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Implementing Independent Living Centers

Conference Proceedings

Edited by G. Timothy Milligan

**Arkansas Rehabilitation Continuing Education Program
Arkansas Rehabilitation Research and Training Center
University of Arkansas
Arkansas Rehabilitation Services
February 1981**

IMPLEMENTING INDEPENDENT LIVING CENTERS
Conference Proceedings

Edited by G. Tim Milligan

ARKANSAS REHABILITATION CONTINUING EDUCATION PROGRAM
Arkansas Rehabilitation Research and Training Center
Hot Springs, Arkansas

February 1981

University of Arkansas

Arkansas Rehabilitation Services

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INTRODUCTION

The funding of new centers for independent living through Title VII, Part B, funds created a need for training in HEW, Region VI.

New program managers and state rehabilitation agency coordinators for independent living were named. Independent living centers and state rehabilitation agencies were given the mandate to develop new service programs, hire and train center staff, and develop cooperative relationships among the centers, the state rehabilitation agencies, and community resource agencies.

The need for training became apparent and in March, 1980. A regional training committee met in Little Rock, Arkansas, to identify common training needs for independent living. The committee agreed that the most pressing need was to provide training that would help smooth the implementation process for the expected new independent living centers. The training content recommended focused on strengthening cooperative relationships between the state rehabilitation agencies and the new independent living centers and providing needed information to help the new centers begin operation.

These Conference Proceedings were developed to share this training experience. We hope that as new centers for independent living develop, this document will provide valuable "starting up" information. Also, existing centers should benefit from a review of the basics offered here.

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AGENDA

IMPLEMENTING INDEPENDENT LIVING CENTERS

September 30 - October 3, 1980

Tuesday, September 30, 1980 - Holiday Inn - Lake Hamilton

An Overview and Update on
Independent Living from RSA
Central and Regional Office
(Informal question and
answer session)

Bill Bean

1st Day

Orientation, Purpose,
Objectives

Tim Milligan

"Cooperative Efforts and
Support - The Challenge"
(Keynote Address)

Vernon Glenn

"Concepts and Philosophies
of Independent Living"

Lex Frieden

"Characteristics and
Functions of Independent
Living Centers - A
National Perspective"

Laurie Gerken

"Independent Living -
Example of an Ongoing
Project"

Beverly Chapman

"Issues in Implementation"
(Small Group Meetings)

State Coordinators of
Independent Living
Independent Living
Center Directors
Other Rehabilitation
and Independent
Living Center
Personnel

2nd Day

"Issues in Implementing
Independent Living Centers
and Linkages with Vocational
Rehabilitation Agencies"

Panel

2nd Day (continued)

"Program Evaluation for
Independent Living Programs"

Tim Muzzio

Curbstone Conferences:

- . Program Evaluation
- . Linkages and Special Concerns
- . Linkages and Special Concerns

3rd Day

"Developing Action Plans
and Agendas to Accomplish
Implementation"

Tim Milligan
Small Groups by
State Agency

GROUP RECORDERS:

Tim Milligan
Michael Leland
Leon Thornton
Doug Rice
Laurie Gerken

Reports from Small Groups

Independent Living
Center Directors/
State Coordinators
of Independent Living

INDEPENDENT LIVING - THE CHALLENGE

Vernon Glenn

Dr. Glenn is Area Coordinator of Rehabilitation Education and Research within the College of Education, University of Arkansas. Dr. Glenn also serves as a Deputy Commissioner for the Arkansas Rehabilitative Services. Under his direction, the area of Rehabilitation Education and Research has become one of the more progressive and comprehensive rehabilitation programs in the conduct of rehabilitation education, research, and training. Program units under his supervision are the Arkansas Rehabilitation Research and Training Center, the Rehabilitation Education Academic Program, and the Arkansas Rehabilitation Continuing Education Program.

INDEPENDENT LIVING - THE CHALLENGE

Today I will talk about change and where I think we are going in rehabilitation. I start with the premise that the word "rehabilitation" should come first when we are discussing kinds or types of rehabilitation services. It is a little disturbing when I hear rehabilitation professionals discuss vocational rehabilitation and independent living rehabilitation as if they were two separate entities. I view both as extensions of rehabilitation, and it seems more appropriate to identify them as "rehabilitation for vocational employment" and "rehabilitation for independent living." By placing rehabilitation first, where it belongs, we can continue to extend the concept of rehabilitation as we have done through the years and will continue to do.

The focus of this conference is on independent living centers, and, as someone has already stated, independent living centers are something new. We sometimes like new things. We like a new suit, a new dress, a new car--but when it comes to new rehabilitation programs we oftentimes prefer the old way, the status quo, and resist new approaches for serving new disability groups. Independent living as something new is causing us to change the way we view rehabilitation. I believe it was Benjamin Franklin who said, "Choose your rut carefully; you'll probably be in it for the next twenty years"--the message being that most of us resist change and find it kind of nice being in a rut. Applying this quote to rehabilitation professionals we could say, "Choose your rehabilitation program carefully; you will probably be believing in it for the next twenty years." When talking about change I am reminded of a rehabilitation counselor, and a friend of mine, who had been in rehabilitation for several years. I was with the R&T Center, and we were conducting a training program on some new ideas we thought were pertinent to rehabilitation counselors. This counselor

listened very attentively, often nodding his head as if he were in agreement with the statements we were making. At the afternoon coffee break he came to me and said, "Vernon, you know I like you and I'm your friend, and I think you R&T people have some good ideas about how to improve rehabilitation counseling; but I just want you to know that it doesn't make any difference what you come up with--I'm not going to change." The counselor was honest, and he didn't change. Like many of us he was in a rut and preferred to stay there.

Independent living represents a change in the way we view rehabilitation. The change may not be in the type of services we deliver, but in the way we deliver them and our attitudes toward the people served and services delivered. Today the trend is toward community-based rehabilitation. Rehabilitation must be provided in a comprehensive and coordinated action within the community. The effects of disability are often multiple and require a complete, coordinated process to be reduced or eliminated. It is important that the services provided by both governmental and voluntary agencies be coordinated and integrated within the community. Rehabilitation should be an integral part of the different levels of services within the community such as hospitals, higher education, vocational training, employment, and all the areas of social insurance and social services. The focus of rehabilitation efforts should constantly be on providing care in the community, and one goal should be that of keeping families together. People with permanent impairments and continuing rehabilitation service needs may thus obtain the services they require within the community, rather than apart from it. Rehabilitation should be a community concern, a community obligation, and a community operation.

The trend in rehabilitation is toward control by consumers. There is every indication this will continue and accelerate. This means that rehabilitation services will be more consumer-directed and the persons needing the services

will determine, manage, and direct their own rehabilitation programs with direction and assistance from professionals as needed and requested. As rehabilitation practitioners, we should advocate and insist that disabled people assume a major role in designing and organizing the services they and their families consider needed. Systems for participation should be developed whereby disabled people are involved in the decision making process in the hospitals, medical centers, training institutions, housing projects, education programs, and other general support systems. The true concept of independent living is severely disabled people taking control of their own lives. The beginning of this is directing their own rehabilitation programs. Consumer involvement means we are moving away from counselor/professional oriented services to client/consumer oriented services. This movement requires that service delivery people change their attitudes about their approaches to the delivery of services.

During the past fifty years rehabilitation has had an excellent record of delivering services to handicapped people, and we can rightly take great pride in this. But we cannot continue to live on this past record. Severely handicapped people in need of services today are not too interested in what happened two years ago, three years ago, or ten years ago in rehabilitation. We can learn a lesson about change or the lack of change from large corporations in this country. For example, U.S. Steel, one of the major steel producers, is now in financial trouble because they failed to review their system, adopt new ideas, and change with the times. The American automobile industry has discovered the hard way that people who buy cars are not too interested in what Chrysler did ten to fifteen years ago. At one time Chrysler had a great delivery system for building and selling cars. But something happened--or did not happen--along the way. The September issue of Time Magazine has an article about the troubled automobile industry, and I offer this quote from that article" "Detroit's old way of doing

business no longer suffice. Workers, plant supervisors, and white collar executives are searching for ways to improve quality and output. The roles and responsibilities of workers, managers, and government officials in the automobile industry are rapidly changing." Apply that quotation to rehabilitation and it reads like this: "Rehabilitation's old way of doing business no longer suffice. Rehabilitation workers, supervisors, and administrators are searching for ways to improve quality and output. The roles and responsibilities of rehabilitation professionals, supervisors, and federal officials in the rehabilitation field are rapidly changing." Rehabilitation is changing, and the independent living movement is speeding up this process of change.

Rehabilitation for independent living is causing us to re-examine the definition of rehabilitation. If you ask a counselor, "What is rehabilitation?", he/she will usually reply that it is a group of services that helps handicapped people get back to work; or it is a process that coordinates services to improve the lives of the handicapped. However, when we examine this, we can see that a group of services or a process does not adequately describe rehabilitation. Rehabilitation is a concept, a concept of independence and equality. It is a concept that is fluid, and always evolving. If we imagine rehabilitation as a circle, we will see that in 1921 it was a very small circle, applying only to the physically handicapped. Through the years the circle has been enlarged to include the blind, the mentally ill, the deaf, the mentally retarded, and other disability groups. Today rehabilitation for independent living is requiring that the circle again be enlarged to include the most severely handicapped people, who may or may not be moving toward a vocational goal. Even today we must view rehabilitation as being larger than vocational or independent living and remain flexible so that we may again enlarge the circle when the need exists.

