Parking Ordinances Are Not Strictly Enforced
You Are Not Denied Service Because of the Type of Assistive Device You Use	Your Utility Bills Are Unaffordable
	Health Care Is Unavailable at an Affordable Cost
	Qualified Disabled Applicants Are Not Given the Same Opportunities as Nondisabled Applicants at Any Available Jobs
	Affordable Housing Is Not Available to All Types of Disabled Residents
	Restrooms Are Not Accessible to Disabled Customers
	Adequate Employment Opportunities Are Not Available

Because of acknowledged differences between Kansas City, Kansas and Kansas City, Missouri, separate meetings will be held for these communities to discuss the special aspects of each community.

KANSAS MEETING PLACES:

WHEN: 7:00 p.m. - 9:00 p.m., Tuesday, June 14, 1983

WHERE: Asbury Methodist Church, Hager Hall, 5400 W. 75th St., Prairie Village

or

WHEN: 7:00 p.m. - 9:00 p.m., Tuesday, June 21, 1983

WHERE: Kansas City, Kansas Community College, Student Union, 75th and State

MISSOURI MEETING PLACE:

WHEN: 3:00 p.m. - 5:00 p.m., Thursday, June 16, 1983

WHERE: Westport House, 4100 Waddell, Kansas City, Missouri

Attend the public meeting in your community. Come share your views on these and other issues on community living for disabled citizens. Let's teach each other what changes can be made to make this community a better place to live for all disabled people!

Call Whole Person (816-361-0304) if you have any questions.

These meetings are sponsored by Whole Person Independent Living Center with the assistance of the American Heart and Stroke Club; Association of the Blind; Easter Seals of Kansas and Missouri; Mayor's Office for Handicapped and Disabled-Kansas City, Kansas; Multiple Sclerosis Society; Muscular Dystrophy Association, and United Cerebral Palsy. This project was supported by funding from the Research & Training Center for Independent Living and staff from the Center for Public Affairs, K.U., Lawrence.

LOCAL CENSUS OF NEED

U.S. Census Data

Number of persons with a work disability: _____

Number of Motor Vehicle Handicap Registrations: _____

Number of persons receiving SSDI: _____

Other Sources of Information:

Priority Concerns:

1. _____
2. _____
3. _____
4. _____
5. _____

Strengths:

1. _____
2. _____
3. _____
4. _____
5. _____

Section 6: Programs and Services of the Organization

Since IL organizations differ according to local circumstances and resources, programs and services also vary. An IL group might focus on providing advice to local policymakers but may also participate actively in local, state, and national coalitions of IL organizations.

IL program services also differ. Data collected in 1983 from both IL programs and state agencies indicate, however, that most centers are involved in direct service provisions, information and referral, training, advocacy, and community development (Budde, Petty, & Nelson, 1984). This balanced approach is consistent with IL philosophy.

A second issue, vocationally oriented services versus nonvocationally oriented services, may also be reaching some resolution. Recent research (Budde et al., 1984) indicates that IL staff and state agencies have agreed that the primary focus of IL should not be on employment but on including those without an immediate vocational goal and those who are not considered employable.

While both ILCs and VR agencies agreed that vocational objectives are not of central importance in evaluating the effectiveness of ILCs (Budde et al., 1984), another RTC/IL survey (Jones, Boles, & Petty, 1983) found four of the top 10 problems for disabled consumers to be job-related (i.e., job training programs, on-the-job training, job placement, follow-through procedures). IL philosophy suggests that eventual job placement should not

be a criteria for participation in an ILC program, but these data indicate that disabled consumers, particularly severely disabled persons, are not being adequately trained and supported as they begin competitive employment.

A five-part classification model has been developed to identify programs and services of IL organizations. This services compendium is provided in Appendix 1. You might review the compendium and compare it with programs and services your organization offers. Your organization's services are shown in the following table.

TOPICS FOR REFLECTION AND DISCUSSION

Is your center moving toward or away from providing direct services? Why? How are consumers' vocational goals addressed at your center? Are there other community agencies that could provide the same services? Does your center focus on commonly shared needs of many disability groups or just one? Why? What role do consumers play in providing services?

CATALOG OF PROGRAMS AND SERVICES OFFERED

The following is a list for you to complete of programs and services offered by your center. Instructions: Appendix 1 lists the range of programs and services provided by organizations around the country. You may review that list to help you describe your organization's activities.

TYPE OF PRIMARY SERVICE	SERVICE/PROGRAM COMPONENT	DESCRIPTION

CHAPTER II - ORGANIZATION

To achieve your goals, you must organize your group in a way that will produce the best decisions and most effective actions. Further, the structure must permit a number of individuals and groups to take responsibility or be involved in the decisions and activities of the organization.

This chapter is designed to answer the following questions: First, how are independent living organizations structured? What are the roles and responsibilities of various groups within the organization? What are the committees within the organization? Who are committee members? And, what are the committees' tasks?

Section 1: Model Structures for Organizations Working to Develop Communities Toward Independent Living

IL organizations may be organized in a number of different ways. The structure of a particular organization reflects the community in which it operates and the basic views of its members about independent living.

Four general models are offered below and suggest the variety of possibilities open to communities. The models are: (1) the Community Advisory Commission model, (2) the Consumer Advisory Committee model, (3) the Advisory Board/Executive Board model, and (4) the Consumer Governing Board model. Each model has different advantages, depending on a particular community's resources and needs. The four approaches are described below and include some mention of costs and benefits.

Community Advisory Commission

The Advisory Commission model assumes there is no existing IL program within a community, but there is a need for efforts to promote IL goals. A group of individuals organizes to advise other service agencies, institutions, and the local government about the needs of persons with disabilities.

Members of the Advisory Commission need not all be handicapped, since its goal is to help a community develop in a desirable direction. The lack of set membership criteria allows it to draw on a broad talent pool within the community, e.g., bankers, physicians, and other community leaders.

This model may be best suited to a community that is just becoming aware of the issues involved in the IL movement. The model may eventually evolve into development of an IL program. It may also be appropriate for a community that has matured beyond the need for autonomous program services. In this case, IL philosophy is an inherent part of the community environment, and necessary services are integrated into the service delivery system. A commission also helps ensure the continued integration and adoption of services.

Consumer Advisory Committee

In this model, an IL program is governed by a board of directors. The board establishes goals, creates policy, and retains final responsibility for all actions of the program. Members of the governing board may or may not be individuals with disabilities or consumers of services. The administrator is hired by the governing board and is responsible for executing its directives. The Consumer Advisory Committee, generally a council of consumers, provides advice to the board of directors and staff based on their direct experience. The group may also participate in a number of other program activities, including providing services (e.g., peer counseling), public education, and advocacy.

The Consumer Advisory Committee model also allows an organization to draw upon a broad talent pool. This arrangement may facilitate achieving the program's goals. The Consumer Advisory Committee advises the board and

the director, thereby shaping program policy and activities. The Advisory Committee may also provide an opportunity for consumers who have not had leadership experience to gain it. This may eventually lead to positions on the governing board or other positions of responsibility.

The Consumer Advisory Committee model may be best suited to smaller communities where there is a limited number of disabled persons with governance skills. The model provides the flexibility needed to recruit experienced leaders and, at the same time, develops leadership skills among consumers.

Advisory Board/Executive Board

Another organization model is the Advisory Board/Executive Board. In this arrangement, an executive board is composed of consumers and staff who have responsibility for day-to-day program operations. An advisory board, composed of professionals and influential community leaders, provides advice to the executive board and facilitates necessary community contacts. Organizational control rests largely in the hands of consumers, but they are not left alone. It is well suited for less experienced consumers, since they have an opportunity to be active in leadership roles.

Consumer Governing Board

This model assumes that the board of directors is composed primarily of disabled individuals or those who are directly associated with disabled

persons. The board is responsible for setting organizational goals, monitoring financial management, and carrying out other tasks described later in the manual. The board has final responsibility for all organizational activities.

This model gives consumers major control over the program. This helps ensure, but does not guarantee, that organizational activities will be sensitive to the needs of consumers. It may also give some individuals their first opportunity to hold a position of responsibility.

The Consumer Governing model may be best suited to larger urban areas where there will be numerous persons with disabilities who are experienced and can assume binding responsibilities immediately. It may also be appropriate for organizations in smaller communities that have had time to develop a consumer talent bank who can assume such responsibilities.

Developmental Stages of a Community Toward Independent Living

These four model arrangements can be viewed on a hypothetical developmental continuum. In a community without an IL organization but with a growing awareness of IL issues, a Community Advisory Commission might be formed. This group might begin by having the mayor appoint both disabled and nondisabled members. The group's first task might involve public education and gathering information about the community.

In the second phase of community development toward independent living, the Advisory Commission, or a group spawned by its activity, might initiate

an IL program. If not enough experienced and influential community members exist who have or are associated with a person with a disability, this second phase might be organized along the Consumer Advisory Committee model. The milestones of this phase include establishing a program, developing community services, and developing a talent bank of consumers who will eventually take responsibility for program operation.

In the third phase, the program might reorganize around the Executive Board/Advisory Board model. Here, consumers would begin to take responsibility for day-to-day program operations and solicit advice and assistance from an experienced and influential citizen group.

In a fourth phase, the program might be organized around a Consumer Governing Board. Here, consumers will have taken complete responsibility for the program and are integrated completely into the Board. Education and service efforts of the program become models for other community agencies to emulate and adopt.

In the final stage, educating the community about IL needs and goals will have been largely completed. Services originally provided by the program will have been demonstrated to be effective and valuable and will have been transferred to other more generic agencies within the community. At this point of maturity, the IL movement in the community may progress to a form similar to the original Community Advisory Commission. In this mature state, the Community Advisory Commission would work to maintain

interest in IL issues in coalition with others, perhaps acting as a model for other communities.

This developmental view has the advantage of offering a number of flexible options. It also implies growth within the community. However, it may have some disadvantages.

All but the final two organizational structures imply a delay in attaining consumer control over services. Conceivably, a program and its supporting community might get stuck in one mode and fail to progress.

The National Council of Independent Living Programs (NCILP) has proposed a mechanism to foster program development. The mechanism involves extending membership to all agencies defining themselves as part of the IL movement. But, importantly, those that have not developed to the point of consumer control are encouraged to submit a transition plan to do so and report on progress toward this goal in order to maintain membership. For more information, you can contact Ray Zanella, NCILP membership coordinator, Community Service Center for the Disabled, 1295 University Avenue, San Diego, CA 92103.

As you begin your affiliation with the board of an IL organization, it is important to consider just what model you are utilizing. You will want to observe whether it is an effective way of operating and whether it involves disabled individuals in the community to the maximum extent possible. If the answer to either of these questions is no, it is your responsibility to advocate for change.

TOPICS FOR REFLECTION AND DISCUSSION

How has your organization developed? Why? Do you expect this to change? How? When? Why? Are the two primary organizational functions being performed adequately? Do members of your board need training in any specific areas? What are your views on the NCILP guidelines? If your center does not meet NCILP guidelines, do you have a plan to do so? Why or why not?

Section 2: Task Roles and Responsibilities

Any IL organization, regardless of which model it follows or which form it takes, performs two primary functions. First, it must manage its internal operations (e.g., service delivery, consumer relations, fund raising, etc.). Second, it must manage its external environment by involving the community in activities to develop support for independent living. This requires that a large number of tasks be performed regularly and effectively.

Typically, the primary responsibility for performing these tasks is assumed by specific boards, committees, divisions, or staff within an organization. However, division of responsibility is often shared. This promotes effective action by the organization, but it can also result in tensions and confusion among different groups.

Tension arises when the organization tries to balance its requirements for efficiency and effectiveness. This tension is natural and can be very positive. But it can dampen your spirits and effectiveness, when there is confusion over what responsibilities are shared within your organization.

The chart that follows is a composite list of internal and external tasks common to many IL organizations. It provides suggested divisions for different groups within the organization, such as staff, governing board, and advisory board. These divisions may be modified according to your needs. Studying it now and reviewing it periodically will help avoid

confusion and make creative use of the tensions inherent in shared responsibilities.

DIVISION OF RESPONSIBILITIES

INTERNAL TASKS	Governing Board	Administrator/ Staff	Other
1. Establish and maintain legal, corporate existence.			
2. Establish the organization's mission.			
3. Oversee financial management.			
4. Take final fiscal authority.			
5. Do fund raising.			
6. Prepare grant proposals.			
7. Establish annual budget priorities.			
8. Set project, program, and service priorities.			
9. Develop an annual plan.			
10. Review and approve annual plan.			
11. Recruit new staff.			
12. Hire staff.			
13. Oversee staff management and supervision.			
14. Provide service delivery.			

Governing Board Administration/ Staff Other

15. Report on routine operations.			
16. Inform organization about important deadlines.			
17. Develop criteria to be used in program monitoring and evaluation.			
18. Monitor projects, policies, and programs.			
19. Evaluate projects, programs, or services.			
20. Review long-range organizational goals.			
21. Review policies, documents, budgets, and agency proposals to assure consistency with IL and organizational goals.			
22. Evaluate executive director.			
23. Evaluate consumer board.			
24. Evaluate governing board.			
25. Recruit new consumer board members.			
26. Develop a pool of talented consumers for positions of responsibility.			
27. Recruit new governing board members.			
28. Provide orientation of new members.			

Governing Board Administration/ Staff Other

29.	Oversee organizational development and renewal.			
30.	Set up special celebrations to honor organizational achievements.			

EXTERNAL TASKS

1.	Develop public relations/education programs.			
2.	Educate the community about disabilities and your organization.			
3.	Organize a speakers' bureau for your organization.			
4.	Publicize your organization's activities and services through local media.			
5.	Conduct public hearings on your organization's plans.			
6.	Advocate for individual service requirements and eligibility.			
7.	Advocate for the goals of independent living.			
8.	Monitor community events for issues of importance.			
9.	Report on important community events.			

Governing Administration/
Board Staff Other

10. Assess consumer satisfaction with services for the disabled.			
11. Assess concerns of disabled residents in the community.			
12. Develop plans for ways your organization can address identified concerns of its consumers.			
13. Develop plans for ways other community organizations can address the broader community concerns of the disabled.			
14. Establish channels of communication with other community groups and agencies.			
15. Establish a collaborative system with community organizations and agencies to increase service effectiveness.			
16. Keep public eye on independent living by writing letters to editors of local papers about important issues.			
17. Write letters to keep public officials informed about how their policies and programs affect independent living.			
18. Provide testimony at public hearings on important issues.			
19. Conduct community accessibility surveys.			

Governing Board **Administration/Staff** **Other**

20. Conduct a community services audit to determine ways other agencies can improve their services for the disabled.			
21. Develop contacts with elected and appointed officials.			
22. Monitor local ordinances, policies, and programs for their impact on independent living.			
23. Monitor legislative issues relevant to independent living at the state and national level.			
24. Network with other independent living organizations in the area.			
25. Set up special ceremonies to honor community members and organizations for their contributions to independent living.			

TOPICS FOR REFLECTION AND DISCUSSION

How are the agendas for meetings in your organization determined? Why? How are the different boards, committees, consumers, staff departments, etc. informed about major changes? How are they involved in decisions? Why? Are the separate tasks of the governing board, staff, and consumer board understood by everyone? Are there areas of tension over responsibilities or authority? Why? How can they be resolved? To whom does each group report? How do the various divisions within your organization communicate? Can it be improved? Are there clear criteria and guidelines for different groups taking action?

Section 3: Committee Structure of an Organization

Using committees is a way to share work and responsibility among several persons. It allows discussion of important issues, and it allows decision making to occur between meetings of the full board. It may also make members more knowledgeable and increase their satisfaction with their membership.

Committees may be formed by the organization as a whole (e.g., including elected officials, staff, and consumer), by any board within the organization (e.g., a consumer board may have a center operations committee and a community advocacy committee), or by the staff of the organization. The Committee Information Chart below can be used as a guide to understanding the roles and responsibilities of each of the committees in your organization.

There are three ways organizations form committees. The first is along functional lines. In this structure, committees are organized for each of the major functions performed by an organization. For example, an organization may develop one committee to deal with internal operations (e.g., financial management, monitoring projects and policies, service delivery) and another to deal with external activities (e.g., public education, advocacy, monitoring important community events).

The advantages to this type of committee structure are that the need to form new committees for specific purposes is less likely to occur, and

committees are better able to respond to problems and issues confronting the board. It is also somewhat easier to distribute workload in this type of structure than with committees that are structured along program lines.

Second, committees may be formed along program lines. This type of organizational structure divides into committees according to the programs it offers or the projects it sponsors. For example, an ILC might establish one committee for transportation, one for housing, and one for attendant care.

The advantage of this system is that committee members are able to focus on only one type of issue and become experts more quickly. However, since many of the board's tasks can be overlooked with this type of structure, the board can become fragmented. It is also extremely difficult to control workload.

Finally, an organization may form into ad hoc committees according to specific issues that come before the board for consideration. For example, a local community may form an ad hoc committee on telephone rates. Ad hoc committees are effective for short-term tasks, but they do not meet ongoing and long-range organizational needs. Ad hoc committees are best used with a functional committee structure, when short-term issues arise that are not part of the responsibilities of existing committees.

TOPICS FOR REFLECTION AND DISCUSSION

What committee structure does your organization use?

Does your committee conform closely to its task

responsibilities? Does the committee structure of

your organization overlook any task responsibilities?

Are members of your committees overworked? Why? Do

any committees meet too often or too seldom? How

might the committee structure of your organization be

improved? When do each of the committees meet? How

do the various committees communicate with one another?

How can this be improved?

COMMITTEE INFORMATION CHART

COMMITTEES OF THE GOVERNING BOARD

TASK RESPONSIBILITIES

_____	_____
_____	_____

COMMITTEES OF THE ADVISORY BOARD

TASK RESPONSIBILITIES

_____	_____
_____	_____

COMMITTEES OF THE STAFF

TASK RESPONSIBILITIES

_____	_____
_____	_____

CHAPTER III - RESOURCES

The resources available to your organization include those who participate in it, funds for its operations, other organizations with similar objectives, and the community at large. This chapter is designed to answer the following questions: First, what other organizations collaborate with your organization? How do they help? What other resources and activities are available? What are the major laws relating to independent living? How do these laws affect funding and advocacy? What resources are available to your organization, and how are they spent? Who is on your board or committee? What strengths do they bring to your organization? How might your organization select new participants to make its boards and committees even stronger?

Section 1: Recruiting Board Members

The individuals who serve on an organization's board and committees are among its most valuable resources. The success of any organization depends on the abilities and productivity of these volunteers. They affect the overall status of the organization and may make the difference between success and failure.

Some boards, such as consumer boards, may be relatively open to all who volunteer. Membership on other boards, such as governing boards, may be specified by laws, regulations, or articles of incorporation. In either case, the ideal board or committee has a membership that is balanced across needs for talent, experience, and action in several different areas. This includes expertise in task-related activities (e.g., fund raising), influence within the broader community, commitment to achieving organizational goals, experience as a consumer, ability to work cooperatively, and willingness to express opinions and question others critically. Balanced membership strengthens a board by exposing its members to varied perspectives, putting it in touch with more segments of the community, and expanding the range of tasks it can perform effectively.

The Board Balance Sheet provided in this section suggests many membership qualities your group may desire. It is also a checklist to help you determine how balanced your group is currently and help you target new members for recruitment. For example, if a review indicates that your

group is composed mainly of males with a background in community services, you may want to target your recruitment efforts at females with a background in business or health care. The membership of your board should be reviewed at least one each year with the goal of ensuring a balanced membership.

TOPICS FOR REFLECTION AND DISCUSSION

Do you have enough members? How many members have experience as consumers? Do they represent consumers sufficiently? Who is participating in selecting these individuals? Is there diversity in age, ethnic background, gender, and disability? If not, why not? Are various community neighborhoods represented? Are there enough board members with needed expertise? Do board members represent a diverse background? Are there board members with enough community influence to help get things done? If you were to add a new member, what characteristics should the member have? Does your board need training or technical assistance in any specific area?

THE BOARD BALANCE SHEET

INSTRUCTIONS: 1) Enter the names of board members. 2) Check each column that applies to each member. 3) Look for patterns of dominance in those columns with a large number of checks, and gaps in those with few or none. 4) Discuss both dominance and patterns and gaps in your group. Determine the desirability of filling gaps or changing dominance patterns. 5) Draw a profile of the type of new members you will recruit by listing their desirable characteristics.

BOARD MEMBER'S NAME											
AGE	Under 21										
	21 - 35										
	36 - 50										
	51 - 85										
GENDER	Female										
	Male										
ETHNICITY	American Indian										
	Asian American										
	Black										
	Hispanic										
	White										
BACKGROUND	Community Services										
	Corporate Business										
	Education										
	Government										
	Health Care										
	Law										
	Private Business										
EXPERTISE	Advocacy										
	Fiscal Management										
	Funding										
	Lobbying/Influence										
	Personnel Management										
	Planning										
	Program Development										
	Public Relations										
	Service Networking										
CONSUMER INVOLVEMENT	Person With Disability										
	Family Member										
	Currently Able-Bodied										

Section 2: Building Resources and Networking for Independent Living

Living independently requires a great deal of individual effort. It also requires access to a variety of resources and opportunities within a community (e.g., transportation, employment opportunities, accessible housing). Often, however, conditions existing within the community and decisions that produced them have the effect of further handicapping individuals with disabilities.

One responsibility of IL organizations is to act as advocates to improve community conditions so that independent living is more feasible. This advocacy may take a number of forms. First, the IL organization might work with other service agencies to develop a comprehensive IL service system within the community. This could be done by showing agencies how their services can be tailored to meet the needs of disabled persons. Second, the IL organization might work with private businesses to gain access to the businesses or their products (e.g., houses and apartments) and to open employment opportunities. Third, the organization might monitor local governmental units (e.g., housing authorities, traffic commissions, and Community Development Block Grant boards) and provide them with information to ensure local policy decisions reflect IL goals. Fourth, the IL organization might secure funding to provide services to fill gaps in a service system (e.g., transportation). Finally, the

organization might work with other state IL organizations to lobby policymakers and legislators on behalf of IL.

The chart on the following page is provided to help keep track of the various collaborative projects on which your organization is working.

TOPICS FOR REFLECTION AND DISCUSSION

What needs or goals are unmet? How were these priorities determined? What resources are required to meet these needs or goals? Who has these resources? What obstacles to independent living still exist in your community? What community organizations are not doing something for independent living? What organizations are engaged in similar activities for any population?

How can seemingly unrelated programs be linked together to benefit the disabled? What can be done to build on your organization's previous successes? How can you contribute to the success of other organizations? How do you honor those who have helped your organization? What unique contributions to the community are made by your organization?

INDEPENDENT LIVING RESOURCES CHART

Instructions: List the key individuals and organizations with which you work and the projects on which you collaborate.

**Major Collaborators and
Cooperating Organizations**
(List key individuals and
organizations, both public
and private, working to
facilitate IL.)

**Projects, Activities, or
Resources Provided by Major
Collaborators**
(For example, referrals, service
provisions, public support, do-
nations, etc.)

Section 3: Funding for Centers, Services, and Projects

The major funding source for providing IL services is currently the federal government. Title VII of the Rehabilitation Act of 1978 authorizes funds for providing comprehensive services for independent living to persons with severe disabilities. The portions of the Rehabilitation Act that deal with independent living are reproduced in part in Section 4 of this chapter.

Part B of the Act provides money to start ILCs. This usually means that a center can apply for 3 years of federal funding. The amount of money awarded by the government is decreased gradually over 3 years. During this time, a center is required to increase the amount of money raised locally for operating the center. This gradual fading of federal funds gives each center a chance to establish itself and demonstrate financial community support.

Part A of the Act provides for federal funds to operate centers over a longer period of time. Centers will have to compete for money, and it may be more difficult to qualify. However, Congress has not yet authorized the money to fund this part of the Act.

As the amount of federal funds for services decreases or becomes more difficult to secure, other resources become more important. There are a number of potential sources of funding for IL services and centers. Some of the most prominent are described below.

The state government may support ILCs in three ways. First, it may allocate a certain portion of the state budget for IL services. Second, the state department of vocational rehabilitation and other departments may purchase IL services from ILCs (e.g., the state might reimburse centers for such services as counseling). Third, the state can authorize city and county governments to levy a tax for the provision of services to citizens with disabilities much as states authorize such taxes for services to senior citizens.

Private foundations may also be a source of money for services or special projects. For example, the Mott Foundation of Kalamazoo, Michigan has provided support for special projects of the National Coalition of Independent Living Programs (NCILP).

Many communities (i.e., cities and counties) receive Community Development Block Grant funds or Revenue Sharing funds. These funds may be used to support centers, services, or special projects (e.g., CDBG funds may be used to remove physical barriers in a community).

Centers may also generate income of their own in several ways. First, a center might charge for its services on a flat-rate or a sliding scale basis. For example, a center could charge a fare for transportation to help support those services. Second, a center could offer its services to a broader population in order to generate income to support its basic program. If a center had good printing equipment (e.g., a mimeograph machine), it might offer to print materials for other human service

agencies for a fee. (These services might also be used as a means for preparing some consumers for employment.) Third, a center might secure other service grants to help support its operation and extend the services it provides. For example, a center might apply for an employment training grant for its consumers and others in need of such assistance.

Finally, volunteers and in-kind contributions represent important organizational resources. An accountant might contribute work on the books of your organization free of charge. Since volunteers and in-kind contributions suggest the level of community support for an organization, several organizations keep careful track of these resources and report them as part of their budgets.

Developing funding sources and resources for ILCs and services often requires a great deal of work and creativity. One important step is to know the funding sources used by your center. The table on the following page lists funding sources your center has used in the past, is currently using, and expects to use in the future.

Raising money appears difficult and sometimes mysterious to many people. One proven method of organizing for fund raising involves the creation of a local IL foundation. Detailed information about the development and operation of a local foundation may be obtained by writing

or calling the Research and Training Center on Independent Living, The
University of Kansas, BCR/348 Haworth, Lawrence, Kansas, 66045-2930, (913)
864-4950.

A PROFILE OF FUNDING SOURCES AND EXPENDITURES

INSTRUCTIONS: Complete the following table by providing the information called for or by providing actual budgets.

<u>Source</u>	<u>Past Year</u>	<u>Current Year</u>	<u>Projected</u>
Title VII, Part A			
Title VII, Part B			
State budget allocation			
State purchase of services			
Mill levy			
Foundation			
Community Development Block Grant			
Revenue sharing			
Consumer services income			
Public service income			
Service grants			
Contributions and gifts			
In-kind contributions (volunteers, equipment, etc.)			
Other (Specify)			
Total			

Program expenditure			
Salaries			
Travel			
Supplies			
Advisory board funds			
Discretionary funds			
Total			

TOPICS FOR REFLECTION AND DISCUSSION

Are your center's funding and services stable? Are they likely to remain stable over the next few years? Are any potential funding sources not being tapped? Why? What current services need more funding? How could this money be raised? What new services are needed? How could they be funded? Are there any unnecessary services or expenditures being made? Can these services be closed or shifted to another agency and the resources they required be used for something more important?

Section 4: Legislation and Independent Living

Laws and policies at all levels of government affect us in nearly everything we do. In the past few years, a great deal of attention has been paid to the rights of disabled individuals by lawmakers at the local, state, and national levels.

Nearly every community has a handicapped parking ordinance. Many communities are careful to consider the effects of other ordinances on citizens with disabilities--often because of the persistent efforts of a local IL organization.

State laws have also reflected sensitivity to the rights and goals of disabled individuals. This has often been expressed in a willingness to provide for funding of IL programs and services. For example, the Governor of the State of Kansas recently signed a law that allows counties in the state to levy a mill tax for IL services (Kansas House Bill 2207 - An Act Concerning Services for Persons With Physically Handicapping Conditions).