Rehabilitation for independent living is causing rehabilitation leaders to examine new ways of utilizing resources. The big question facing rehabilitation state directors today is how to provide more services to more people with fewer resources. When we try to answer this question, it leads us to several other questions that also must be addressed: How to establish priorities? Who should establish priorities? How should funds be allocated? What kinds and levels of personnel are most appropriate for service delivery? Perhaps the most important question is--Do we need to spend more money or do we need to spend the money we have more wisely? Legislators and consumers would probably tell us to examine the latter in more detail. As we learn and demonstrate the use of money more wisely, we will probably find more funding will be available. Funding is a problem; it always has been and always will be. But looking on the positive side, a delay in or lack of funding for independent living programs may be positive in that it gives us time to think through how we can most effectively utilize resources. Although independent living centers have limited funding, it gives us an opportunity to experiment and evaluate approaches so that when funds do become available we will know how to use them more wisely.

The lack of resources and the need for services require strong leadership in rehabilitation. Organizing and delivering rehabilitation services is more difficult today than ever before, and strong leadership is needed more than ever before. We need leaders who can establish priorities, allocate resources, and follow through. This is difficult because there are many advocate groups who are pushing for a specific service. Today, in our society, each organ of the body has a national organization working for it. These organizations will lobby for funds to be allocated to their specific organ of concern. We need rehabilitation leaders who can look at the needs of the whole person and who will advocate total rehabilitation. We have a need for leaders who are

generalists, as opposed to specialists. They need to be generalists in the sense that they can look at total needs and not be an advocate for one specific type of rehabilitation. State administrators should advocate just as strongly for rehabilitation for independent living as they do for rehabilitation for vocational employment.

Since independent living centers are a new service, there are three areas that must be given concern to effectively initiate and develop the program. First, is knowledge and information. We need all the knowledge and information available in reference to independent living and independent living centers. Second, we need personnel who have the skills, or who are trained to effectively use this knowledge, to implement this service. Third, we must have personnel who are committed, who have a positive attitude about independent living, and who have a desire to serve clients eligible for independent living services. I believe that sufficient knowledge and information are now available to implement independent living centers. I think there are personnel available in the general rehabilitation agencies who are adequately trained and, for those who are not, we have training programs that can provide the skills needed to implement independent living centers. The one area where we may be lacking is commitment and attitude. Commitment is the basic ingredient on which implementation depends. So, we need rehabilitation leaders and rehabilitation practitioners who believe that rehabilitation services should be provided to all people in need of them, without discrimination on the basis of age, sex, financial capabilities, ethnic backgrounds, type of impairment, cause, severity, or prognosis.

Earlier I stated that independent living is a new service. I now want to reverse that statement and say that independent living is not new. The goal of rehabilitation has always been independent living. When rehabilitation services were provided to assist an individual to become employed, the goal was to make that person more independent.

The goal of rehabilitation has not changed. We are just redefining the objectives and are broadening the circle to include another level of people.

Rehabilitation means independence. Independence includes independent living, which means freedom--freedom of movement, freedom to learn, freedom to know what your options are, and freedom to act on those options. Freedom to the same rights other people within our society have--the right to participate, the right to contribute, the right not to participate, the right not to contribute, and even the right to be dependent if you want to be. All systems of society must be open to disabled people, and it is only through integration and full participation of community resources that this can happen.

During the last six months, approximately 125,000 persons from Cuba have come to this country looking for freedom. They are looking for the kinds of freedom I have mentioned and the things that you and I more or less take for granted. Today in Iran there are 52 Americans who have had their freedom taken from them. From all indications they are getting adequate food, shelter, and clothing, which are the basic necessities of life; but the one thing that concerns us, and perhaps concerns them, more than anything else is that they are being confined and their basic freedoms taken from them. Today in the United States we have millions of handicapped people, citizens of this country, who are seeking the same kinds of freedom that the Cubans are seeking and who are longing for the same kinds of freedom that the hostages in Iran are longing for--these being the freedom to move about, the freedom to exercise their options, the freedom to involve themselves in all areas of society. As rehabilitation professionals it is our business to support and advocate freedom for the handicapped people of this country.

What are we going to do about it? Today, in this meeting, we are interested in promoting and implementing

independent living centers. Independent living centers can only be established and implemented with people like you-- people who have the proper attitude, people who are committed, people who are motivated to improving the quality of life for all handicapped people--people who are willing to collaborate, cooperate, and involve the community and community resources--people who are so involved that they do not give in, give out, burn up, or burn out. I believe these kinds of people are represented in the rehabilitation community and each of you exemplify these kinds of people.

CONCEPTS AND PHILOSOPHIES OF INDEPENDENT LIVING

Lex Frieden

Lex Frieden is Director of the Independent Living Research Utilization Project at the Institute for Rehabilitation and Research in Houston, Texas, and a faculty member of the Baylor College of Medicine. Mr. Frieden has been involved in the organization of several groups of disabled individuals including the American Coalition of Citizens with Disabilities, Coalition of Texans with Disabilities, and Houston Coalition for Barrier Free Living. Because of his extensive involvement in the independent living movement since the early 1970's, Mr. Frieden is a frequent speaker at training conferences and has published several papers on independent living.

CONCEPTS AND PHILOSOPHIES OF INDEPENDENT LIVING

I think it is significant that the Arkansas RCEP has undertaken the task of doing this training, and I also think it is significant that you are all here. Some of you are rehabilitation professionals who have been involved in services for many years, and others are consumers who have been involved in rehabilitation in one capacity or another for some time and are now having the opportunity to be involved from the perspective of providing services to disabled people.

I would like to begin this presentation by getting you all involved in discussion for the next few minutes. First, I want to focus on the basic tenets of rehabilitation by asking you to think of what rehabilitation really means. What are the concepts and philosophies behind rehabilitation? What does rehabilitation mean to you? If someone came up to you on the street and said "rehabilitation," what words would come to mind?

A GROUP BRAINSTORMING SESSION IDENTIFIED THE FOLLOWING:

1. People helping people through services
2. Making it
3. Independence
4. Equalization
5. Involvement
6. Hard work and low pay
7. Evaluation and training
8. Learning to cope with new situations
9. Utilization of potential
10. Freedom of choice
11. Opportunity

I think we have identified many important aspects of rehabilitation right here.

Now, I would like to do the same thing again, this time dealing with one aspect of rehabilitation. Focus on the word "independence," and particularly, what does independent living mean to you? What kinds of associations do you make about the term independent living?

THE GROUP SUGGESTED THE FOLLOWING:

1. Options
2. Dignity
3. Normalcy
4. Responsibility
5. A way of life
6. Personal care
7. Living on your own
8. Freedom

Take a look at these now and compare them to the list we came up with on rehabilitation. I notice several similarities, and in some cases we actually used the same phrases to describe independent living that we used for rehabilitation. The words "options" and "freedom" are immediately apparent.

One difference is that the words we use to describe independent living tend to be more personally oriented. We have also gotten more specific, having come down from the previous level of abstraction.

One particular aspect of independent living we did not specifically mention here is integration or mainstreaming, that is generally being active in everyday life, doing the same kinds of things others do.

Independent living is a social movement, in an era of social movements. Equal Rights, Civil Rights, Title V, The Women's Movement, 94-142, the Great Society, Naderism, the Consumer Movement are all examples of the age in which we live, and to some extent they are related to independent living in that they relate to individual control.

It is interesting to note that very few of the terms we use to describe independent living are related solely to handicapped people. The terms could relate to anyone, handicapped or not. I think there is a difference that may not be readily apparent, however. The difference is that disabled people are just trying to get what everyone else has anyway.

I think it is important to look at independent living as part of something that is happening not just to disabled

people, but to our society in general. It is an awakening and an awareness as are many of the movements we have seen since World War II. I think the independent living movement as we know it is a growing thing, something that has been building for a long time. It is not something that just occurred in 1978 when President Carter signed the Amendments to the Rehabilitation Act. It is not something that occurred when Ed Roberts went to Berkeley in 1972, and it is not something that occurred last week when New Mexico got a grant to fund an independent living program. It is something that has been going on for years and years.

A lot of people we run into at conferences and training programs around the country say "independent living" is a bad term, that independent living programs really make people more dependent. They talk about what independent living programs are and how people who have not before needed a program are now dependent on a program to be independent. There is a paradox there. If someone is living at home under their parents' care and suddenly the community provides attendant care, the person leaves home and becomes dependent on an attendant care program, then they are dependent and independent at the same time. They are dependent on that independent living program or that attendant care program to be independent. So, there are some problems with the terms "independent living" and "dependent living." However, I think we can call it anything as long as we understand what it is.

I think it is important to examine who we are talking about when we talk about independent living and maybe specify some of the different disability groups that independent living programs are relevant for. Who is going to benefit from independent living programs?