Of course, a number of national laws and policies, such as the 1978 Amendments to the Rehabilitation Act, have been the most prominent. These laws have provided a strong foundation for the IL movement in two ways. First, they have provided for the direct or indirect funding of programs designed to achieve IL goals. Second, they have provided tools for advocating for the rights of citizens with disabilities. Several of the

national laws and policies related to the IL movement are listed below.

The intent of the law and its uses for funding and advocacy are described briefly.

INDEPENDENT LIVING LEGISLATION

Legislation and its Intent

TITLE VII OF THE 1978 AMENDMENTS TO THE REHABILITATION ACT: The purpose of this amendment was to authorize grants to establish and operate ILCs. These centers can provide the following programs and services: intake counseling, attendant care referral, advocacy, independent living skills training, housing and transportation referral, community needs and resource assessments, health maintenance, peer counseling, community group living arrangements, attendant care training, and other necessary programs and services. Importantly, this Act calls for assurances that handicapped individuals will be employed by the center and will be substantially involved in policy direction and management of centers.

SECTION 504 OF THE REHABILITATION ACT OF 1973: This important section prohibits discrimination against the otherwise qualified handicapped person (i.e., services or employment) by any program or activity receiving federal financial assistance. Methods of enforcement include injunctions prohibiting noncompliance, a private right of action by individuals for damages, fines, imprisonment, or suspension of funding.

Funding and Advocacy Uses

This Act has been used primarily for direct funding of ILCs in a number of communities.

To the extent that the Act pays for advocacy services and specifies substantial involvement by consumers, it has helped advocate for the rights of citizens.

This section of the Act has been used primarily for advocacy. Considering the number of programs and activities receiving financial assistance, this provision has extremely broad impact.

Indirectly, this portion of the Act funds independent living services by making other services and employment for the handicapped available.

ARCHITECTURAL BARRIERS ACT: This legislation is designed to ensure that facilities housing programs funded in whole or in part by the federal government (e.g., post office building) are accessible. Many states have similar laws for their facilities. But there are important variants in each state law, such as the facilities covered and exemptions.

This legislation has been used to advocate for renovations and construction of accessible facilities across the country.

Indirectly, this act funds IL services by making a broad array of buildings and programs accessible.

Studying laws and policies is difficult and time-consuming. Efforts to change a law or establish a new one at a local or state level can sometimes take 2 or more years. But the benefits of understanding important laws and policies--as well as efforts to establish new ones--almost always exceed the costs.

TOPICS FOR REFLECTION AND DISCUSSION

What local ordinances have been established that facilitate independent living? Is there a procedure for considering the impact of all local ordinances on persons with disabilities? What state laws have contributed to achieving IL goals? How has your state's government expressed support for the IL movement? What national laws has your organization used for funding or advocacy? How might your group make better use of the legislative process?

CHAPTER IV - YOUR ORGANIZATION

Any organization that endures over a long period of time relies on documents of one sort or another for legitimacy and continuity. New organizations hoping to endure are wise to follow this lead.

This section of the workbook is intended for the important documents that guide the operation of your organization. These documents will help answer questions about how your organization is structured and how its parts relate to each other.

Section 1: Profile of Your Organization

There are a number of documents that guide the operation of your organization. These documents include the articles of incorporation, by-laws, policies, procedures, and memoranda of agreement. Everyone working within your organization should be familiar with these documents. If you do not have written policies covering the operation of your organization, they should be developed.

In addition, there are a number of individuals who are critical to the planning, operation, and maintenance of the organization. These individuals include staff and board members (governing and advisory, where applicable). In order to function effectively as a contributing member of the group, it is important that you know how each of these individuals contributes to the organization. The following section provides some of this information about people in your organization.

TOPICS FOR REFLECTION AND DISCUSSION

What have been the best, most helpful policies of the organization? Who has the most unique background of the board members? Who do you think has the most interesting job of the staff? Who on the board is most like you? Least like you? From whom do you think you might learn something?

STAFF PROFILES

INSTRUCTIONS: Use this form to keep a list of those who have worked and are currently working in the organization.

Staff Member	Job Title	Responsibilities

BOARD PROFILE

INSTRUCTIONS: Use this form to keep a list of all those who have served and are currently serving on boards.

Board Member	Committees	Background

Appendix 1

SERVICES COMPENDIUM FOR INDEPENDENT LIVING

INSTRUCTIONS: Review each major type of program and service and each component to identify the activities of your organization. List the type, component, and definition on the chart in Section 6.

TYPE OF PRIMARY SERVICE

SERVICE/PROGRAM COMPONENT

DEFINITION, EXAMPLES, CONFLICTING, OR VARYING INTERPRETATIONS

DIRECT SERVICE

COUNSELING

Typical counseling services include: rights & benefits, sexuality, crisis, financial. Provided by either professionally trained counselor (peer or nonpeer) or by nonprofessional peer.

Recent research conducted by Moses (1982) has begun to bring the issue of peer counseling into perspective. Peer counseling has traditionally been considered a service. Moses' research has concluded that peer counseling should be considered a method of service delivery rather than a service. Peer, then, becomes a descriptor of a job qualification for a counselor.

	ASSESSMENT/EVALUATION	Assessment/evaluation involves determination of individual needs in any of a number of areas. Assessment often takes place during the intake process and periodic reassessments.
	TRANSPORTATION SERVICES	Center operates a bus system that provides transportation to consumers, often at reduced or no cost to the user.
	ATTENDANT CARE SERVICES	Center locates, trains, and employs attendants who provide attendant care services to consumer.
	RECREATIONAL-SOCIAL SERVICES	Center directly sponsors and/or provides recreational services for consumers.
	ACCESS SURVEYING	Center surveys housing, restaurants, public buildings for consumer. Considered a direct service when survey benefits primarily one consumer.
INDIRECT SERVICES	HOUSING ASSISTANCE	Center maintains a file of accessible low-cost housing. Provides locations to consumer, but consumer is responsible for making contact. May also include arrangements for adaptations to housing.

**ATTENDANT CARE
ASSISTANCE**

Center maintains file of attendants to be used by consumers. Consumers are responsible for making all arrangements with attendants. Attendant is employee of consumer.

**TRANSPORTATION
ASSISTANCE**

Maintains file of public transportation providers. Assist with procuring adapted vehicles. Assists with ride-sharing arrangements.

**RIGHTS AND BENEFITS
INFO & REFERRAL**

Advises consumers of available benefits and rights. Provides information about appropriate contact person.

**PEER COUNSELING
INFO & REFERRAL**

Provides information about available peer counseling in the community.

**ACCESSIBILITY
INFO & REFERRAL**

Informs consumers about public buildings and other inaccessible public areas.

LEGAL INFO & REFERRAL

Maintains file of low-cost legal services and attorneys knowledgeable about rights of disabled persons. Assists consumer in making contact.

**RECREATIONAL-SOCIAL
INFO & REFERRAL**

Maintains information about special recreational or social activities for persons with disabilities, e.g., wheelchair basketball league, beep softball, support groups.

INTERPRETERS & READERS

Maintains records of individuals trained and available to provide interpreter services or to serve as readers. May provide training to those individuals.

**INDEPENDENT LIVING
SKILLS**

**PERSONAL
ADVOCACY**

Provides advocacy training to consumers often through peer counseling.

**TRANSPORTATION &
MOBILITY SKILLS**

Provides training in mobility in the community via public transportation or personal vehicle. Might also involve perceptual training for directions.

**COMMUNICATION &
ASSERTIVENESS**

Provides assistance to consumer to communicate better. Typical services might include assistance with obtaining adaptive devices or speech therapy. Peer counseling in assertiveness might also be included.

**GOAL SETTING/DECISION
MAKING/PROBLEM SOLVING**

Typically, counseling to the individual to set personal goals and make decisions about his/her life.

**ATTENDANT MANAGEMENT
SKILLS**

Provides training in skills necessary to interview and hire attendants, schedule attendants appropriately, and maintain productive relationship.

**SELF-IMAGE
DEVELOPMENT**

Typically, a counseling relationship with a peer to develop positive self-image.

**MONEY MANAGEMENT
SKILLS**

Training in setting priorities, budgeting, handling money, and banking.

**HOUSEKEEPING/
SHOPPING/COOKING**

Provides training to individual in skills necessary to live in independent setting. May include assisting the individual in identifying those areas in which assistance is required or assisting in adapting environment to meet individual needs.

**RECREATION &
LEISURE SKILLS**

Assistance to the individual identifying information sources about community activities, making social arrangements, and using leisure time productively and satisfyingly.

	COPING SKILLS	Counseling provided by peer to individual in coping with his/her disability, with personal crisis, and with day-to-day demands on individual.
	BOARD PARTICIPATION	Training to individual in community decision making through participation on boards of directors, civic activities, and other leadership roles in the community.
COMMUNITY/ ENVIRONMENT	TRANSPORTATION DEVELOPMENT	Involvement of the center in community planning and implementation of public transportation services to meet needs of disabled persons. Includes participation on Transportation Advisory Boards, spearheading cooperative transportation projects to maximize specialized transportation availability.
	HOUSING DEVELOPMENT	Includes direct involvement with housing authority, city county planning commissions, federal authorities providing funds and other assistance in housing for special populations (HUD).

**PUBLIC INFO &
AWARENESS**

Includes public information and media campaigns about rights of disabled, needs of disabled, and services available. Enhances sensitivities of public to needs.

**ATTENDANT
DEVELOPMENT**

Develops pool of attendants, both volunteer and paid, through public speaking engagements and public information campaigns. Develops and provides training to individuals. Also maintains emergency attendant pool.

**PEER HELPER &
COUNSELOR
DEVELOPMENT**

Develops pool of individuals willing to serve as peer helpers/counselors. Develops and provides training for individuals.

**COMMUNITY BARRIER
REMOVAL**

Inventories community and actively works with community officials to remove barriers.

**RECREATION
DEVELOPMENT**

Encourages development of recreation opportunities for disabled by working actively with city parks and recreation, youth groups, and civic clubs to identify and remove barriers from existing programs, and promotes community interest in developing more programs.

**EMPLOYMENT
DEVELOPMENT**

To work with employers, job service agencies, and educational institutions in the area to develop employment opportunities for disabled. May include identifying barriers and potential adaptations of work sites, providing special assistance to employees or employers.

ADMINISTRATION

CASE MANAGEMENT

The system an agency uses to track an individuals needs and progress. Case management also ensures accountability of the agency.

**CONSUMER
INVOLVEMENT**

The activities an agency is involved in to ensure consumer involvement. Examples are providing staff assistance to a consumer advisory committee, holding special meetings to solicit consumer input and advice.

**CONSUMER
SATISFACTION
EVALUATION**

Evaluation activities conducted by the staff or board to measure consumer satisfaction with center operations.

**COMMUNITY RESOURCE
DEVELOPMENT**

Activities sponsored by the center to develop resources in the community--financial or human. Resource development activities can include special events, sponsorship of special advisory committees to local governments, or inventorying resources.

**CENTER FINANCING
LOCAL, STATE, FEDERAL
FOUNDATION**

Includes grant writing, special local fund-raising activities, and activities to encourage local government financing of the center.

**PROGRAM IMPACT
EVALUATION**

Evaluation of all center activities to measure the center's impact on quality of life for disabled people in the community. Impact evaluation includes setting measureable objectives, recording data, and measuring changes in the community.

**AGENCY SERVICE
NETWORKING**

Activities the center is involved in to encourage coordination of services and reduce duplication of services through participation in special community councils, cooperation with other agencies in conducting communitywide needs assessments.

CENTER EVALUATION

Evaluation to determine what services were provided and how much, impact of the center on the community, and cost effectiveness of service delivery.

STAFF DEVELOPMENT & TRAINING

To ensure quality of service and to retain well-qualified staff members, the center is involved in providing or arranging activities to train staff and keep them up-to-date with IL developments.

NEEDS ASSESSMENT

Center activities to assess needs of disabled individuals in the community.

CENTER PLANNING

Long-range goal setting and short-term planning to ensure consistence of center activities with IL philosophy and to prioritize activities according to community needs and available resources.

LEGISLATIVE ADVOCACY

Activities in which the center is involved to support improved quality of life for disabled persons. Examples include lobbying local, state, or federal legislators, providing supporting data to legislators, writing legislation.

SYSTEMS ADVOCACY

Activities supporting changes in social and environmental systems to improve conditions. Examples include changes in government and changing social attitudes about the disabled and their right to live the way they want.

REPORTING

Providing information in report form to funding agencies, the community, and consumers. Includes program reporting and financial reporting.

Appendix 2

GLOSSARY OF TERMS AND OTHER IMPORTANT IDEAS

Because IL covers so many aspects of day-to-day living, many new terms have developed. These terms include those associated with legislation, government programs, research and literature associated with independent living, and local projects that provide services to disabled consumers. The following information is divided into two parts. The first is a list of basic terms and ideas associated with independent living. The second is a list of common acronyms that you may come across in your advisory committee activities. Review these lists, and ask someone at the local center for clarification, if there are terms you don't understand.

Space is provided at the end of each list to allow you to add any new terms. Write them down, find out what they mean, and share them with the rest of the group. You may find that new terms or ideas represent new activities or new policy directions that need group attention. Possibly, a new resource will emerge that can be used by the group.

Try to keep your list up-to-date by making notes when you come across changes. This is especially important when dealing with federal programs. They change rapidly, and it is difficult to keep information current. Share changes with other group members.

GLOSSARY OF SELECTED TERMS

ADVOCACY	General and specific intervention to support or ensure the rights of those who are otherwise unable to assert their rights.
COMPREHENSIVE COMMUNITY DEVELOPMENT PLAN	A statement identifying current housing conditions, needs, major problems, and a comprehensive strategy for addressing them.
COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING	Any service that enhances the ability of a disabled individual to live independently and, if appropriate, secure suitable employment.
DUE PROCESS	Requires the government or other administrative agency to act in a fair manner. May involve a hearing process in which the individual must be given the opportunity to present evidence, cross-examine, and be represented by counsel.
GRANTEE	The agency, institution, organization, or individual that receives an award and is accountable to the granting agency for all project funds, noncash contributions to the project, and performance of supported activity.
MATCH OR MATCHING SHARE	The portion of allowable program costs not borne by the federal government. Often, the law that establishes a program also sets a formula or percentage of the total costs that must be contributed from other sources.
MEANS TEST	Examination of a person's resources, assets, and income to determine if she/he is eligible to receive program benefits.
NEEDS ASSESSMENT	The process of finding out what types and what quantities of service are most needed in an area. Also, may identify needs that services cannot meet or presently do not meet.

NONCOMPLIANCE	Instances in which programs fail to comply with statutory regulations that govern the program.
NONPROFIT OR NOT-FOR-PROFIT ORGANIZATION	An organization no part of whose net earnings (after salaries) may lawfully benefit any shareholder or individual.
SITE VISIT	A visit by federal officials and experts to evaluate center performance and to suggest constructive methods for dealing with deficiencies.
START-UP FUNDS	Funds from any source used to help initiate a program by paying some of its initial expenses.
VENDOR	A person or organization paid to provide services.

COMMONLY USED ABBREVIATIONS

APTD	Aid to the Permanently and Totally Disabled
BEH	Bureau of Education for the Handicapped
CDBG	Community Development Block Grant
CMHC	Community Mental Health Centers
CSA	Community Services Administration
DD	Developmental Disabilities
DI	Disability Insurance
DOT	Department of Transportation
DOE	Department of Education
EEOC	Equal Employment Opportunity Commission
ESEA	Elementary and Secondary Education Act

FY	Fiscal Year
HAL	Handicapped Assistance Loans
HAP	Housing Assistance Plan
HHS	Department of Health and Human Services
HUD	Department of Housing and Urban Development
IEP	Individual Education Plan
ILCs	Independent Living Centers
IWRP	Individualized Written Rehabilitation Program
JTPA	Jobs Training Partnership Act
LEA	Local Educational Agency
NIH	National Institute of Health
NIHR	National Institute of Handicapped Research
OASDHI	Old-Age, Survivors and Disability Insurance
OHDS	Office of Human Development Services
OILD	Office of Independent Living for the Disabled (HUD)
OJT	On-the-Job Training
P & A	Protection and Advocacy
PCEH	President's Committee on Employment of the Handicapped
RFP	Request for Grant Proposal
RSA	Rehabilitation Services Administration
RSDI	Retirement, Survivors and Disability Insurance
R & T	Research and Training

SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TTY	Teletypewriter
VA	Veterans Administration
VE	Vocational Education

Appendix 3

References and Suggested Readings

The following lists those works cited in the text and other readings related to the topic. The starred items are highly recommended for advanced orientation and study.

*Bowe, F. (1978). Handicapping America: Barriers to disabled people.

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Jones, M. L., Boles, C., & Petty, R. (1983). Survey of technology needs in independent living. Independent Living Forum, 1(1).

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Varella, R. (1979). Self-help groups in rehabilitation. Washington, D.C.: The American Coalition of Citizens with Disabilities.

Guiding Your Independent Living Organization

*A Workbook for
Active Decision Makers
in the Independent
Living Movement*

Tom Seekins, Roger Keffer, and James Budde
The Research and Training Center
on Independent Living

Foreward to Orientation Coordinators

**An Introduction to the Purpose,
Organization, and Use of
"Guiding Your
Independent Living Organization"**

**Tom Seekins, Roger Keffer, and James Budde
The Research and Training Center on Independent Living
The University of Kansas
Lawrence, Kansas**

those who are involved in independent living organizations, including those who have been in the field for a long time.

Benefits

The workbook has several benefits. First, it is designed specifically for independent living (IL) organizations. Other tools for organizational development are often too general or designed for other populations. Second, the workbook presents standard information concerning independent living. This information will help participants in your organization gain a broader understanding of the movement, even if there are points about which you may disagree. Third, the workbook is designed specifically to encourage debate about basic ideas involved in the IL movement and the operation of IL organizations. Fourth, we recognize that each organization is unique. The workbook provides a number of places to describe the characteristics of your local center. Fifth, the workbook and this pamphlet are designed to help conduct organizational development sessions. In short, both provide IL organizations with a simple package for orienting new members and maintaining a common understanding of the organization's goals and the roles its members play.

An Overview of the Workbook

The workbook is designed to help decision makers of local IL organizations orient new members to the organization and maintain a common understanding of both the organization and the roles its members play.

Anyone making decisions that affect how one or more persons with disabilities can share in human society needs to review--and often redefine--both what one is trying to do and how one goes about doing it. Further, any group organized to promote independent living--whether local, regional, national, passive monitoring group, support group, advocacy group, or active service program, publicly or privately supported--must pause from time to time to ensure that its efforts are effective and its goals worthwhile. We have tried to fashion a tool to make frequent organizational renewal easier and more meaningful to you, whether you have recently joined an IL organization or you have served long and hard throughout its development.

Each workbook section clarifies basic ideas about tasks facing organizations. It is followed by Topics for Reflection and Discussion. Topics are designed to encourage discussion about the basic ideas presented in the section. In addition, several uncompleted TABLES will help you define--and redefine--important policy decisions of your organization. Active consideration of these topics and completion of the TABLES--the "work" in this workbook--will amount to a thorough review of your organization.

We hope the workbook will fill important needs for guidance in operating IL organizations. The first chapter starts with a look at what is meant by independent living. Organizations that have been developed to foster independent living are reviewed, and methods for determining needs and setting priorities are discussed. How persons with disabilities can take part in society at large, and especially in independent living organizations, is also examined.

Chapter II goes into organization in more detail. First, it shows what forms IL organizations may take, how each might best fit different levels of community awareness and support, and how these forms may lead from one to another. Next, it looks closer to see how authority and responsibility may be shared by governing and advisory boards, full-time staff, and committees. The chapter also explains how the progress of an IL organization can be evaluated.

A third chapter talks about available resources--the tools, materials, and collaboration networks you use to promote independent living in your community. It begins with a review of current national laws directly affecting independent living and independent living organizations. Next, it considers funding sources and how funds are used.

Chapter IV discusses the details of your organization. The important documents of the organization, such as the bylaws, should be inserted in this section. Three Appendices are included. Appendix 1 lists and defines

services and activities of independent living centers. This is intended to offer a quick overview of the range of potential center activities.

Appendix 2 provides a glossary of terms frequently encountered by those active in the IL movement. A number of orientation coordinators have commented on its usefulness in the orientation process.

Finally, a list of suggested readings is offered. These readings are selected to provide a more comprehensive understanding of independent living and to provide approaches to solving particular problems.

A systematic review of ends and means is needed time and again throughout an IL organization's life. It becomes, of course, the main focus when founding your IL organization. In addition, each new member, director, or staffperson must be "ORIENTED"--made familiar with the basics of your operation. Further, many funding sources require thorough analysis of your overall program and purposes. Finally, everyone active in your organization should have periodic chances to help renew your organization and his or her personal commitment to it.

Using the Workbook

We recommend that a committee (if you choose to call it such) of one or more of your members be assigned responsibility for organizational orientation and development (OD) activities. This OD committee should plan and develop enough OD activities to keep your IL organization current and

every member fully informed. It should decide, among other things, how to make best use of material in this workbook. Here are a few suggestions:

The TABLES must be completed to tailor this workbook to your organization. You can do this in several ways.

If you are forming a new organization, you can give each member a copy to read, asking him or her to complete each TABLE. As members debate the issues and return completed TABLES, you can prepare and hand out a tentative, and later an operating, set of TABLES based on these discussions. We have three-hole-punched and carefully arranged these pages to make loose-leaf handling simpler.

If you are just beginning to form an IL organization, you may be able to use these operating TABLES as guides to writing your formal documents. After your IL organization begins operating its OD committee, it should see that every member, new and old, has a current copy of what has now become your organization's individualized workbook. Un-completed TABLES may be replaced by completed ones. Alternatively, they may be used as exercises to help focus group discussions during organizational renewal sessions.

If your IL organization has been established, the "Topics for Reflection and Discussion" become your most active tool. Many topics are already frequently discussed, but periodic

open discussion may improve everyone's understanding of your organization. Your OD committee should, therefore, prompt and arrange OD activities. You can do it by reserving parts of regularly scheduled meetings to discuss these important, often decisive, organizational issues.

Or, you can set up annual OD workshops or weekend retreats to study them in depth. In any case, you must tailor your OD activities to needs and capabilities of your organization.

Tailoring the Workbook to Your Organization

A number of the workbook chapters require you to provide information about your center. These chapters and the information needed are listed below. Forms for presenting this information are provided in each of the sections:

In Chapter I, Section 4, you will need to indicate the purpose of your organization and its major goals.

In Chapter II, Section 2, you will need to indicate who has responsibility for performing various organizational tasks.

In Chapter II, Section 3, you will need to list the committees that operate within your organization.

In Chapter I, Section 3, you will need to list and describe the services your organization provides.

Appendix 1, A Services Compendium for Independent Living, is designed to help you complete this task. It lists typical services and their common definitions.

In Chapter I, Section 4, you must describe the information your organization has collected about the number of disabled residents in your community and the needs they have expressed.

In Chapter III, Section 1, you are to describe the cooperative relationships you have developed with other organizations. You are also asked to describe how your organization is unique.

In Chapter III, Section 3, you will need to list the amounts of money your organization has received, receives, or plans to receive from different sources. You are asked to present a budget of how organizational funds are spent.

In Chapter IV, you will be asked to identify staff and board members and briefly describe their responsibilities. In addition, this section asks you to provide a number of important organizational documents such as its bylaws.

Discussion Sessions for Orientation and Development

There are eight discussion sessions that can be organized around the workbook. The Discussion Guide that follows lists the topic of each session and the sections of the workbook that provide basic information about the topic.

You may want to supplement the information contained in the workbook with information about your organization. You may also provide other information you have found useful in considering the topic.

You should schedule each session in advance. For example, you may have a discussion session announced in the agenda for a future meeting. You might also refer members to appropriate sections of their workbooks, so they can have an opportunity to review material and prepare for discussion.

The Discussion Guide lists each session, a challenge related to the topic, and pertinent questions to prompt discussion. At the beginning of each session, you might remind participants of the topic being discussed, read the challenge, and ask the discussion question you feel would provide the most interesting and fruitful discussion.

If the discussion around the topic and question seems slow or seems to come to an end, you might ask another question. Alternatively, you might ask participants if they have any questions about the topic.

Finally, you may find it worthwhile to keep a log of the discussion sessions. This involves summarizing the basic points made during the

discussion. Such a log can help orient new members and may prompt action relative to your discussion.

BRIEF DISCUSSION GUIDE

Session Topic and Challenge

Consumerism: Consumers should be involved in our center to the maximum extent possible. (Chapter I: Sections 1, 2, and 5. Chapter II: Section 1.)

Recruiting: The ideal board or committee is a balance of talent, experience, and action. (Chapter III: Section 4.)

Determining Needs and Setting Priorities: The organization must continually adapt to changing requirements of independent living in the community (Chapter I: Section 4.)

Task Roles and Responsibilities
Responsibilities for the operations of an organization must be shared in a manner that promotes effectiveness. (Chapter II: Sections 2 and 3.)

Questions to Prompt Discussion

Who are the consumers of the organization? How are they involved in the organization? What obstacles exist to greater consumer involvement? How can consumer participation be made more meaningful?

Are there enough members? How many members have experience as consumers? Do members represent a diverse background? If you were to add a new member, what characteristics should the member have?

How are priority concerns of consumers determined? Do these methods present a complete picture of need? What is left out? What other informational methods might add to your understanding of your community's independent living needs and priorities.

Are the separate tasks of the governing board, etc. understood by everyone? Are the tasks performed effectively? Are there areas of tension over responsibility or authority? What are the criteria for different groups taking action? How are the agendas of meetings determined? Does everyone have access to the agenda and other important information?

Resources: Money is important, but it is not the only important resource. (Chapter III: Sections 1, 2, and 3.)

Programs and Services: Independent living organizations should provide only those services not provided by others. (Chapter I: Sections 3, Appendix 1.)

Networking: One responsibility of independent living organizations is to act as advocates to improve community life so independent living becomes more possible. (Chapter III: Section 1. Chapter I: Section 2.)

What organizations are not doing something for independent living in the community? How can seemingly unrelated programs/organizations be linked together in a way that facilitates independent living? What laws has the organization used for funding or advocacy? Has the organization created any laws or local ordinances that facilitate independent living? What current services are at risk because of lack of funding? What new services or programs need to be funded? How can funds for these programs be raised?

Does your organization focus on commonly shared needs of many disability groups or just one? What role do consumers play in providing services? How does the organization encourage other agencies to serve citizens with disabilities? How is the organization trying to "work itself out of a job?"

How does the organization work with human services agencies in the community? How does it work with private business? Local government units? Who else should you know from these sectors? What other organizations in the area are engaged in similar activities? How might you cooperate? How can you contribute to the success of other organizations working to facilitate independent living? How do you honor those who have done something to promote independent living? How are consumers involved?

Policy Review: The organization must adapt to changes in the community and changes in the priorities of citizens with disabilities. (Organizational bylaws, policies and procedures.)

What politics are outdated or need clarification? What policies have worked well? What new policies are needed? How are consumers involved in organizational policy and review?

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PREFACE

Many people have pointed out the difficulty of orienting new participants to the independent living (IL) movement. Executive directors, board members of consumer groups, and state advisory council staff have all expressed their concern. They have found it frustrating to try to communicate a sense of their organization's goals and the roles its members play.

This workbook was designed to meet those needs. First, it helps orient new participants to IL goals, in general, and to their local organization and its operations. Second, it will help boards and committees do periodic reviews of their organization's structure and operation.

One way to learn more about the IL movement is to review the growing number of excellent publications, many of which are listed as suggested readings at the end of the workbook. We hope these materials, in combination with the workbook, will be helpful.

Because the IL movement includes people of varied backgrounds and experiences, we have tried to be aware of our broad audience. Some may have had more experience with a disability and less with community organizations, while it may be the opposite for others. The workbook has been set up to cover as many aspects of the IL movement as possible.