For example, let's look at mentally retarded people. Is the independent living movement meant for them also? When we talk about independent living, we talk of self-determination. Many people say that independent living programs do

not relate to mentally retarded individuals because they cannot be involved in complicated decision-making processes. I think we would agree, however, that the concept of independent living applies to everyone. It does not make any difference how profoundly retarded a person may be; they can still make some basic choices. All of us have limitations in terms of decision-making ability. My wife would probably say I have trouble making decisions that relate to managing money. Mentally retarded persons, just as other persons, have potential and should have the freedom to make use of that potential. The concepts of freedom of choice, of maximizing one's potential, utilizing one's abilities and so on relate to any group, disabled and non-disabled, and within the disabled population any categorical group.

The next question which we shall address here is frequently raised in discussion. That is, "Where does independent living occur?" Let us assume that we have a severely disabled person whom we are trying to help live independently. Where does that person live independently? What is the goal? What is the objective of an independent living program as it relates to people who probably have been institutionalized, either in a nursing home or a facility of some other kind, or perhaps even in the home of their parents? Where is independent living?

Independent living is in the least restrictive environment, where one can manage most independently. You have to look at each case individually. Who needs attendant care and who needs transportation? The place one functions independently depends on the individual. Independent living can be anywhere.

It should be pointed out that there may be some kind of conflict or paradox here between the concept of least restrictive alternative and our basic concept of independent living. If, in fact, we push people to progress to the point where they are able to dwell in the least restrictive alternative, we may be pushing them away from making a

choice not to live in the least restrictive alternative. If one has freedom to choose, one may not necessarily choose the least restrictive alternative. We have to be very careful lest we confuse some of these different ideas and concepts. I think it is appropriate to look at least restrictive alternatives. Normalization is one association within independent living, but at the same time I think probably the basic association is "freedom to choose." Independent living may relate to nursing homes or facilities or institutions. Independent living may be a nursing home for one person, it may be an institution for another person. The idea is that independent living means the freedom to choose.

I think we can agree that the concept of independent living is basically unlimited. Let me foul things up a bit now, and talk about reality. What do you do with that concept? How do you make that concept relevant to people? You do so with programs and services. I think it is important to make the distinction where you cross the line from concept and philosophy and begin dealing with programs and services. One thing we frequently do in human service programs is lose touch with the philosophy and concept and forget why we are providing services. We can look at a lot of human service programs and see where this happens.

In independent living we have an opportunity to develop programs and provide services and hopefully we will not lose contact with the concepts. When we begin to deal with reality it sometimes interferes with our ability to talk in terms of philosophy. We begin to find barriers and boundaries to what we are trying to do. If we can work around those barriers, if we can make them work for us, I think we can stay in much closer contact with the philosophy of the program and have a better, cleaner, longer lasting program.

Going back to the definition we had earlier for rehabilitation, the words "responsibility" and "self-determination" came out. Hopefully we are going to develop

programs where people have the support they need to develop their skills. If they need assistance they will not be totally on their own but will have the helper there to aid them.

There is going to be a lot of responsibility on the individual helper. Some people who have been involved as helpers in other service delivery programs will be limited in their effectiveness because they have always been told what to do and will bring some of those behaviors to the independent living program. Consequently, we are going to have to deal with some retraining.

Peer helpers may sometimes put more limitations on people with similar disabilities than are really there. I had a rehabilitation counselor right after I got hurt who told me I could not be an engineer because it would involve a lot of travel. I now probably travel much more than I would have as an engineer, and that counselor had the same disability I have. I don't think that we can say that just because someone is disabled they can make better or worse judgements.

There is something to be learned from having a disability, however, and from growing with that disability. Learning how to cope is a valuable experience that peer helpers can share. We really need to be careful about making absolute kinds of statements and judgements.

We recognize that the success of our programs will depend greatly on the people involved in those programs, the limitations they put on the programs and the people they are serving. We need to be cognizant of that and deal with it. We have to have staff development and we have to do training. We have to stay open-minded and encourage staff people to be that way.

I would like to skip over to the limitations the participants in the program may put on themselves. We talked about individual potential, but I think it may more accurately be labeled the individual's perception of

potential rather than actual potential. Sometimes people limit themselves through their perception of what they are able to do. This happens frequently with disabled people. Those of you in rehabilitation have experienced the other side of the coin, where people think they can do things beyond their capacity, but I think that doesn't happen as often as people being afraid of what they can do. They are afraid to try things because they are disabled.

In terms of what people actually feel about themselves, many people with disabilities don't know what they can accomplish. I felt this myself, not knowing what I could accomplish because I was disabled traumatically. People struggle to learn what their abilities and limitations are, and then when they suddenly become disabled they have no point of reference to go back to. I think that happens with people who are sheltered and people who have never had the opportunities because they were considered too disabled to get out of the house, to play with other kids, and so on. They don't really know what their abilities and limitations are, which sometimes creates false limitations.

Independent living is not only the opportunity to succeed, but also the opportunity to fail. Because there are learning processes involved, failing may also be valuable. Sometimes we do not recognize that.

I think we have an opportunity to provide valuable services and I think we have to choose what we are going to do with that opportunity. There are probably a couple of scenarios that relate to the future of rehabilitation. One of those scenarios is a rosy, happy picture in which independent living centers turn out well. All the states, consumers, and government join hands and all the providers get together, and we get all the money we need to have our independent living programs and our vocational rehabilitation programs.

There is another scenario that says we screw the whole thing up. Someone says it isn't being done right and gives the money to others. We may already have seen the

beginning of that scenario. The draft of the White House plan for independent living has all kinds of agencies doing independent and rehabilitation. Those agencies include CETA, Community Services Administration, etc. We may discover that rehabilitation is not needed anymore, that CETA or CSA or VISTA can do all the rehabilitation needed.

The choice of scenarios is really up to us. It is going to require a good bit of imagination and creativity to make our independent living programs pay off the way they are going to have to pay off if we are going to continue to have rehabilitation programs.

CHARACTERISTICS AND FUNCTIONS OF
INDEPENDENT LIVING PROGRAMS:
A NATIONAL PERSPECTIVE

by Laurel Richards
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CHARACTERISTICS AND FUNCTIONS OF
INDEPENDENT LIVING PROGRAMS:
A NATIONAL PERSPECTIVE

I would like to begin by relating an incident regarding independent living I think is indicative of where things are in the field. Last June I received a phone call from a vocational rehabilitation counselor. She called because she had a client she wanted to purchase independent living services for and she wanted information about independent living programs. The only independent living program she had heard of was the Center for Independent Living in Berkeley, California. Somehow she had gotten our name and was calling to get more information on independent living in general.

She did not know it, but for the last couple of years we have been conducting research on independent living programs in this country. At the time she called, we had surveyed and documented 83 programs delivering independent living services in the country. Eighty-three programs, and this VR counselor had only heard of one.

I think this counselor is fairly representative of many people in the field who have not been able to keep up with the rapid growth of independent living programs. It is really not surprising because tremendous changes have been taking place. Two years ago, we identified 35 programs delivering independent living services. As of last week we had documented 95. This number will almost double as soon as the 76 programs receiving Part B grants since November 1979 become operational.

I think Region VI is representative of the rest of the nation. Texas has received a grant and will be establishing two programs. New Mexico has received a grant, as have Louisiana and Arkansas. Having invested a substantial amount of time in developing a proposal to operate an independent living program, certain persons in this room will now be responsible for implementing these programs. They will have to find staff members, find office space, conduct

client outreach, develop a good relationship with a board of directors, and satisfy the expectations and concerns of the various disability groups in the community.

Today, I would like to provide you an overall perspective of the characteristics and functions of independent living programs on a national scale. Later, I believe Beverly Chapman is going to talk about her program in particular.

I will begin with an overview of services existing independent living programs typically provide. These services can be divided into two categories - those delivered by the program and those delivered indirectly through referral to existing services in the community. Direct services include residential facilities, attendant care services, transportation, independent living skills training, advocacy, wheelchair equipment repair, peer counseling, and other kinds of services. Indirect services include apartment registry, attendant care, interpreter/reader registry, information exchange registry, political lobbying and organizing, communications and newsletters, community consultation, and other kinds of services.

As you can see, direct services are those which program staff deliver directly to clients, whereas with indirect services, clients are referred to other organizations and programs within the community. Since each independent living program is organized around a set of services dictated by the community in which it is located, each program is different from every other. However, there are three basic models of independent living programs. Lex Frieden discussed these earlier. They are the transitional model, the residential model, and the center model. As you might imagine, a program is defined by the kinds of services it provides.

We are going to look first at a very specialized kind of program, the transitional program. Its primary focus is on facilitating the movement of severely disabled persons from comparatively dependent living situations to comparatively independent living situations. Its primary services,

therefore, must include independent living skills training. Independent living skills training may involve attendant management, financial management, medical needs, social skills, living arrangements, and so forth. It should be noted that in order to support the training in independent living skills, a transitional program will probably offer other kinds of services. These other services may range from peer counseling to housing to advocacy services. In addition, the transitional program's services must be time linked or goal oriented. That is, they must be provided on a temporary basis. Since the transitional model for independent living programs is specifically designed to facilitate a client's passage to a higher level of functioning, all of its services are designed to enhance that process. Once the passage is accomplished, the client no longer requires the services of a transitional program. A transitional program is definitely not designed to provide support to a severely disabled person on an on-going, permanent basis.