Each section of the workbook introduces an important aspect of how an independent living organization operates. It is followed by a section called Topics for Reflection and Discussion. These questions are intended to prompt careful consideration of how an organization can apply the ideas presented in the main chapter. There are also several sections and tables dealing with the structure of your organization.

The independent living movement is setting new directions, expanding into new communities, and gaining new participants. Since much of the work is conducted by independent living centers (ILCs), located in approximately 300 communities around the country, this workbook focuses on them. However, there are many more communities without such centers. Other organizations have sprung up to address the problems of independent living in those communities. We hope that this workbook, and other similar products from the Research and Training Center on Independent Living, will be helpful to all those working to achieve independent living.

The Authors

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We would like to express our appreciation to Pat Weaver who prepared an early draft of the workbook. If Pat had remained with the Center, she surely would have been the primary force behind the project. We would also like to express our deep appreciation to June Keffer who acted as translator and collaborator. Finally, Sue Elkins provided magical editorial assistance, Pam Willits handled the mystery of wordprocessing, and Chris Boles completed the graphics. Finally, the RTC/IL staff is a collaborative group. The contributions of its other members to this project are many.

CHAPTER I - DEFINITIONS/GOALS

Every organized group shares some set of common ideas. This chapter deals with the ideas and values of the independent living (IL) movement. It answers the following questions: What is meant by independent living? What roles should individuals with disabilities play in the IL movement? What are IL organizations? What is the mission of your organization? What are the needs and priorities in your community? How is the mission of your organization achieved?

Section 1. Defining Independent Living and the IL Movement

Rice, Roessler, Greenwood, and Frieden (1983) define independent living as the ability of disabled persons to participate actively in society: to work, own a home, raise a family, participate to the fullest extent possible in normal activities, and exercise freedom of choice.

The IL movement consists of a number of efforts at the personal, community, state, and national levels to make this definition a reality for all disabled people. Rice et al. (1983) trace the origins of the movement back to 1959. The movement did not catch fire until the late 1970s, however, when Congress appropriated funds to start independent living centers (ILCs) in communities across the country. Now, there are as many as 300 ILCs and many other community organizations whose goal is to promote the independence of persons with disabilities.

Four themes dominate the philosophy of the movement: environmental handicaps, civil rights, deinstitutionalization, and consumer control. An environmental handicap is when a physical or social environment is responsible for limiting the independence of someone with a disability. This suggests that environmental conditions, rather than individuals, are a productive target for intervention or change. For example, a great many IL organizations have focused on attempts to eliminate architectural barriers in communities.

The civil rights of disabled people are at risk when they do not have access to education, employment, housing, transportation, community events, and public places. Many IL activities have been aimed at securing or protecting the civil rights of persons with disabilities. For example, many advocates have lobbied heavily to extend the coverage of local ordinances, state laws, and national legislation that prohibit discrimination against those with disabilities.

Deinstitutionalization refers to the effort to move away from the "care of persons with disabilities" in institutions and toward developing communities and providing generic services to facilitate independent living. A prime example involves establishing ILCs.

Finally, consumer control involves the right of community residents who are disabled to decide the type of services (e.g., medical, transportation, housing, etc.) they will receive and how the services will be provided. For example, many ILCs are governed by boards of directors with a majority of members having a disability.

These four themes will be explored in many of the following chapters. We urge you pursue them in more depth by reviewing some of the materials listed as suggested readings (See Appendix 3).

TOPICS FOR REFLECTION AND DISCUSSION

How do you define independent living? Do you believe it is possible for everyone to achieve independent living? Are there limitations? Who is responsible for facilitating independent living in your community? What is your role? What aspects of the physical and social environment might handicap individuals with disabilities in your community? Are there ways your community might be more integrated? How much community/consumer involvement is there in your organization?

Section 2: Consumerism

Freedom of choice is a key concept in defining independent living. The notion of consumerism helps put this ideal into practice.

Individuals with disabilities are consumers on three levels. First, each individual is a consumer of services provided by public and private agencies. This includes services provided by grocery stores, realtors, department stores, schools, helping agencies, and health care providers. Second, each individual is, as all citizens are, a consumer of public affairs. This includes local business practices, such as employment policies, and governmental policies, such as local ordinances on handicapped parking. Finally, an individual with a disability is a consumer of the services offered by local IL organizations.

One goal of the IL movement is to help individuals with disabilities become more effective consumers on all three levels. First, individuals who are effective consumers of public and private services are more likely to achieve their independent living goals. To enhance an individual consumer's effectiveness, an IL organization might provide information about available options, information about their rights, and training in how to advocate for the options they choose.

Second, public affairs can influence the extent to which all consumers in a community can achieve independent living. Presumably, the more individuals with disabilities who participate effectively in public

affairs, the more likely decisions will be made about community conditions that will facilitate independent living for everyone. To enhance consumer effectiveness in public affairs, an organization might support and train self-advocacy groups, monitor public affairs, and propose programs designed to facilitate independent living.

Finally, to be considered an IL organization, a substantial number of individuals with disabilities must be directly involved in decisions affecting the organization's operation. For example, federal legislation that established ILCs (discussed in more detail in Chapter II) calls for centers to be "administered and staffed primarily by handicapped individuals themselves." To enhance consumer involvement, individuals with disabilities can be appointed to the organization's board of directors, hired as staff, or organized into consumer advisory and advocacy groups.

The way in which consumerism is expressed in any community or IL organization will depend on a number of factors. After all, not all consumers want to be active at all three levels of consumerism.

The theme of consumerism is implicit in each of the following chapters. The questions asked below should be asked about topics in each chapter.

TOPICS FOR REFLECTION AND DISCUSSION

Who are the consumers in your organization? What obstacles exist to greater consumer involvement?

How can consumer participation be made more meaningful? How do you help consumers become more knowledgeable and articulate?

Section 3: What Are Independent Living Organizations?

Any organization whose mission is to facilitate the goal of independent living for individuals having physically disabling conditions may be considered an IL organization. Generally, there are two types, IL groups and IL programs.

IL groups include organizations that work to achieve independent living goals but provide no direct services. Examples include: (1) Local community advisory commissions (e.g., a mayor's commission) on the needs of persons with disabilities which engage in community-level advocacy and educational activities, (2) Local self-help support groups composed of disabled individuals and/or their families, (3) State government advisory committees composed of disabled individuals appointed to advise government agencies about the role of a state department in facilitating independent living, and (4) Local, state, and national coalitions of IL organizations.

Independent living programs are nonprofit corporations based in a community. They provide direct and support services to persons with severe physical disabilities, enabling them to live as independently as possible in their communities. Custodial care facilities or programs operating on a medical model are specifically excluded from being IL programs. In addition, IL programs must demonstrate substantial consumer involvement. Their ideal form is policy and administrative control by consumers. Examples of IL programs include: (1) Nonresidential ILCs that provide or

coordinate programs, attendant care, peer counseling, housing, financial and legal advocacy, community awareness, barrier removal, and other services, (2) IL residential programs that provide long-term residential options for individuals, (3) IL transitional programs that provide skill training and other temporary services to help an individual move from relative dependence to relative independence.

TOPICS FOR REFLECTION AND DISCUSSION

Which form of IL organization do you have? What type of members does your organization have? How are you connected to other IL organizations locally? Statewide? Nationally? Has your organization ever taken a different form? Is it planning to change form?

Section 4: The Mission of Your Organization

Every organization shares a set of common ideas and has a mission to achieve. The ideas your organization shares and its mission focus on the ability of residents in your community to live independently.

A clear statement of your organization's mission serves as a touchstone for all its activities. A mission statement is a short, concise statement of an organization's purpose. It can be as simple as "promoting independent living," or it can be more detailed. In either case, it should help you judge whether your organization's activities are achieving its purpose.

More specific goals may also be written to reflect major activities your organization will pursue to achieve its mission. An example might be, "To involve citizens with disabilities in the development of our community toward independent living." Goals focus activities and help organize projects and tasks. Whereas a mission statement is unlikely to change, goals may change often. In fact, they should be reviewed and reconsidered frequently.

The following table describes the mission and goals of your organization.

Writing a mission statement and specifying goals appears simple at first glance. But it can be very difficult work. Since your community and the needs of your consumers are constantly changing, the mission and goals of your organization should be reviewed periodically. If you need

direction, a number of books listed in the appendix may help. You may also find local business managers or college professors willing to lend a hand.

TOPICS FOR REFLECTION AND DISCUSSION

Is the mission statement clear? Is its wording acceptable? Do the goals reflect the mission? Are there goals that should be added? Deleted?

MISSION STATEMENT

MISSION OF THE ORGANIZATION

--

MAJOR GOALS

1.	
2.	
3.	
4.	
5.	

Section 5: Determining Needs and Setting Priorities

Whether your organization is new or old, it must continually adapt to the changing requirements of independent living in your community. A critical step in facilitating IL goals is to monitor the changing needs of disabled people. How you determine needs will help you make judgments about the types of programs, services, projects, and activities your organization might pursue. This information will also help you focus on what community resources your organization should develop to achieve IL goals.

There are two general ways to determine local need for services provided by IL organizations. The first is to determine how many people with what kinds of disabilities live in the area. This information provides a general impression of the scope of problems people with disabilities might face. Sources include the U.S. census data for your area, motor vehicle registrants possessing disability licenses, service records from a local ILC and social security reports.

The second method is to involve persons with disabilities--consumers of IL programs living in your area--in defining their own needs and concerns. This process is consistent with the philosophy of the IL movement. It is invaluable for setting service priorities and focusing on important community issues (e.g., parking or accessibility obstacles).

One proven method for involving persons with disabilities in setting priorities is the Independent Living Consumers' Concerns Report Method

developed by the Research and Training Center on Independent Living at the University of Kansas. The Concerns Report Method has been used by a wide variety of independent living organizations in both rural and urban areas.

The Concerns Report Method is designed to help citizens with disabilities develop a local IL agenda. The Concerns Report provides information, from the perspective of consumers, about local factors that facilitate IL or pose obstacles to IL in a community. The Concerns Report also lists consumers' suggestions about ways to solve identified problems.

The Concerns Report Method involves consumers in developing a Concerns Survey, conducting communitywide problem-solving discussions, developing a final report, and publicly presenting the final report. A sample of a flier announcing results of the Kansas City Concerns Report and their problem-solving discussions is reproduced below. Information about the use of the Concerns Report Method may be obtained by writing or calling the Research and Training Center on Independent Living, 348 Haworth, University of Kansas, Lawrence, KS 66045 (913-864-4950).

The table on page 17 shows information about your local priorities.

TOPICS FOR REFLECTION AND DISCUSSION

What are good information sources about the number of individuals with disabilities? Do they present a complete picture? What other sources might you add? How were consumers' priority concerns determined? Is the list of priorities believable? Is it complete? What other methods of information gathering might you add? How accurate is the information you have?

A SAMPLE OF THE KANSAS CITY CONCERNS REPORT

A Public Meeting For All Disabled People

THE SURVEY OF DISABLED CITIZENS' COMMUNITY CONCERNS IS COMPLETE!

Come to the Public Meeting to Share Ideas on Those Issues
That You Identified as Being Important

Below is a brief list of most important strengths and problems of the Kansas City area that residents of Kansas City, Kansas and Kansas City, Missouri identified:

<u>Relative Strengths</u>	<u>Relative Problems</u>
Support and Help Is Available from Friends and Neighbors	Handicapped Parking Ordinances Are Not Strictly Enforced
You Are Not Denied Service Because of the Type of Assistive Device You Use	Your Utility Bills Are Unaffordable
	Health Care Is Unavailable at an Affordable Cost
	Qualified Disabled Applicants Are Not Given the Same Opportunities as Nondisabled Applicants at Any Available Jobs
	Affordable Housing Is Not Available to All Types of Disabled Residents
	Restrooms Are Not Accessible to Disabled Customers
	Adequate Employment Opportunities Are Not Available

Because of acknowledged differences between Kansas City, Kansas and Kansas City, Missouri, separate meetings will be held for these communities to discuss the special aspects of each community.

KANSAS MEETING PLACES:

WHEN: 7:00 p.m. - 9:00 p.m., Tuesday, June 14, 1983

WHERE: Asbury Methodist Church, Hager Hall, 5400 W. 75th St., Prairie Village
or

WHEN: 7:00 p.m. - 9:00 p.m., Tuesday, June 21, 1983

WHERE: Kansas City, Kansas Community College, Student Union, 75th and State

MISSOURI MEETING PLACE:

WHEN: 3:00 p.m. - 5:00 p.m., Thursday, June 16, 1983

WHERE: Westport House, 4100 Waddell, Kansas City, Missouri

Attend the public meeting in your community. Come share your views on these and other issues on community living for disabled citizens. Let's teach each other what changes can be made to make this community a better place to live for all disabled people!

Call Whole Person (816-361-0304) if you have any questions.

These meetings are sponsored by Whole Person Independent Living Center with the assistance of the American Heart and Stroke Club; Association of the Blind; Easter Seals of Kansas and Missouri; Mayor's Office for Handicapped and Disabled-Kansas City, Kansas; Multiple Sclerosis Society; Muscular Dystrophy Association, and United Cerebral Palsy. This project was supported by funding from the Research & Training Center for Independent Living and staff from the Center for Public Affairs, K.U., Lawrence.

LOCAL CENSUS OF NEED

U.S. Census Data

Number of persons with a work disability: _____

Number of Motor Vehicle Handicap Registrations: _____

Number of persons receiving SSDI: _____

Other Sources of Information:

Priority Concerns:

1. _____
2. _____
3. _____
4. _____
5. _____

Strengths:

1. _____
2. _____
3. _____
4. _____
5. _____

Section 6: Programs and Services of the Organization

Since IL organizations differ according to local circumstances and resources, programs and services also vary. An IL group might focus on providing advice to local policymakers but may also participate actively in local, state, and national coalitions of IL organizations.

IL program services also differ. Data collected in 1983 from both IL programs and state agencies indicate, however, that most centers are involved in direct service provisions, information and referral, training, advocacy, and community development (Budde, Petty, & Nelson, 1984). This balanced approach is consistent with IL philosophy.