The second type of program is the residential program. A residential program's basic purpose is to provide severely disabled persons an alternative to living in an institution or with their family. Its services include, of course, a residential facility. It also should provide, either directly or through referral, attendant care services. In addition, transportation may be offered as a primary or secondary service. Unlike a transitional independent living program, a residential program offers its services on an on-going basis.

The third kind of program is the independent living center. An independent living center's primary objective is to assist severely disabled persons to continue living independently. It also has specific characteristics and offers the following kinds of services: apartment registry, attendant services or registry, paralegal and financial counseling, peer counseling. It will also offer at least one of the following: political lobbying and organizing,

advocacy, communications in newsletters, information exchange registry, and other kinds of services. An independent living center is non-residential and non-profit and offers its services on an on-going basis. In addition, at least 50% of its board of directors or at least 50% of its staff is disabled. So, an independent living center is consumer controlled.

When analyzing the data returned from our 1978 survey of programs and the data from the surveys we conducted this past spring and summer, we found many programs which provided services to facilitate independent living but did not fit the criteria for any of the three programs we just talked about. For lack of a better name, we called these programs "independent living service providers." A program is an independent living service provider under certain kinds of conditions.

- . If it identifies any of the following services as a primary function - medical treatment services, protective supervision, or a sheltered workshop.
- . If it does not offer at least two of the following services - transportation, peer counseling, political lobbying and organizing, advocacy, social-recreational activities, independent living skills training, and/or wheelchair equipment and repair.
- . If less than 30% of its staff is disabled.

As this indicates, an independent living program is characterized by substantial consumer involvement and a set of essential services which assist severely disabled persons to live independently. Also, it is community based rather than based in a hospital or in an institutional setting. All organizations which provide independent living services but do not conform to this three-part qualification are independent living service providers.

It might interest you to know of the 75 plus programs receiving Part B funding, including the ones in Region VI, most are styled after the center model. There are good reasons for this, and the overriding one, I think, is financial. It is terribly expensive to operate a residential program and \$200,000 simply will not go very far. In addition, because of their nature, neither transitional nor residential programs can serve as many clients as a center which puts its staff energy into peer counseling, maintaining registries, advocacy, information, and referral kinds of services. We all realize that in this time of few dollars for independent living it is important to serve as many people as possible. But by no means is this to say that a center is the best of the three models. Without doubt, the best kind of independent living program is the one which meets the needs of your community, which understands the resources within the community, and the needs and desires of the disabled people living within the community. It is likely that all three types of programs are needed in any given community.

There are specific kinds of services independent living programs have in common and I would like to spend a few minutes looking at those. I have an example of a computer printout from our registry of independent living programs. I will go over the categories and comment briefly on each.

- . "Type of Program" - This will be center, residential, transitional, or service provider, depending on services provided.
- . "Disability Served" - Single or many.
According to our research, more than two-thirds of the programs serve persons with many different disabilities.
- . "Target Disability Type" - This enlarges on the previous category and provides a description of the typical clients served.

- . "Number of Persons Served Per Year" - This will vary according to programs. Residential programs may serve fewer than 50 while non-residential programs may serve more than 500.
- . "Goal Orientation" - On-going or transitional. There are more than twice as many on-going programs as transitional.
- . "Service Setting" - Residential or non-residential. Both types are about equally represented, while some offer services in both settings - Boston's Center for Independent Living is an example.
- . "Neighborhood" - By far, most programs are in urban areas; we identified only three rural programs. In the past, university campuses were common sites for programs, but there is a definite shift to urban settings.
- . "Service Delivery Method" - This may be direct, indirect, or both. Most programs provide both direct and indirect services. A few of the older programs provide only direct services with no referrals, but most newer programs emphasize information and referral services. This reflects a growing concern for utilization of community resources and reflects a growing emphasis on advocacy.
- . "Service Delivery Style" - This category relates to the extent to which consumers are involved in the operation of the program. About half of the programs have

a majority of disabled persons on the staff. Those programs not primarily staffed by disabled people are generally directed or managed by a disabled person.

- . "Vocational Emphasis" - This has to do with whether or not vocational goals are pre-requisites for participation in the program or incidental to participation. The programs are about evenly divided on this.
- . "Specific Services" - This also varies among programs. The most frequently listed service is residential facilities. Other common ones include peer counseling, independent living skills training, attendant care, advocacy, financial counseling, transportation, and social/recreational activities.

Here is an example from our data registry. I have the New Options program in Houston since many of you are familiar with it.

TYPE OF PROGRAM:	INDEPENDENT LIVING TRAINING PROGRAM
DISABILITY SERVED:	MANY
TARGET DISABILITY TYPE:	PHYSICALLY DISABLED, 17-50 YEARS
NO. PERSONS SERVED/YR.:	50-150
GOAL ORIENTATION:	TRANSITIONAL
SERVICE SETTING:	RESIDENTIAL
NEIGHBORHOOD:	URBAN, CENTRAL BUSINESS DISTRICT
SERVICE DELIVERY METHOD:	BOTH DIRECT AND INDIRECT
SERVICE DELIVERY STYLE:	CONSUMER
VOCATIONAL EMPHASIS:	INCIDENTAL

SPECIFIC SERVICES:

*INDICATES A PRIMARY FOCUS

RESIDENTIAL	SOCIAL/RECREATIONAL
ATTENDANT SERVICES	*RESEARCH
TRANSPORTATION	COMMUNICATIONS
PEER-COUNSELING	FOOD PREPARATION
FAMILY COUNSELING	HOUSKEEPING
OUTPATIENT SERVICES	FINANCIAL AID OR COUNSELING
COMMUNITY CONSULTING	*INDEPENDENT LIVING SKILLS TRAINING
& ADVISING	VOCATIONAL EDUCATIONAL COUNSELING
ADVOCACY	

Another example, to illustrate the differences in programs, is the Center for Independent Living in Central Florida. Beverly Chapman will be providing you with details about this program later.

TYPE OF PROGRAM:	INDEPENDENT LIVING CENTER
DISABILITY SERVED:	MANY
TARGET DISABILITY TYPE:	SCT,MR,BL,DF,CP,AMP,MI,BR,STKE
NO. PERSONS SERVED/YR.:	150-500
GOAL ORIENTATION:	ONGOING
SERVICE SETTING:	BOTH RESIDENTIAL & NON-RESIDENTIAL
NEIGHBORHOOD:	URBAN, CENTRAL BUSINESS DISTRICT
SERVICE DELIVERY METHOD:	BOTH DIRECT AND INDIRECT
SERVICE DELIVERY STYLE:	CONSUMER
VOCATIONAL EMPHASIS:	PRIMARY

SPECIFIC SERVICES:

*INDICATES A PRIMARY FOCUS

APARTMENT REGISTRY
ATTENDANT SERVICES
ATTENDANT REGISTRY
TRANSPORTATION
PEER-COUNSELING
COMMUNITY CONSULTING & ADVISING
POLITICAL LOBBYING & ORGANIZING
ADVOCACY
RESEARCH
COMMUNICATIONS
INFORMATION EXCHANGE REGISTRY
FINANCIAL AID OR COUNSELING
INDEPENDENT LIVING SKILLS TRAINING

Our research over the last three years has developed some information relating to the successes and failures of existing programs. I think those of you responsible for implementing independent living programs will find these useful.

- . Provisions must be made for substantial consumer involvement in planning, managing, operating, and monitoring the program.
- . Programs should be as community based as possible.

- . Services should be related directly to the needs of the community the program serves. They should directly provide a set of services not available elsewhere in the community, and should coordinate and provide referral to existing services in the community.
- . Programs should provide a combination of on-going and transitional services-- usually independent living skills training. These may be provided temporarily in a residential setting.
- . Programs should establish straightforward management policies, modeled after other successful community-based social service programs.
- . Programs should maintain sound fiscal management and adopt effective accounting procedures.
- . Consultation and assistance from existing programs and other sources of technical assistance should be utilized.
- . Program evaluation and program outcome measures should be built into the program.
- . Multiple sources of funding should be actively sought.
- . Accountability to both funding sources and program clientele should be built into the program.
- . Strong supportive relationships with existing local and state rehabilitation agencies and the private sectors should be developed.

- . Programs should avoid compromising the idealistic principles of independent living.
- . Programs should continue to be innovative and creative.

Successful programs seem to have these things in common, while those programs which fail usually have not attended to some of these factors.

We have talked about the characteristics and functions independent living programs have in common. I want to emphasize again that most independent living programs are totally unique. They are completely different from other programs, because successful independent living programs are in tune with their communities. They are in touch with the community's pattern of life, and so, they develop a personality around their community.

It is true that many of the programs receiving Part B grants have been modeled explicitly after a few well-known independent living programs. It is just as true, however, that Berkeley is not like Hayes, Kansas; or Rochester, New York; or Little Rock, Arkansas; or Shreveport, Louisiana; even large cities like Chicago or Houston. People are different, the communities are different, the program will have to be different, too. The challenge is to those of you responsible for implementing the recently awarded independent living programs, and to you goes the task of translating the goals expressed so effectively in your grant into reality. Your charge of assisting severely disabled persons to achieve lives of greater independence must be fulfilled.

We at the Independent Living Research Utilization project are delighted with Region VI's showing in securing these grants and we are looking forward to the time when the programs become operational and more severely disabled persons will be able to participate as full members in our society.

INDEPENDENT LIVING - EXAMPLE OF AN ONGOING PROJECT

Beverly Chapman

Beverly Chapman is Executive Director and one of the founding members of the Center for Independent Living in Central Florida. A former Miss Wheelchair America, Ms. Chapman has traveled and lectured extensively as a proponent of the independent living movement..

INDEPENDENT LIVING - EXAMPLE OF AN ONGOING PROJECT

I would like to begin by telling you about our program at the Center for Independent Living in Central Florida. We recognized that we needed to find a way to bring support services to our community for severely disabled people. We looked at the models such as Houston, Berkeley, and Boston and we heard about what was happening in other parts of the country. We thought we wanted housing; I think that everybody initially feels that is the answer. But yet, the more we talked the more we realized that disabled people did not necessarily want to live next to Shirley, Tom, or Debbie, or in a certain part of town, but that people were individuals who wanted to live where they wanted to live. The fact that they needed a barrier free environment has nothing to do with their individuality.

I may be married, another person may be single, another person may be into the college scene, others may be into the country club set. Yet originally we talked about building a cripple castle, you know, a place to put all the disabled people. I think it was described as a ghetto earlier, which is probably true. Fortunately, none of us could agree on what we wanted. We finally realized that what we really wanted was services. We wanted to bring services to our community which would enable us to choose the way we wanted to live, to choose where we wanted to live, and with whom we wanted to live. That was the beginning of our center for independent living.

We are presently not funded with any Title VII money. Our program is funded by a myriad of dollars and I will explain exactly what they are, what they do, where they came from, and give you recommendations on where to go to get them.

We do have many of the services that are linked with independent living programs. Peer counseling is very important. Presently we have a staff of seventeen, ten of

whom are through the CETA program and seven from other projects. Of those seventeen individuals, 70% have a disability and they range from deaf/blind to severe mobility impairment. The staff is made up of people with degrees and without degrees, with experiences and some who have never been given the opportunity to fully utilize what they were taught. Even though some may have a Bachelors degree, no one would hire them. It takes an independent living program such as ours in many cases to give individuals the opportunity to develop themselves. We can see beyond the wheelchair or the guide dog and look at their potential. The benefits to our program are many. They are not just measured in terms of what we have done for our clients, but in terms of what has happened to us through the growth experience we have been able to offer people on the staff. For example, one member of the staff is an individual with a third grade education who lived in an institution all her life. She is one of our best peer counselors. We hired her because we saw what she could do, not just what she couldn't do.

When people come into the program they may not be interested in vocational potential or in a vocational goal; they may just be interested in a place to live or they may be interested in a job or a way to get to the mall or go to get their food stamps. Frequently, they find the world and people working in it and people being very active in it, and they want to become part of it. I think one of the most remarkable things I have seen is the number of people who have given up social security. They did not start out that way; they started out wanting to work part-time not making over \$70 a week so they would not lose their benefits. What happened was they caught that bug, that fever, that we call a lust for life. And life is most lustful when you can choose to live it the way you want, when you can reap all the benefits of it.

I get excited and get a little ahead of myself when I think about all the lives that have been affected, so back

to the program. We offer an attendant registry. We advertise in newspapers for people looking for jobs as attendants and we work toward matching up individuals. Often two or three people will want to live together to qualify for a rent subsidy from HUD to enable them to pool their resources and pay the cost of one attendant. An example of a match that often works is pairing retarded or emotionally disturbed individuals who are going through a rehabilitation program with severely physically disabled people who can give them the emotional and other kinds of support that they need. This has been successful on several occasions. We find that one of our biggest problems in dealing with attendants is where to find the funding to pay for them. Our program is working with other organizations of disabled people in the state of Florida to change Florida's state plan to allow funding for attendant services through Title 20. Title 19, which is Medicaid, will pay for attendnat services on a 50/50 match basis and there is no cap or ceiling on that money. If your state plan indicates that there are state monies for attendant services, those attendant services can be yours with half of the money being paid for through the state and the other half coming from the federal government. This may seem like a lot of money, but the \$200 a month for an attendant is not a lot when measured against the \$1,000 that it costs us as taxpayers to keep people in institutions. So there is money available for attendant services. You do have to lobby for it, and you do have to determine that it is a priority in your state, in order to tap into those resources, however.

QUESTION: Beverly, is that attendant money through Title 19 or 20?

MS. CHAPMAN:

Both - Title 19 is 50/50 match basis. The federal government matches state government 50/50. Title 20 is Medicare and must be part of the state plan, and there is

a ceiling on the number of Medicare dollars that can go into any given state. You would have to check with your state agency to determine whether or not your state has met its Medicare ceiling. Several have not, and that is an 80/20 percent; for example, a state would put up 20% and the federal government would match with 80% of the cost of an attendant care service. Where the state VR agency has gone after dollars within the state budget just for an attendant program, it offers the severely disabled individual the attendant service money they need when they start that first job until they can afford to come up with the money to wean them off of services altogether. Or, until some other creative solution can be found.

QUESTION: Is there a time frame on duration?

MS. CHAPMAN: No.

QUESTION: Assuming that someone starts to work, are we talking about six months, a year?

MS. CHAPMAN:

There is no time frame. Well, I will back up a little. I would say it depends on your state, and you need to deal with the appropriate people. In Florida, Health and Rehabilitative Services administers the Title 20 funds.

A BRIEF AUDIENCE DISCUSSION CONCERNING TITLE 19 AND 20 FUNDING SITUATIONS AND WHAT IS ALLOWABLE IN THE VARIOUS STATES FOLLOWED.

I think this points out that there is really no pat solution, if you try to be creative there are systems which we can use or which we can change. Title 19 and 20 definitions were developed years ago. There is nothing to say that you cannot try to get those definitions changed in order to accommodate this very severe and crucial need we have. But it has to be sold creatively to legislators on the basis of its cost effectiveness. Especially now, you are just not going to get anything through unless you

can document that they are investing their money wisely rather than just spending it.

Another thing I was going to mention was CETA. CETA is a prime area to develop an attendant training program. Recently I submitted a proposal for governor's special discretionary funds. It was reviewed very highly, but unfortunately the reviewing committee arbitrarily decided not to fund any new programs. But that program would have been funded had they not made this decision. Now I have taken it back to my local prime sponsor and the prime sponsor is going to fund it and provide for training, work experience, and practicum experience for 20 individuals to serve as personal care attendants to severely disabled people. My target area for the attendant population is people with developmental disabilities, people who are educable mentally retarded individuals, and people who are primarily or have been considered economically disadvantaged, or vocationally disadvantaged in the past.

I think there is a lot to be said for linking a person looking for work as an attendant with someone who is seeking the physical support. The best attendant matches seem to be those where people actually need each other. I do not think you will be successful in working out a long range employment situation with a severely physically disabled person if you are recruiting on college campuses or if you are recruiting people who are looking for unsubsidized employment or careers. They only stay as long as they need to before moving on. However, if you recruit creatively and you look for people who are looking for something other than \$3.10 an hour, who are looking for the emotional bond, a live-in situation, a tie, a belonging, these are the matchings that are working very well for us.

The other work we are doing is housing development and registry. Our program did not want to put up a building, we did not want to be the individual providing housing. There is a housing authority in our community, and we

wanted the private sector to develop the housing. However, we had an opportunity to apply for a community development block grant to purchase and renovate a facility to be used for a transitional living program, and we have purchased that. Within the next four months we will institute a transitional living program as part of the overall advocacy program our center offers. It will not be a permanent residential facility. It will probably be nine to twelve months in duration. The individuals who will be accepted through the program will be highly motivated, severely disabled people who are either involved in a work program or an educational program or a volunteer program, where they are actively pursuing personal developments. The money to purchase and renovate the facility was free with no strings. We did not pay a dime for it, it came with the community development block grant, so there is no repayment of money. The money to fund the individuals who will live in the facility will be paid through HUD Section 8 rent subsidy and/or congregate living program monies, so actually this type of transitional living program can serve as an income to an independent living service program. That was our hope when we started it.

However, you cannot have people participate in a transitional living program if there is no money for transportation services. So while we have lobbied very actively with the local transportation authority and we have severely disabled people serving on all tiers of the transportation authority boards and committees, and while transportation will be 50% accessible within the next three years, and we do have a para-transit system, it is not enough for people who are actively pursuing educational or vocational goals. If we have six people living in a transitional living program, they each have to get to college and/or work between the hours of 8 and 9 in the morning. We also needed vans to provide the transportation support to them. Also we felt that there were clients such as Status 06

vocational rehabilitation clients and also clients who have just come through VR programs who without transportation services could not complete their vocational goal. We have applied for two vans. One will provide transportation services to the individuals in the transitional living program and transportation services to sixty different clients who are served through VR programs who will be referred to us from the Vocational Rehabilitation local office.

Under services to the deaf, we are really expanding. We have a TTY, and an interpreters' registry. When people need an interpreter, they can call us and we can make the proper matchup. Our deaf community was not really easy to get in to. In our case, we have a deaf individual on our board of directors who is also the president of the TTY organization locally. There is a deaf social organization too, but they are really not activists or interested in service provisions. They have really made their way in the world and they are comfortable with it. However, that does not mean that the deaf people in our community have the services that they need.