A second issue, vocationally oriented services versus nonvocationally oriented services, may also be reaching some resolution. Recent research (Budde et al., 1984) indicates that IL staff and state agencies have agreed that the primary focus of IL should not be on employment but on including those without an immediate vocational goal and those who are not considered employable.

While both ILCs and VR agencies agreed that vocational objectives are not of central importance in evaluating the effectiveness of ILCs (Budde et al., 1984), another RTC/IL survey (Jones, Boles, & Petty, 1983) found four of the top 10 problems for disabled consumers to be job-related (i.e., job training programs, on-the-job training, job placement, follow-through procedures). IL philosophy suggests that eventual job placement should not

be a criteria for participation in an ILC program, but these data indicate that disabled consumers, particularly severely disabled persons, are not being adequately trained and supported as they begin competitive employment.

A five-part classification model has been developed to identify programs and services of IL organizations. This services compendium is provided in Appendix 1. You might review the compendium and compare it with programs and services your organization offers. Your organization's services are shown in the following table.

TOPICS FOR REFLECTION AND DISCUSSION

Is your center moving toward or away from providing direct services? Why? How are consumers' vocational goals addressed at your center? Are there other community agencies that could provide the same services? Does your center focus on commonly shared needs of many disability groups or just one? Why? What role do consumers play in providing services?

CATALOG OF PROGRAMS AND SERVICES OFFERED

The following is a list for you to complete of programs and services offered by your center. Instructions: Appendix 1 lists the range of programs and services provided by organizations around the country. You may review that list to help you describe your organization's activities.

TYPE OF PRIMARY SERVICE	SERVICE/PROGRAM COMPONENT	DESCRIPTION

CHAPTER II – ORGANIZATION

To achieve your goals, you must organize your group in a way that will produce the best decisions and most effective actions. Further, the structure must permit a number of individuals and groups to take responsibility or be involved in the decisions and activities of the organization.

This chapter is designed to answer the following questions: First, how are independent living organizations structured? What are the roles and responsibilities of various groups within the organization? What are the committees within the organization? Who are committee members? And, what are the committees' tasks?

Section 1: Model Structures for Organizations Working to Develop Communities Toward Independent Living

IL organizations may be organized in a number of different ways. The structure of a particular organization reflects the community in which it operates and the basic views of its members about independent living.

Four general models are offered below and suggest the variety of possibilities open to communities. The models are: (1) the Community Advisory Commission model, (2) the Consumer Advisory Committee model, (3) the Advisory Board/Executive Board model, and (4) the Consumer Governing Board model. Each model has different advantages, depending on a particular community's resources and needs. The four approaches are described below and include some mention of costs and benefits.

Community Advisory Commission

The Advisory Commission model assumes there is no existing IL program within a community, but there is a need for efforts to promote IL goals. A group of individuals organizes to advise other service agencies, institutions, and the local government about the needs of persons with disabilities.

Members of the Advisory Commission need not all be handicapped, since its goal is to help a community develop in a desirable direction. The lack of set membership criteria allows it to draw on a broad talent pool within the community, e.g., bankers, physicians, and other community leaders.

This model may be best suited to a community that is just becoming aware of the issues involved in the IL movement. The model may eventually evolve into development of an IL program. It may also be appropriate for a community that has matured beyond the need for autonomous program services. In this case, IL philosophy is an inherent part of the community environment, and necessary services are integrated into the service delivery system. A commission also helps ensure the continued integration and adoption of services.

Consumer Advisory Committee

In this model, an IL program is governed by a board of directors. The board establishes goals, creates policy, and retains final responsibility for all actions of the program. Members of the governing board may or may not be individuals with disabilities or consumers of services. The administrator is hired by the governing board and is responsible for executing its directives. The Consumer Advisory Committee, generally a council of consumers, provides advice to the board of directors and staff based on their direct experience. The group may also participate in a number of other program activities, including providing services (e.g., peer counseling), public education, and advocacy.

The Consumer Advisory Committee model also allows an organization to draw upon a broad talent pool. This arrangement may facilitate achieving the program's goals. The Consumer Advisory Committee advises the board and

the director, thereby shaping program policy and activities. The Advisory Committee may also provide an opportunity for consumers who have not had leadership experience to gain it. This may eventually lead to positions on the governing board or other positions of responsibility.

The Consumer Advisory Committee model may be best suited to smaller communities where there is a limited number of disabled persons with governance skills. The model provides the flexibility needed to recruit experienced leaders and, at the same time, develops leadership skills among consumers.

Advisory Board/Executive Board

Another organization model is the Advisory Board/Executive Board. In this arrangement, an executive board is composed of consumers and staff who have responsibility for day-to-day program operations. An advisory board, composed of professionals and influential community leaders, provides advice to the executive board and facilitates necessary community contacts. Organizational control rests largely in the hands of consumers, but they are not left alone. It is well suited for less experienced consumers, since they have an opportunity to be active in leadership roles.

Consumer Governing Board

This model assumes that the board of directors is composed primarily of disabled individuals or those who are directly associated with disabled

persons. The board is responsible for setting organizational goals, monitoring financial management, and carrying out other tasks described later in the manual. The board has final responsibility for all organizational activities.

This model gives consumers major control over the program. This helps ensure, but does not guarantee, that organizational activities will be sensitive to the needs of consumers. It may also give some individuals their first opportunity to hold a position of responsibility.

The Consumer Governing model may be best suited to larger urban areas where there will be numerous persons with disabilities who are experienced and can assume binding responsibilities immediately. It may also be appropriate for organizations in smaller communities that have had time to develop a consumer talent bank who can assume such responsibilities.

Developmental Stages of a Community Toward Independent Living

These four model arrangements can be viewed on a hypothetical developmental continuum. In a community without an IL organization but with a growing awareness of IL issues, a Community Advisory Commission might be formed. This group might begin by having the mayor appoint both disabled and nondisabled members. The group's first task might involve public education and gathering information about the community.

In the second phase of community development toward independent living, the Advisory Commission, or a group spawned by its activity, might initiate

an IL program. If not enough experienced and influential community members exist who have or are associated with a person with a disability, this second phase might be organized along the Consumer Advisory Committee model. The milestones of this phase include establishing a program, developing community services, and developing a talent bank of consumers who will eventually take responsibility for program operation.

In the third phase, the program might reorganize around the Executive Board/Advisory Board model. Here, consumers would begin to take responsibility for day-to-day program operations and solicit advice and assistance from an experienced and influential citizen group.

In a fourth phase, the program might be organized around a Consumer Governing Board. Here, consumers will have taken complete responsibility for the program and are integrated completely into the Board. Education and service efforts of the program become models for other community agencies to emulate and adopt.

In the final stage, educating the community about IL needs and goals will have been largely completed. Services originally provided by the program will have been demonstrated to be effective and valuable and will have been transferred to other more generic agencies within the community. At this point of maturity, the IL movement in the community may progress to a form similar to the original Community Advisory Commission. In this mature state, the Community Advisory Commission would work to maintain

interest in IL issues in coalition with others, perhaps acting as a model for other communities.

This developmental view has the advantage of offering a number of flexible options. It also implies growth within the community. However, it may have some disadvantages.

All but the final two organizational structures imply a delay in attaining consumer control over services. Conceivably, a program and its supporting community might get stuck in one mode and fail to progress.

The National Council of Independent Living Programs (NCILP) has proposed a mechanism to foster program development. The mechanism involves extending membership to all agencies defining themselves as part of the IL movement. But, importantly, those that have not developed to the point of consumer control are encouraged to submit a transition plan to do so and report on progress toward this goal in order to maintain membership. For more information, you can contact Ray Zanella, NCILP membership coordinator, Community Service Center for the Disabled, 1295 University Avenue, San Diego, CA 92103.

As you begin your affiliation with the board of an IL organization, it is important to consider just what model you are utilizing. You will want to observe whether it is an effective way of operating and whether it involves disabled individuals in the community to the maximum extent possible. If the answer to either of these questions is no, it is your responsibility to advocate for change.

TOPICS FOR REFLECTION AND DISCUSSION

How has your organization developed? Why? Do you expect this to change? How? When? Why? Are the two primary organizational functions being performed adequately? Do members of your board need training in any specific areas? What are your views on the NCILP guidelines? If your center does not meet NCILP guidelines, do you have a plan to do so? Why or why not?

Section 2: Task Roles and Responsibilities

Any IL organization, regardless of which model it follows or which form it takes, performs two primary functions. First, it must manage its internal operations (e.g., service delivery, consumer relations, fund raising, etc.). Second, it must manage its external environment by involving the community in activities to develop support for independent living. This requires that a large number of tasks be performed regularly and effectively.

Typically, the primary responsibility for performing these tasks is assumed by specific boards, committees, divisions, or staff within an organization. However, division of responsibility is often shared. This promotes effective action by the organization, but it can also result in tensions and confusion among different groups.

Tension arises when the organization tries to balance its requirements for efficiency and effectiveness. This tension is natural and can be very positive. But it can dampen your spirits and effectiveness, when there is confusion over what responsibilities are shared within your organization.

The chart that follows is a composite list of internal and external tasks common to many IL organizations. It provides suggested divisions for different groups within the organization, such as staff, governing board, and advisory board. These divisions may be modified according to your needs. Studying it now and reviewing it periodically will help avoid

confusion and make creative use of the tensions inherent in shared responsibilities.

DIVISION OF RESPONSIBILITIES

INTERNAL TASKS	Governing Board	Administrator/ Staff	Other
1. Establish and maintain legal, corporate existence.			
2. Establish the organization's mission.			
3. Oversee financial management.			
4. Take final fiscal authority.			
5. Do fund raising.			
6. Prepare grant proposals.			
7. Establish annual budget priorities.			
8. Set project, program, and service priorities.			
9. Develop an annual plan.			
10. Review and approve annual plan.			
11. Recruit new staff.			
12. Hire staff.			
13. Oversee staff management and supervision.			
14. Provide service delivery.			

1

Governing Board	Administration/ Staff	Other
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15. Report on routine operations.			
16. Inform organization about important deadlines.			
17. Develop criteria to be used in program monitoring and evaluation.			
18. Monitor projects, policies, and programs.			
19. Evaluate projects, programs, or services.			
20. Review long-range organizational goals.			
21. Review policies, documents, budgets, and agency proposals to assure consistency with IL and organizational goals.			
22. Evaluate executive director.			
23. Evaluate consumer board.			
24. Evaluate governing board.			
25. Recruit new consumer board members.			
26. Develop a pool of talented consumers for positions of responsibility.			
27. Recruit new governing board members.			
28. Provide orientation of new members.			

Governing Board Administration/ Staff Other

29. Oversee organizational development and renewal.			
30. Set up special celebrations to honor organizational achievements.			

EXTERNAL TASKS

1. Develop public relations/education programs.			
2. Educate the community about disabilities and your organization.			
3. Organize a speakers' bureau for your organization.			
4. Publicize your organization's activities and services through local media.			
5. Conduct public hearings on your organization's plans.			
6. Advocate for individual service requirements and eligibility.			
7. Advocate for the goals of independent living.			
8. Monitor community events for issues of importance.			
9. Report on important community events.			

Governing Board Administration/ Staff Other

10. Assess consumer satisfaction with services for the disabled.			
11. Assess concerns of disabled residents in the community.			
12. Develop plans for ways your organization can address identified concerns of its consumers.			
13. Develop plans for ways other community organizations can address the broader community concerns of the disabled.			
14. Establish channels of communication with other community groups and agencies.			
15. Establish a collaborative system with community organizations and agencies to increase service effectiveness.			
16. Keep public eye on independent living by writing letters to editors of local papers about important issues.			
17. Write letters to keep public officials informed about how their policies and programs affect independent living.			
18. Provide testimony at public hearings on important issues.			
19. Conduct community accessibility surveys.			

Governing Administration/
Board Staff Other

20. Conduct a community services audit to determine ways other agencies can improve their services for the disabled.			
21. Develop contacts with elected and appointed officials.			
22. Monitor local ordinances, policies, and programs for their impact on independent living.			
23. Monitor legislative issues relevant to independent living at the state and national level.			
24. Network with other independent living organizations in the area.			
25. Set up special ceremonies to honor community members and organizations for their contributions to independent living.			

TOPICS FOR REFLECTION AND DISCUSSION

How are the agendas for meetings in your organization determined? Why? How are the different boards, committees, consumers, staff departments, etc. informed about major changes? How are they involved in decisions? Why? Are the separate tasks of the governing board, staff, and consumer board understood by everyone? Are there areas of tension over responsibilities or authority? Why? How can they be resolved? To whom does each group report? How do the various divisions within your organization communicate? Can it be improved? Are there clear criteria and guidelines for different groups taking action?

Section 3: Committee Structure of an Organization

Using committees is a way to share work and responsibility among several persons. It allows discussion of important issues, and it allows decision making to occur between meetings of the full board. It may also make members more knowledgeable and increase their satisfaction with their membership.

Committees may be formed by the organization as a whole (e.g., including elected officials, staff, and consumer), by any board within the organization (e.g., a consumer board may have a center operations committee and a community advocacy committee), or by the staff of the organization. The Committee Information Chart below can be used as a guide to understanding the roles and responsibilities of each of the committees in your organization.

There are three ways organizations form committees. The first is along functional lines. In this structure, committees are organized for each of the major functions performed by an organization. For example, an organization may develop one committee to deal with internal operations (e.g., financial management, monitoring projects and policies, service delivery) and another to deal with external activities (e.g., public education, advocacy, monitoring important community events).

The advantages to this type of committee structure are that the need to form new committees for specific purposes is less likely to occur, and

committees are better able to respond to problems and issues confronting the board. It is also somewhat easier to distribute workload in this type of structure than with committees that are structured along program lines.

Second, committees may be formed along program lines. This type of organizational structure divides into committees according to the programs it offers or the projects it sponsors. For example, an ILC might establish one committee for transportation, one for housing, and one for attendant care.

The advantage of this system is that committee members are able to focus on only one type of issue and become experts more quickly. However, since many of the board's tasks can be overlooked with this type of structure, the board can become fragmented. It is also extremely difficult to control workload.