We have a deaf person who has just been hired to work on the staff. During this year, one program goal is to bring more comprehensive deaf services to our program. Our first goal will be to deal with the deaf individuals in our community directly, to find out what they want, what they would like from us and how we can provide the services they need. There are several other things we want to do. Through the TTY we provide a message service. If a deaf individual wants to call for a bus schedule with the local transportation authority, our TTY number is listed with the local transportation authority. We found that the local CETA program was very inaccessible to deaf people. We try with everything we do, every application we make, every sign we paint, with every brochure to be just as open and available as we can, to help remove barriers, whatever they

may be, regardless of the disability.

We have two people on the staff who are blind, and who are both very experienced in working with blind people. One is a counselor from the Division of Blind Services. Another is an advocate, a very active advocate for blind people in the state of Florida. They do much of the work serving many of the blind clients we have. And, the blind client's needs are the same as everyone else's. They are looking for jobs and school.

Most of the people we find really do have vocational goals or vocational potential as defined in its broadest sense. Many lack the ability to feel that they really can achieve, that they can have a life which is full.

The next thing I was going to talk about is a community based program. We are consumer directed, managed, and operated. We have a membership of 200 people with disabilities and people who are concerned about the lives of people with disabilities. A membership is open to anyone for just a \$5 membership fee each year. Our members elect our board of directors. Our board of directors consists of twelve persons, at least 60% of whom have a physical disability.

The board of directors is charged with providing the direction and making the overall decisions of where our program will go. The board makes up the budget and votes on it, approves it, and decides overall directions. There was some concern when we first got organized that maybe there were disabled people who knew what they needed and who knew what other disabled people needed in the community, but who might not have expertise in fiscal management, personnel management, resource development, etc. So we decided to appoint an advisory committee to observe and provide advice and direction to the board of directors and to the executive director.

This advisory committee is appointed by the board and is made up of fifteen to thirty individuals who are professionals; primarily lawyers, doctors, media

specialists, resource development specialists, the director of the vocational rehabilitation program in the state of Florida, our congressman on a federal level, our state representative, state senator, our mayor and city councilmen. Just about everybody owns a little piece of the Center for Independent Living in Central Florida.

This advisory committee does not meet; the people who are on it are much too busy. I do not think that we would ever be able to get all thirty of them together in the same room if we tried now or four years from now. But, as the executive director, I can pick up a phone and call the vice president of the local bank for help with a problem. I can call the president of the local community college and ask for help with rewriting personnel policies or the director of personnel and ask what I should do about an individual I am having problems with on my staff. I do not have that kind of expertise, yet it is there; it is very readily and freely available in our community. We find this advisory committee a good way to tap into community expertise. As I said, this advisory committee gives our program the credibility and support we need by lending their names and support.

The board of directors consists of fifteen individuals. The officers are the president, vice president, secretary, and treasurer. The board's primary function is to direct and give overall direction to our program. The board hires the executive director, then leaves the executive director alone. The board allows the executive director to make the day to day operating decisions, to hire and fire personnel, and to run the program.

From what I have seen in my travels, this can be a big problem because people who serve on boards often do not actually know what their function is. I have been very fortunate to have had a board that will tell me where they want me to go, give me the ball and allow me to do it. Fortunately, they have never told me where to go but I am

sure that the day I am not pleasing them anymore, that is precisely what they will do. What that does for me is allows me to surround myself with the staff I need in order to work effectively. It allows my staff to know who they have to answer to, and it gives me the kind of leverage I need in running a team. I do not have one board member calling me and telling me one thing and another board member calling me and telling me another. Things are dealt with on a professional basis with communication through the board president and it works for us.

This function of the board has certainly circumvented many of the problems that other places and many other new programs are having.

Most of our clients come from the immediate Orlando area because of the way the population is centralized. We require our clients to come to the office; we are very strict about that. Some people will disagree with that, but we think that if people really want the services of the independent living program, if they really want to live independently, and they want us to invest our time in them, then they need to figure out a way to get to the office. We help them by providing them with the names and phone numbers of para-transit systems, or refer them to people who can provide transportation. Once they are at the office, we help with personal service assistance so that they can come alone next time, without Mom and Dad, or whoever comes with them.

We deal with people on a professional level and we structure our units of service on a professional level. A peer counseling session is an hour. New clients first see a case manager who helps them develop an independent living plan. We write a plan which is similar to the VR plan. We try to structure our services so that they are as professional as possible for several reasons. A primary reason is that we do want to survive and at some point we will be operating on a fee-for-service basis. We do

that now whenever we can; however, that does not happen as often as I would like. Somehow VR does not like it when they are giving you money to pay for staff and then you turn around and bill them for services that staff provided. They frown on things like that. But when we do provide services to the private sector, whether it is an architectural barrier survey or consulting work of any kind, we charge a fee whenever we can.

We really do not have a formal scale. I think it is fair to say that we will put on a public education presentation to anybody who needs us. We let them know there is a fee; then if needed, we waive the cost. We think it is important for them to know that what they are getting is professional consultation. We tell them that we are consultants, that we do charge but will waive the fee this year and remind them that next year they need to keep consultation for the handicapped in mind when planning their budget. I will have to wait till next year to let you know if it works. In theory it should.

The point is that we do want the public to be educated. However, we also want them to recognize that what we provide is very necessary and valuable information to them, because they should be serving all the public including the disabled.

QUESTION: You were talking earlier about your staff. I was wondering, does each member of your staff serve all your clients or do you have separate programs for different disability groups?

MS. CHAPMAN:

Our case manager knows what is in every individual's case file, follows every individual through our program to see that no one is forgotten and that no one falls through the cracks. The case manager supervises the overall management of cases, but refers clients, depending on their independent living plans, to other appropriate people on our

staff. The people on our staff are specialists in different areas of service, but they are not specialists with regard to their disabilities. We have a blind individual who is a specialist on transportation. We have a woman who has severe rheumatoid arthritis who is a specialist on attendants. We have a post-polio individual who is a specialist on employment services. So, those specialists are not necessarily related to the disability of the staff person. The only individual who does have a related disability and speciality is the person we are hiring to coordinate deaf services. She is the one who can communicate most effectively with deaf people in our community. Our staff has been taking signing classes for the past four months. We need to make ourselves accessible to all disabled people and to deaf people by learning to sign. Hopefully with the knowledge we are gaining, with our hunger to communicate with our new staff person and our new clients, we are all going to grow from this experience.

In regard to peer counselors, almost anyone on our staff qualifies as a peer counselor. Peer counseling is not solely relegated to those individuals who are specialized advocates. Most of our peer counselors, however, are part-time employees, and most are under the CETA program. We call them community outreach advocates. One of their prime functions is to do peer counseling, as well as to attend every public meeting held in our community, to put on public education presentations, and to travel to the nursing homes. These individuals are given a lot of responsibility and they work primarily as a team. When they do peer counseling they are trained first of all not to tell people how to live. Our peer counselors never say, "you should do this," or "you should move in here." Our peer counselors do a lot of listening and talk about what they know as a result of their experience. They present options but they never ever make choices or say, "I think you should do this." After all, we want our clients to make their own decisions.

We want to offer them choices, or options, and let them make those choices. We encourage our counselors to provide a lot of information and encourage people to take the step to make a decision, but we do not tell them exactly what to do. If we did, I do not think we would have an independent living program.

Admittedly, our training is "loose." We had VR counselors and a psychological counselor with many years of experience come in and train us for a week. They used role playing and talked about techniques in counseling, what works and what doesn't, how to understand someone's feelings. So it is training, but it is not highly structured, not six weeks in a classroom or that kind of thing. A lot of learning takes place in our twice-a-week staff meetings. The case manager will lead discussions about specific clients, and everyone brainstorms. They really work together as a team.

Our disabilities vary on the staff, representing most disability groups. Sometimes we find that clients will request counselors based on disability, but other times they do not. Usually they request counselors based on personalities. If one counselor is working well with a person, we honor that person's request, and try to schedule the counselor they want.

Forms, statistics, and files are all vital. We keep records on everything, down to every phone call we place for any client. We have to keep statistics if we want to get money. And in a program like ours, without the money, we turn into a pumpkin next September 18.

We were funded primarily under I&E funds for three years starting last year, but then President Carter put a stop to the third year so we are really under pressure this last year to develop alternative sources of funding. As I said earlier, we hope our transitional living program will bring in some monies.

We recently received a \$100,000 Community Development block grant. We purchased a house for \$65,000 so we can

spend up to \$35,000 in renovations. What we hope to do, however, is to take most of that \$35,000 and use it as a down payment on another place, get the labor for renovations donated through the CETA program, and get lumber and other materials by just scrounging. We hope to be able to offer transitional programs to ten to twelve people within the next year. We will be offering transitional living to at least six during the next four months.

We received money from the city of Orlando's general revenue sharing funds that go to community based organizations and we received the same type of funding from Orange County. From the Department of Labor we operated a contract last year. I indicated we received I&E funding through VR. We are also under contract with the state of Florida's VR program for what we call the CAAP contract, the Client Assistance Advocacy Project. I think many of you may be familiar with that type of project.

The state of Florida funds six consumer based organizations to provide advocacy services on a local level. We have one of those contracts. We are funded under CETA through 2B, which is handicapped work experience, 2D which is public service employment, and Title VI which is also public service employment. I indicated earlier we have an application with the Department of Transportation for two vans under the 16B2 grant. We have applied for monies next year through the United Way.

Mostly what I try to do is to stress to the community that the center is a program that operates within Central Florida and since disabled people are part of Central Florida, they should be responsible for a piece of it. One agency should not be the sole supporter of the program. We have always felt that an investment from many diverse areas has given our program the foundation it has. The city thinks we are theirs, the county thinks we are theirs, the state of Florida thinks we are theirs, and our members think we are theirs. It has worked out really nice for us,

and I would rather have it that way even though it is much more taxing on me.

When we first got started, the local community college helped us a great deal. They gave us our first equipment, desks, fiscal management, and support free of charge. At that time they also offered us the opportunity to become a college program, to not have to worry about funding the next year, to do that worrying for us. There were a great many nice things about that, but I think that our primary responsibility must be to the disabled people who live in Central Florida. They have to be our bosses and I think that is where our loyalty must lie. Also, I think that we have to have the flexibility to take a position on any issue without having to check with someone in the public relations department.

VR in the state of Florida is our best friend. We work hand in hand with them. We complement Vocational Rehabilitation. Our VR counselors are as bogged down as are counselors in any part of this country. They spend countless hours with everything that they have to do. Yet, how can they possibly complete a case or help an individual reach his potential if there are no accessible apartments in the community, no attendant referral service, and no accessible employers? Our VR counselors are too busy to be advocating for an increase in accessible housing and lobbying for transportation and other needed services. That is the CIL's job, and we do it very well. We work hand in hand with counselors. We are at the other end of the phone when they have a client who needs a place to live, or when they have a client looking for a job. We get calls from employers. They don't call VR; they call us because they know there are disabled people down at CIL looking for jobs. Those affirmative action officers want to go directly to the source; we get the initial calls, then we call VR.

Next month, Orlando, Florida, will be the host site for the state VR directors meeting. That meeting will be

held four blocks from our office. Guess who they called when they knew they had state VR directors and disabled people who were coming into our community, who needed lifts and vans, and other kinds of services? I think that is probably the nicest thing our program could do, give back a little bit to what VR has given us. For us to be at the other end of the phone when Dave Sellers says we are having disabled people who are involved in VR all over this county coming to our community, I can say don't worry about a thing. We will help them with their transportation, we will help them find accessible restaurants and bars, and we will show them the best time they ever had. I guess in the final analysis, I feel very comfortable in saying that if my VR program supervisor was here, he would say the same thing, that we really need each other and that we are, I think, a natural marriage. We belong together and we complement each other. We are in the same business, that of helping people develop themselves. The areas we work in are a little different, yet one is incomplete without the other. Certainly I feel that our program would be incomplete without VR and I know they feel the same about us right now. I hope they always will.

PROGRAM EVALUATION FOR INDEPENDENT LIVING PROGRAMS

Tim Muzzio

Tim Muzzio is a Research Associate on the staff of the Urban Institute in Washington, D.C. He is currently managing a project on independent living arrangements for the developmentally disabled population. The project analyzes a number of issues involved in success or failure in state efforts to serve developmentally disabled persons in the community. Mr. Muzzio has conducted analyses of several independent living projects and has been involved in development of measures of independent living gains by disabled persons.

PROGRAM EVALUATION FOR INDEPENDENT LIVING PROGRAMS

Because independent living is one of the few programs which can be planned and altered by its target population, it has great potential for effectively providing services. Evaluation is an important part of realizing that potential. When I am asked to speak on program evaluation to people in independent living programs, I often receive the reaction, "Why evaluate? Money can be better used to provide services." Program evaluation is often grudgingly accepted as a necessary evil. The White House Conference papers, and a number of other publications, all refer to program evaluation as a necessary evil. A lot of the comments we received while doing our evaluation of the independent living demonstrations* were very similar.

Looking at present accountability and evaluation systems one can understand why program evaluation is not fondly embraced. People who are familiar with the VR reporting system feel that it is lengthy and cumbersome. A lot of program people question what the data is really used for. They will submit a number of forms to a federal agency and much later they receive a report which reveals that the clients they served were 50% female, 48% male, and 2% other. I do not know what you do with that information.

Evaluation does not have to be that way. Evaluation can be useful, and the independent living field has a golden opportunity to show that evaluation can be functional. Right now under Title VII all programs have to be accountable; they have to be evaluated somehow. We presently have no common reporting system. RSA is presently working on one and for a variety of reasons it is in very brief form,

*A project which evaluated the ILR demonstration projects mandated by the Rehabilitation Act of 1973.

collecting very basic information. We are years away from a comprehensive common reporting instrument.

Until then, independent living centers are going to be responsible for developing evaluation systems of their own. This represents a golden opportunity because the centers can take command by developing a system directly geared toward their own needs.

The purpose of this presentation is to help you understand a little about the many reasons for program evaluation, and try to spark your imagination when you actually design systems. I cannot tell you exactly what to do, because that is going to vary greatly depending on the set-up of your program. Most of the centers have taken a variety of approaches to providing services, and because of the differences there are going to be variations in how you evaluate.

REASONS TO EVALUATE

Independent living is a new program and as any new program it has a lot to learn about improving services. We do not know the best way to provide independent living services under a particular set of constraints. Instead, centers are trying a variety of approaches. One of the first things we want to do is to see what seems to be effective under what circumstances. We are not going to be able to find that out unless we have some sort of basic information to work from. If we can collect some very basic types of data, we will have a basis from which to start evaluating our program's effectiveness. The most important purpose of evaluation in independent living is to look at center operations, how effective they are, where their weaknesses are, and where their strengths are, so they can take appropriate action based on the findings.

There are a number of other reasons why evaluation is needed. Centers must justify the existence of the independent living program. ILR is a new program without much money, and all social programs are now facing financial

problems. Funding is going down in many programs. Independent living could well join the ranks of those facing reduced funding if we cannot justify its existence, show that it is doing something, that it is serving the target population, that it is having some impact on the people we are trying to serve. Congress is going to look very closely at what has been done and how effective it has been, and upon that decide whether to extend the program, or reduce, or even close it down. We have to have some basic data to present Congress so we can justify ILR and request needed funds. Along the lines of limited funds, it should also be said that we have to make sure that we use other program funds efficiently. In the independent living rehabilitation demonstrations funded under the Rehabilitation Act of 1973, there were five demonstration projects. Very little money went into those demonstrations and they had to rely heavily on other funding sources. The demonstrations kept track of those funding sources, and by looking at cost information and funding sources were able to improve their use of other funding sources. They found out how to tap into other systems to get particular types of needed services. The evaluation system helped to identify these sources so they could be systematically used.

Another reason we need evaluation systems concerns accountability, or answer-ability, to federal, state, and local governments. In this era, taxpayers are questioning expenditures of public money. They have a right to know where their money is going. ILR programs need to show that they are doing something with their funds, and must be able to back it up with data. ILR is also accountable to the users of the centers. Centers must understand where their money is going, improve weak areas, and know they are making the best effort they can with the money available.

We also have to be accountable to the community. Independent living is very much tied to the community, and we have to be able to show that we are having a positive

impact on the community.

There are other reasons for evaluation systems. Most importantly, ILR programs must make sure the target population is served. The ILR target population is basically those who cannot be totally served by other programs. The best way to get services to them is to get some sort of basic information on service needs.

Another reason for evaluation is that RSA has reporting requirements under Title VII. They have to make an annual report on how many persons were served, who they were, and what happened with the money. ILR programs have to feed information to RSA so they can make their reports and justify continuation of the program.

I want to reemphasize that the main reason for evaluation is to help find the best ways of meeting the needs of people served by the program. The best route, many people say, is to have a common reporting system. As I said before, there are many problems with that. First of all, you cannot do that quickly. It takes years and great developmental effort to build a common reporting system. Second, since programs' purposes are varied, their evaluation formats and needs differ.

PRINCIPLES FOR DEVELOPING EVALUATION SYSTEMS

I first want to offer some guiding principles for centers trying to develop evaluation systems. Following that, I will describe some of the components that should go into an evaluation system. And finally, I would like to talk about tying together the system into a meaningful whole.

The first guiding principle is to keep it simple, straightforward, and basic. Independent living is a new program and most effort should go into making sure centers are getting services and programs set up to effectively meet needs. We do not want to spend a lot of time filling out forms or take a lot of time to develop systems when we could better be working with people. Also, ILR programs need to

be sure the information they collect is valid. Until we have the time to really examine the system, it is best to just collect very basic information that has validity.

Another guiding principle is to make sure evaluation is linked to program needs. Often, when we get tied into developing evaluation systems we get caught up in the means rather than the ends. One thing we have to keep in mind is the purpose of the program, which will go a long way toward insuring responsive evaluation.

The system should be economical. Centers should collect the needed information with the fewest possible questions. This reduces staff time needed to fill out forms, and helps keep the analysis simple. For every item of information we collect, one should ask the questions, "Is it needed?" "Why?" "What is it going to be used for?" Often items are included simply because they are in most other evaluation systems. If an item is not needed, eliminate it. It is important to keep the system economical.