Finally, an organization may form into ad hoc committees according to specific issues that come before the board for consideration. For example, a local community may form an ad hoc committee on telephone rates. Ad hoc committees are effective for short-term tasks, but they do not meet ongoing and long-range organizational needs. Ad hoc committees are best used with a functional committee structure, when short-term issues arise that are not part of the responsibilities of existing committees.

TOPICS FOR REFLECTION AND DISCUSSION

What committee structure does your organization use?

Does your committee conform closely to its task responsibilities? Does the committee structure of your organization overlook any task responsibilities?

Are members of your committees overworked? Why? Do any committees meet too often or too seldom? How might the committee structure of your organization be improved? When do each of the committees meet? How do the various committees communicate with one another? How can this be improved?

COMMITTEE INFORMATION CHART

COMMITTEES OF THE GOVERNING BOARD

TASK RESPONSIBILITIES

_____	_____
_____	_____

COMMITTEES OF THE ADVISORY BOARD

TASK RESPONSIBILITIES

_____	_____
_____	_____

COMMITTEES OF THE STAFF

TASK RESPONSIBILITIES

_____	_____
_____	_____

CHAPTER III - RESOURCES

The resources available to your organization include those who participate in it, funds for its operations, other organizations with similar objectives, and the community at large. This chapter is designed to answer the following questions: First, what other organizations collaborate with your organization? How do they help? What other resources and activities are available? What are the major laws relating to independent living? How do these laws affect funding and advocacy? What resources are available to your organization, and how are they spent? Who is on your board or committee? What strengths do they bring to your organization? How might your organization select new participants to make its boards and committees even stronger?

Section 1: Recruiting Board Members

The individuals who serve on an organization's board and committees are among its most valuable resources. The success of any organization depends on the abilities and productivity of these volunteers. They affect the overall status of the organization and may make the difference between success and failure.

Some boards, such as consumer boards, may be relatively open to all who volunteer. Membership on other boards, such as governing boards, may be specified by laws, regulations, or articles of incorporation. In either case, the ideal board or committee has a membership that is balanced across needs for talent, experience, and action in several different areas. This includes expertise in task-related activities (e.g., fund raising), influence within the broader community, commitment to achieving organizational goals, experience as a consumer, ability to work cooperatively, and willingness to express opinions and question others critically. Balanced membership strengthens a board by exposing its members to varied perspectives, putting it in touch with more segments of the community, and expanding the range of tasks it can perform effectively.

The Board Balance Sheet provided in this section suggests many membership qualities your group may desire. It is also a checklist to help you determine how balanced your group is currently and help you target new members for recruitment. For example, if a review indicates that your

group is composed mainly of males with a background in community services, you may want to target your recruitment efforts at females with a background in business or health care. The membership of your board should be reviewed at least one each year with the goal of ensuring a balanced membership.

TOPICS FOR REFLECTION AND DISCUSSION

Do you have enough members? How many members have experience as consumers? Do they represent consumers sufficiently? Who is participating in selecting these individuals? Is there diversity in age, ethnic background, gender, and disability? If not, why not? Are various community neighborhoods represented? Are there enough board members with needed expertise? Do board members represent a diverse background? Are there board members with enough community influence to help get things done? If you were to add a new member, what characteristics should the member have? Does your board need training or technical assistance in any specific area?

THE BOARD BALANCE SHEET

INSTRUCTIONS: 1) Enter the names of board members. 2) Check each column that applies to each member. 3) Look for patterns of dominance in those columns with a large number of checks, and gaps in those with few or none. 4) Discuss both dominance and patterns and gaps in your group. Determine the desirability of filling gaps or changing dominance patterns. 5) Draw a profile of the type of new members you will recruit by listing their desirable characteristics.

BOARD MEMBER'S NAME		/ / / / / / / / / / / / / / / /																		
AGE	Under 21																			
	21 - 35																			
	36 - 50																			
	51 - 85																			
GENDER	Female																			
	Male																			
ETHNICITY	American Indian																			
	Asian American																			
	Black																			
	Hispanic																			
	White																			
BACKGROUND	Community Services																			
	Corporate Business																			
	Education																			
	Government																			
	Health Care																			
	Law																			
	Private Business																			
EXPERTISE	Advocacy																			
	Fiscal Management																			
	Funding																			
	Lobbying/Influence																			
	Personnel Management																			
	Planning																			
	Program Development																			
	Public Relations																			
CONSUMER INVOLVEMENT	Service Networking																			
	Person With Disability																			
	Family Member																			
	Currently Able-Bodied																			

Section 2: Building Resources and Networking for Independent Living

Living independently requires a great deal of individual effort. It also requires access to a variety of resources and opportunities within a community (e.g., transportation, employment opportunities, accessible housing). Often, however, conditions existing within the community and decisions that produced them have the effect of further handicapping individuals with disabilities.

One responsibility of IL organizations is to act as advocates to improve community conditions so that independent living is more feasible. This advocacy may take a number of forms. First, the IL organization might work with other service agencies to develop a comprehensive IL service system within the community. This could be done by showing agencies how their services can be tailored to meet the needs of disabled persons. Second, the IL organization might work with private businesses to gain access to the businesses or their products (e.g., houses and apartments) and to open employment opportunities. Third, the organization might monitor local governmental units (e.g., housing authorities, traffic commissions, and Community Development Block Grant boards) and provide them with information to ensure local policy decisions reflect IL goals. Fourth, the IL organization might secure funding to provide services to fill gaps in a service system (e.g., transportation). Finally, the

organization might work with other state IL organizations to lobby policymakers and legislators on behalf of IL.

The chart on the following page is provided to help keep track of the various collaborative projects on which your organization is working.

TOPICS FOR REFLECTION AND DISCUSSION

What needs or goals are unmet? How were these priorities determined? What resources are required to meet these needs or goals? Who has these resources? What obstacles to independent living still exist in your community? What community organizations are not doing something for independent living? What organizations are engaged in similar activities for any population?

How can seemingly unrelated programs be linked together to benefit the disabled? What can be done to build on your organization's previous successes? How can you contribute to the success of other organizations? How do you honor those who have helped your organization? What unique contributions to the community are made by your organization?

INDEPENDENT LIVING RESOURCES CHART

Instructions: List the key individuals and organizations with which you work and the projects on which you collaborate.

Major Collaborators and Cooperating Organizations
(List key individuals and organizations, both public and private, working to facilitate IL.)

Projects, Activities, or Resources Provided by Major Collaborators
(For example, referrals, service provisions, public support, donations, etc.)

Section 3: Funding for Centers, Services, and Projects

The major funding source for providing IL services is currently the federal government. Title VII of the Rehabilitation Act of 1978 authorizes funds for providing comprehensive services for independent living to persons with severe disabilities. The portions of the Rehabilitation Act that deal with independent living are reproduced in part in Section 4 of this chapter.

Part B of the Act provides money to start ILCs. This usually means that a center can apply for 3 years of federal funding. The amount of money awarded by the government is decreased gradually over 3 years. During this time, a center is required to increase the amount of money raised locally for operating the center. This gradual fading of federal funds gives each center a chance to establish itself and demonstrate financial community support.

Part A of the Act provides for federal funds to operate centers over a longer period of time. Centers will have to compete for money, and it may be more difficult to qualify. However, Congress has not yet authorized the money to fund this part of the Act.

As the amount of federal funds for services decreases or becomes more difficult to secure, other resources become more important. There are a number of potential sources of funding for IL services and centers. Some of the most prominent are described below.

The state government may support ILCs in three ways. First, it may allocate a certain portion of the state budget for IL services. Second, the state department of vocational rehabilitation and other departments may purchase IL services from ILCs (e.g., the state might reimburse centers for such services as counseling). Third, the state can authorize city and county governments to levy a tax for the provision of services to citizens with disabilities much as states authorize such taxes for services to senior citizens.

Private foundations may also be a source of money for services or special projects. For example, the Mott Foundation of Kalamazoo, Michigan has provided support for special projects of the National Coalition of Independent Living Programs (NCILP).

Many communities (i.e., cities and counties) receive Community Development Block Grant funds or Revenue Sharing funds. These funds may be used to support centers, services, or special projects (e.g., CDBG funds may be used to remove physical barriers in a community).

Centers may also generate income of their own in several ways. First, a center might charge for its services on a flat-rate or a sliding scale basis. For example, a center could charge a fare for transportation to help support those services. Second, a center could offer its services to a broader population in order to generate income to support its basic program. If a center had good printing equipment (e.g., a mimeograph machine), it might offer to print materials for other human service

agencies for a fee. (These services might also be used as a means for preparing some consumers for employment.) Third, a center might secure other service grants to help support its operation and extend the services it provides. For example, a center might apply for an employment training grant for its consumers and others in need of such assistance.

Finally, volunteers and in-kind contributions represent important organizational resources. An accountant might contribute work on the books of your organization free of charge. Since volunteers and in-kind contributions suggest the level of community support for an organization, several organizations keep careful track of these resources and report them as part of their budgets.

Developing funding sources and resources for ILCs and services often requires a great deal of work and creativity. One important step is to know the funding sources used by your center. The table on the following page lists funding sources your center has used in the past, is currently using, and expects to use in the future.

Raising money appears difficult and sometimes mysterious to many people. One proven method of organizing for fund raising involves the creation of a local IL foundation. Detailed information about the development and operation of a local foundation may be obtained by writing

or calling the Research and Training Center on Independent Living, The
University of Kansas, BCR/348 Haworth, Lawrence, Kansas, 66045-2930, (913)
864-4950.

A PROFILE OF FUNDING SOURCES AND EXPENDITURES

INSTRUCTIONS: Complete the following table by providing the information called for or by providing actual budgets.

<u>Source</u>	<u>Past Year</u>	<u>Current Year</u>	<u>Projected</u>
Title VII, Part A			
Title VII, Part B			
State budget allocation			
State purchase of services			
Mill levy			
Foundation			
Community Development Block Grant			
Revenue sharing			
Consumer services income			
Public service income			
Service grants			
Contributions and gifts			
In-kind contributions (volunteers, equipment, etc.)			
Other (Specify)			
Total			

Program expenditure			
Salaries			
Travel			
Supplies			
Advisory board funds			
Discretionary funds			
Total			

TOPICS FOR REFLECTION AND DISCUSSION

Are your center's funding and services stable? Are they likely to remain stable over the next few years? Are any potential funding sources not being tapped? Why? What current services need more funding? How could this money be raised? What new services are needed? How could they be funded? Are there any unnecessary services or expenditures being made? Can these services be closed or shifted to another agency and the resources they required be used for something more important?

Section 4: Legislation and Independent Living

Laws and policies at all levels of government affect us in nearly everything we do. In the past few years, a great deal of attention has been paid to the rights of disabled individuals by lawmakers at the local, state, and national levels.

Nearly every community has a handicapped parking ordinance. Many communities are careful to consider the effects of other ordinances on citizens with disabilities--often because of the persistent efforts of a local IL organization.

State laws have also reflected sensitivity to the rights and goals of disabled individuals. This has often been expressed in a willingness to provide for funding of IL programs and services. For example, the Governor of the State of Kansas recently signed a law that allows counties in the state to levy a mill tax for IL services (Kansas House Bill 2207 - An Act Concerning Services for Persons With Physically Handicapping Conditions).

Of course, a number of national laws and policies, such as the 1978 Amendments to the Rehabilitation Act, have been the most prominent. These laws have provided a strong foundation for the IL movement in two ways. First, they have provided for the direct or indirect funding of programs designed to achieve IL goals. Second, they have provided tools for advocating for the rights of citizens with disabilities. Several of the

national laws and policies related to the IL movement are listed below.

The intent of the law and its uses for funding and advocacy are described briefly.

INDEPENDENT LIVING LEGISLATION

Legislation and its Intent

TITLE VII OF THE 1978 AMENDMENTS TO THE REHABILITATION ACT: The purpose of this amendment was to authorize grants to establish and operate ILCs. These centers can provide the following programs and services: intake counseling, attendant care referral, advocacy, independent living skills training, housing and transportation referral, community needs and resource assessments, health maintenance, peer counseling, community group living arrangements, attendant care training, and other necessary programs and services. Importantly, this Act calls for assurances that handicapped individuals will be employed by the center and will be substantially involved in policy direction and management of centers.

SECTION 504 OF THE REHABILITATION ACT OF 1973: This important section prohibits discrimination against the otherwise qualified handicapped person (i.e., services or employment) by any program or activity receiving federal financial assistance. Methods of enforcement include injunctions prohibiting noncompliance, a private right of action by individuals for damages, fines, imprisonment, or suspension of funding.

Funding and Advocacy Uses

This Act has been used primarily for direct funding of ILCs in a number of communities.

To the extent that the Act pays for advocacy services and specifies substantial involvement by consumers, it has helped advocate for the rights of citizens.

This section of the Act has been used primarily for advocacy. Considering the number of programs and activities receiving financial assistance, this provision has extremely broad impact.

Indirectly, this portion of the Act funds independent living services by making other services and employment for the handicapped available.

ARCHITECTURAL BARRIERS ACT: This legislation is designed to ensure that facilities housing programs funded in whole or in part by the federal government (e.g., post office building) are accessible. Many states have similar laws for their facilities. But there are important variants in each state law, such as the facilities covered and exemptions.

This legislation has been used to advocate for renovations and construction of accessible facilities across the country.

Indirectly, this act funds IL services by making a broad array of buildings and programs accessible.

Studying laws and policies is difficult and time-consuming. Efforts to change a law or establish a new one at a local or state level can sometimes take 2 or more years. But the benefits of understanding important laws and policies--as well as efforts to establish new ones--almost always exceed the costs.

TOPICS FOR REFLECTION AND DISCUSSION

What local ordinances have been established that facilitate independent living? Is there a procedure for considering the impact of all local ordinances on persons with disabilities? What state laws have contributed to achieving IL goals? How has your state's government expressed support for the IL movement? What national laws has your organization used for funding or advocacy? How might your group make better use of the legislative process?

CHAPTER IV – YOUR ORGANIZATION

Any organization that endures over a long period of time relies on documents of one sort or another for legitimacy and continuity. New organizations hoping to endure are wise to follow this lead.

This section of the workbook is intended for the important documents that guide the operation of your organization. These documents will help answer questions about how your organization is structured and how its parts relate to each other.

Section 1: Profile of Your Organization

There are a number of documents that guide the operation of your organization. These documents include the articles of incorporation, by-laws, policies, procedures, and memoranda of agreement. Everyone working within your organization should be familiar with these documents. If you do not have written policies covering the operation of your organization, they should be developed.

In addition, there are a number of individuals who are critical to the planning, operation, and maintenance of the organization. These individuals include staff and board members (governing and advisory, where applicable). In order to function effectively as a contributing member of the group, it is important that you know how each of these individuals contributes to the organization. The following section provides some of this information about people in your organization.

TOPICS FOR REFLECTION AND DISCUSSION

What have been the best, most helpful policies of the organization? Who has the most unique background of the board members? Who do you think has the most interesting job of the staff? Who on the board is most like you? Least like you? From whom do you think you might learn something?

STAFF PROFILES

INSTRUCTIONS: Use this form to keep a list of those who have worked and are currently working in the organization.

Staff Member	Job Title	Responsibilities

BOARD PROFILE

INSTRUCTIONS: Use this form to keep a list of all those who have served and are currently serving on boards.

Board Member	Committees	Background

Appendix 1

SERVICES COMPENDIUM FOR INDEPENDENT LIVING

INSTRUCTIONS: Review each major type of program and service and each component to identify the activities of your organization. List the type, component, and definition on the chart in Section 6.

**TYPE OF PRIMARY
SERVICE**

**SERVICE/PROGRAM
COMPONENT**

**DEFINITION, EXAMPLES,
CONFLICTING, OR VARYING
INTERPRETATIONS**

**DIRECT
SERVICE**

COUNSELING

Typical counseling services include: rights & benefits, sexuality, crisis, financial. Provided by either professionally trained counselor (peer or nonpeer) or by nonprofessional peer.

Recent research conducted by Moses (1982) has begun to bring the issue of peer counseling into perspective. Peer counseling has traditionally been considered a service. Moses' research has concluded that peer counseling should be considered a method of service delivery rather than a service. Peer, then, becomes a descriptor of a job qualification for a counselor.

	ASSESSMENT/EVALUATION	Assessment/evaluation involves determination of individual needs in any of a number of areas. Assessment often takes place during the intake process and periodic reassessments.
	TRANSPORTATION SERVICES	Center operates a bus system that provides transportation to consumers, often at reduced or no cost to the user.
	ATTENDANT CARE SERVICES	Center locates, trains, and employs attendants who provide attendant care services to consumer.
	RECREATIONAL-SOCIAL SERVICES	Center directly sponsors and/or provides recreational services for consumers.
	ACCESS SURVEYING	Center surveys housing, restaurants, public buildings for consumer. Considered a direct service when survey benefits primarily one consumer.
INDIRECT SERVICES	HOUSING ASSISTANCE	Center maintains a file of accessible low-cost housing. Provides locations to consumer, but consumer is responsible for making contact. May also include arrangements for adaptations to housing.

**ATTENDANT CARE
ASSISTANCE**

Center maintains file of attendants to be used by consumers. Consumers are responsible for making all arrangements with attendants. Attendant is employee of consumer.

**TRANSPORTATION
ASSISTANCE**

Maintains file of public transportation providers. Assist with procuring adapted vehicles. Assists with ride-sharing arrangements.

**RIGHTS AND BENEFITS
INFO & REFERRAL**

Advises consumers of available benefits and rights. Provides information about appropriate contact person.

**PEER COUNSELING
INFO & REFERRAL**

Provides information about available peer counseling in the community.

**ACCESSIBILITY
INFO & REFERRAL**

Informs consumers about public buildings and other inaccessible public areas.

LEGAL INFO & REFERRAL

Maintains file of low-cost legal services and attorneys knowledgeable about rights of disabled persons. Assists consumer in making contact.

**RECREATIONAL-SOCIAL
INFO & REFERRAL**

Maintains information about special recreational or social activities for persons with disabilities, e.g., wheelchair basketball league, beep softball, support groups.

INTERPRETERS & READERS

Maintains records of individuals trained and available to provide interpreter services or to serve as readers. May provide training to those individuals.

**INDEPENDENT LIVING
SKILLS**

**PERSONAL
ADVOCACY**

Provides advocacy training to consumers often through peer counseling.

**TRANSPORTATION &
MOBILITY SKILLS**

Provides training in mobility in the community via public transportation or personal vehicle. Might also involve perceptual training for directions.

**COMMUNICATION &
ASSERTIVENESS**

Provides assistance to consumer to communicate better. Typical services might include assistance with obtaining adaptive devices or speech therapy. Peer counseling in assertiveness might also be included.

**GOAL SETTING/DECISION
MAKING/PROBLEM SOLVING**

Typically, counseling to the individual to set personal goals and make decisions about his/her life.

**ATTENDANT MANAGEMENT
SKILLS**

Provides training in skills necessary to interview and hire attendants, schedule attendants appropriately, and maintain productive relationship.

**SELF-IMAGE
DEVELOPMENT**

Typically, a counseling relationship with a peer to develop positive self-image.

**MONEY MANAGEMENT
SKILLS**

Training in setting priorities, budgeting, handling money, and banking.

**HOUSEKEEPING/
SHOPPING/COOKING**

Provides training to individual in skills necessary to live in independent setting. May include assisting the individual in identifying those areas in which assistance is required or assisting in adapting environment to meet individual needs.

**RECREATION &
LEISURE SKILLS**

Assistance to the individual identifying information sources about community activities, making social arrangements, and using leisure time productively and satisfyingly.

	COPING SKILLS	Counseling provided by peer to individual in coping with his/her disability, with personal crisis, and with day-to-day demands on individual.
	BOARD PARTICIPATION	Training to individual in community decision making through participation on boards of directors, civic activities, and other leadership roles in the community.
COMMUNITY/ ENVIRONMENT	TRANSPORTATION DEVELOPMENT	Involvement of the center in community planning and implementation of public transportation services to meet needs of disabled persons. Includes participation on Transportation Advisory Boards, spearheading cooperative transportation projects to maximize specialized transportation availability.
	HOUSING DEVELOPMENT	Includes direct involvement with housing authority, city county planning commissions, federal authorities providing funds and other assistance in housing for special populations (HUD).

**PUBLIC INFO &
AWARENESS**

Includes public information and media campaigns about rights of disabled, needs of disabled, and services available. Enhances sensitivities of public to needs.

**ATTENDANT
DEVELOPMENT**

Develops pool of attendants, both volunteer and paid, through public speaking engagements and public information campaigns. Develops and provides training to individuals. Also maintains emergency attendant pool.

**PEER HELPER &
COUNSELOR
DEVELOPMENT**

Develops pool of individuals willing to serve as peer helpers/counselors. Develops and provides training for individuals.

**COMMUNITY BARRIER
REMOVAL**

Inventories community and actively works with community officials to remove barriers.

**RECREATION
DEVELOPMENT**

Encourages development of recreation opportunities for disabled by working actively with city parks and recreation, youth groups, and civic clubs to identify and remove barriers from existing programs, and promotes community interest in developing more programs.

**EMPLOYMENT
DEVELOPMENT**

To work with employers, job service agencies, and educational institutions in the area to develop employment opportunities for disabled. May include identifying barriers and potential adaptations of work sites, providing special assistance to employees or employers.

ADMINISTRATION

CASE MANAGEMENT

The system an agency uses to track an individuals needs and progress. Case management also ensures accountability of the agency.

**CONSUMER
INVOLVEMENT**

The activities an agency is involved in to ensure consumer involvement. Examples are providing staff assistance to a consumer advisory committee, holding special meetings to solicit consumer input and advice.

**CONSUMER
SATISFACTION
EVALUATION**

Evaluation activities conducted by the staff or board to measure consumer satisfaction with center operations.

**COMMUNITY RESOURCE
DEVELOPMENT**

Activities sponsored by the center to develop resources in the community--financial or human. Resource development activities can include special events, sponsorship of special advisory committees to local governments, or inventorying resources.

**CENTER FINANCING
LOCAL, STATE, FEDERAL
FOUNDATION**

Includes grant writing, special local fund-raising activities, and activities to encourage local government financing of the center.

**PROGRAM IMPACT
EVALUATION**

Evaluation of all center activities to measure the center's impact on quality of life for disabled people in the community. Impact evaluation includes setting measureable objectives, recording data, and measuring changes in the community.

**AGENCY SERVICE
NETWORKING**

Activities the center is involved in to encourage coordination of services and reduce duplication of services through participation in special community councils, cooperation with other agencies in conducting communitywide needs assessments.

CENTER EVALUATION

Evaluation to determine what services were provided and how much, impact of the center on the community, and cost effectiveness of service delivery.

STAFF DEVELOPMENT & TRAINING

To ensure quality of service and to retain well-qualified staff members, the center is involved in providing or arranging activities to train staff and keep them up-to-date with IL developments.

NEEDS ASSESSMENT

Center activities to assess needs of disabled individuals in the community.

CENTER PLANNING

Long-range goal setting and short-term planning to ensure consistence of center activities with IL philosophy and to prioritize activities according to community needs and available resources.

LEGISLATIVE ADVOCACY

Activities in which the center is involved to support improved quality of life for disabled persons. Examples include lobbying local, state, or federal legislators, providing supporting data to legislators, writing legislation.

SYSTEMS ADVOCACY

Activities supporting changes in social and environmental systems to improve conditions. Examples include changes in government and changing social attitudes about the disabled and their right to live the way they want.

REPORTING

Providing information in report form to funding agencies, the community, and consumers. Includes program reporting and financial reporting.

Appendix 2

GLOSSARY OF TERMS AND OTHER IMPORTANT IDEAS

Because IL covers so many aspects of day-to-day living, many new terms have developed. These terms include those associated with legislation, government programs, research and literature associated with independent living, and local projects that provide services to disabled consumers. The following information is divided into two parts. The first is a list of basic terms and ideas associated with independent living. The second is a list of common acronyms that you may come across in your advisory committee activities. Review these lists, and ask someone at the local center for clarification, if there are terms you don't understand.

Space is provided at the end of each list to allow you to add any new terms. Write them down, find out what they mean, and share them with the rest of the group. You may find that new terms or ideas represent new activities or new policy directions that need group attention. Possibly, a new resource will emerge that can be used by the group.

Try to keep your list up-to-date by making notes when you come across changes. This is especially important when dealing with federal programs. They change rapidly, and it is difficult to keep information current. Share changes with other group members.

GLOSSARY OF SELECTED TERMS

ADVOCACY	General and specific intervention to support or ensure the rights of those who are otherwise unable to assert their rights.
COMPREHENSIVE COMMUNITY DEVELOPMENT PLAN	A statement identifying current housing conditions, needs, major problems, and a comprehensive strategy for addressing them.
COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING	Any service that enhances the ability of a disabled individual to live independently and, if appropriate, secure suitable employment.
DUE PROCESS	Requires the government or other administrative agency to act in a fair manner. May involve a hearing process in which the individual must be given the opportunity to present evidence, cross-examine, and be represented by counsel.
GRANTEE	The agency, institution, organization, or individual that receives an award and is accountable to the granting agency for all project funds, noncash contributions to the project, and performance of supported activity.
MATCH OR MATCHING SHARE	The portion of allowable program costs not borne by the federal government. Often, the law that establishes a program also sets a formula or percentage of the total costs that must be contributed from other sources.
MEANS TEST	Examination of a person's resources, assets, and income to determine if she/he is eligible to receive program benefits.
NEEDS ASSESSMENT	The process of finding out what types and what quantities of service are most needed in an area. Also, may identify needs that services cannot meet or presently do not meet.

NONCOMPLIANCE	Instances in which programs fail to comply with statutory regulations that govern the program.
NONPROFIT OR NOT-FOR-PROFIT ORGANIZATION	An organization no part of whose net earnings (after salaries) may lawfully benefit any shareholder or individual.
SITE VISIT	A visit by federal officials and experts to evaluate center performance and to suggest constructive methods for dealing with deficiencies.
START-UP FUNDS	Funds from any source used to help initiate a program by paying some of its initial expenses.
VENDOR	A person or organization paid to provide services.

COMMONLY USED ABBREVIATIONS

APTD	Aid to the Permanently and Totally Disabled
BEH	Bureau of Education for the Handicapped
CDBG	Community Development Block Grant
CMHC	Community Mental Health Centers
CSA	Community Services Administration
DD	Developmental Disabilities
DI	Disability Insurance
DOT	Department of Transportation
DOE	Department of Education
EEOC	Equal Employment Opportunity Commission
ESEA	Elementary and Secondary Education Act

FY	Fiscal Year
HAL	Handicapped Assistance Loans
HAP	Housing Assistance Plan
HHS	Department of Health and Human Services
HUD	Department of Housing and Urban Development
IEP	Individual Education Plan
ILCs	Independent Living Centers
IWRP	Individualized Written Rehabilitation Program
JTPA	Jobs Training Partnership Act
LEA	Local Educational Agency
NIH	National Institute of Health
NIHR	National Institute of Handicapped Research
OASDHI	Old-Age, Survivors and Disability Insurance
OHDS	Office of Human Development Services
OILD	Office of Independent Living for the Disabled (HUD)
OJT	On-the-Job Training
P & A	Protection and Advocacy
PCEH	President's Committee on Employment of the Handicapped
RFP	Request for Grant Proposal
RSA	Rehabilitation Services Administration
RSDI	Retirement, Survivors and Disability Insurance
R & T	Research and Training

SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TTY	Teletypewriter
VA	Veterans Administration
VE	Vocational Education

Appendix 3

References and Suggested Readings

The following lists those works cited in the text and other readings related to the topic. The starred items are highly recommended for advanced orientation and study.

*Bowe, F. (1978). Handicapping America: Barriers to disabled people.

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