Another guiding principle is to keep in mind the life of the system. RSA is working on developing a system. Centers should remember that one of these days the system they develop may not be in use anymore, so they should not spend a lot of time developing an elaborate system that may not be used in a few years.

Another very practical guiding principle is to format the system so that it is easy to use. This cuts down on the time necessary to fill out forms and insures the accuracy of the data. For example, let's look at the use of the branching concept. Under this concept, if one response is given to a question, you are instructed to skip one section of data and go on to another. That can be very useful and timesaving if it is done properly. It can also lead to a lot of problems. Some forms with branching systems are so complicated that the user is not sure where he should be next. We want to use carefully such things as branching. We also want to be sure the physical layout of forms is very

simple to follow. With some systems the user starts in the right corner, goes halfway down the page and back up to the top, then on to other sections. Complicated forms make for unreliable data. While we are not collecting a lot of data in an ILR reporting system, it is still very important that the data we do collect is accurate. The physical layout is quite important to insuring accuracy.

Another guiding principle is to develop a data analysis plan well ahead of time. This ties into something stated before; for each item in a system, you should ask yourself, "What are we going to use this for?" Not only what are you going to use it for, but how are you going to analyze it, what are you going to do with the results? Are we simply going to tally up responses, or are we going to use them to compare with other types of information we are collecting? If we can determine this ahead of time (and it takes time to do this) we can develop a very simple process for putting all the information together, tabulating it, and coming out with a useful report in a timely fashion. I am sure all of us are familiar with submitting information to state or local government and waiting a long time to get the results. By the time we receive it, the data has often outlived its usefulness. It is no longer applicable because the program has changed. If we can develop a prior plan for analysis, we can quickly get that information back to the users or others who need the information.

While on the topic of data analysis, a couple of side comments are relevant. I cannot tell you exactly how to analyze the data, because as I said, your data elements are going to change depending on your program. There are a couple of things you might want to keep in mind though. First, think about comparing your data to other data sources. It is very easy to make a system that is applicable to other existing systems, and from a political standpoint it would be very useful to do this. For example, if centers can compare some of their data to the data collected by the VR

program, they may be able to demonstrate that they are filling an important gap in the service delivery system. Such a finding would make a strong argument for continuation and expansion of Title VII efforts. Second, centers might want to compare their data to data from other independent living programs. This will help to identify gaps in one's program and learn how other programs are coping with similar problems. There are a couple of other things centers might want to do. You might wish to look at quality of services; which, though difficult to get at, is being worked on. For example, the Research and Training Center at the University of Wisconsin is looking at client satisfaction measures. Under their system, the client is involved in developing his or her rehabilitation plans at that center. They develop very specific goals for themselves ahead of time. They review occasionally to see how they're progressing and change their programs if needed. There is constant feedback into the plan. Such information is very helpful in examining quality of services. For an overall program evaluation, one can develop more general measures of client satisfaction in which the client responds to certain items on how have these services helped him or her, or items which ask for client reaction on how they think services could have been better provided. This is very simple, but effective. The information can be very useful and can help to obtain continual consumer input for strengthening the program. For those interested in looking into client satisfaction measures at the University of Wisconsin, Nancy Crew is one person to contact. She has worked with functional measures and client satisfaction measures for some years, and has always been interested in sharing information.

These are a few guiding principles. There are others, but I want to keep this very basic. Often we are finding the most basic principles are those most often overlooked. If we can keep the development of systems tied to the program purpose, if we always keep in mind that we want the system

to be economical, if we remember to look at the life of the system, if we remember the people who will be using this, if we develop a-priori data analysis plans so we can get quick feedback of our information, we can develop very useful evaluation systems in a relatively brief period of time.

COMPONENTS OF AN EVALUATION SYSTEM

I would like to turn to some components of the system centers have to develop.

The first component is a program description. Centers must first identify what their program is all about and what they are trying to do in their program. Is the purpose of the program largely tied into advocacy efforts to change systems, or is it more involved with trying to impact directly on the client, or is it doing both? Is it targeting on transportation systems, or housing programs? If a center can clearly lay out what it is trying to do, it knows what it is trying to evaluate. A critical first step is to describe the program's purposes and goals, services, and areas of emphasis. A center needs to describe its staffing, target populations and program coordination efforts, and other foci in a brief, simple, and clear fashion. This will not only help to decide what to evaluate, but it will also help others to look at the data in context. Developing a program description is a one-shot affair, updated occasionally, and is a very important component of an evaluation system.

The second major component is demographic characteristics--information such as sex, age, education, diagnostic category, and the like. Such information is typically called for by federal agencies. Such items are also very good for combining with other variables. For example, if we are going to take a look at the income of the people we are working with in the center, we might want to look at it from a couple of perspectives. We might want to look at the 18 through 65 year old category. To do that, we need the demographic variable of age. To create demographic items,

a center might want to look at some already existing systems. For example, for diagnostic categories, a center might want to collapse the R-300 categories used in the VR system. There are so many categories that few ever use all of them. But if a center lumps them into meaningful units, it can collect some information on diagnostic categories for comparison to the VR program, and thus demonstrate that it is meeting the needs of some important population missed by other programs. I would suggest that centers look at some other basic data collection systems and try to make their systems congruent with them in some respects.

There is another area, severity of disability indicators, needed for your reporting requirements. We have a program purpose, according to the Act, to serve those with either no immediate vocational potential or the severely disabled person needing extensive services. Somehow centers have to show that they are doing what they are supposed to be doing. That means collecting some sort of severity indicator information. There are a few indicators available, a description of some of these is included in "A Functional Limitation State of the Art Review" by Indices, Inc., in Arlington, Virginia.

Another area we need to collect information on involves services, costs, and funding sources. This can be simple, as manifested in our Section 130 demonstrations study. Every time a project expended money it was recorded in one of 25 cost categories. Those categories could easily be collapsed into eight or nine. In our system, we recorded the amount of money expended, what percent was paid for by project funds, and what percent was paid for from other funds. We had another column which identified the source of funds. Such information can be very useful. We can see what funding streams were being utilized. We can go to other projects and see what funding sources they are using for various types of services, explore under what conditions those funding sources could be used, make better use of other

funding sources, and save dollars.

Since ILR dollars are very few, it is very important to use as many other funding streams as possible and the system discussed above is a very simple way to collect that information regularly. In fact, it would be further simplified by setting up three columns, one for service, one for cost, and one for primary funding source. If you can identify the primary funding source and link it to the services it paid for, you can get some information which will indicate under what conditions those funds can be used to provide those services.

Another area in which we need to collect information concerns improvement indicators. In VR we know generally what we are trying to do. In oversimplified terms, we are trying to get people back into employment. So in one sense, improvement is very easy to identify, at least conceptually. In independent living it is very difficult. How do we measure improvement? It is very difficult. There are such things as functional indicators out in the field and I am sure if you surveyed the field, you could find numerous examples of functional measures of improvement. The problem is that most systems of functional measurement developed today were developed for other uses. I completed a study of functional limitations a few years ago. When we first started the study we were finding that even the term "functional limitations" meant different things to different people within the same field. We started thinking about this and realized that a functional limitation is just that-- it is "functional" to what you are trying to do. It is going to be different if you are measuring improvement in a nursing home or in some sort of group home facility. If you are dealing with physical rehabilitation, improvement means one thing. If you are dealing with vocational improvement it means something else. Functional indicators must be tailored to need. Unfortunately, in independent living we do not have too much that is applicable because independent

living is relatively new. There are a couple of efforts going on now that could have a lot of importance for independent living and you might want to borrow from some of those. For example, the University of Washington is doing some work with the state VR agency. It has been a while since I have spoken with them about what they are doing, but this is one area they said they were going to look into quite heavily. You may wish to contact them to see what they are doing.

There is a functional assessment system being developed at the University of Minnesota, again by Nancy Crew, whom I mentioned earlier. Hers is a very brief system, simple to use, requiring very little time, and can be used with a great diversity of client types. It is relevant to a number of functional areas rather than specific to certain types of disability. It is based heavily on client functioning in the community. At the Rehab Indicators Project in New York, Margaret Brown, at the Institute of Rehabilitation Medicine, reports that they have a system which is very simple to use and takes little time. I have seen the stack of materials for this system, and they are frightening, but she says they are developed so you need only use certain portions to obtain information you want to work with. They report that the system does not take long to use. You might want to check into it. In summary, one approach in measuring improvement is to use already existing available things.

Another approach is to develop your own measures. That scares a lot of people off, but actually it does not have to be all that difficult. In our Section 130 demonstrations, we had a very lengthy evaluation form. We examined all the information being collected and found that we could make most analyses with a very small subset of the information we collected. We used some very simple measures of improvement and found them to be very effective. Some of those measures included amount of social interaction. It was very simple to collect such information. For example, "Within the past 30 days how often did you go shopping, go to a group meeting,

go to some sort of public entertainment?" Six months later, a year later, whatever your interval is, we asked the same questions. In the 130 demonstrations we found a lot of change. Social interaction seems to be at the heart of independent living, and as such provides us with a very simple way to collect meaningful information and is a very strong indicator of improvement.

Another thing we looked at was unmet needs. Essentially, the form asked the clients what their service needs were and if their needs were being met (categories were provided).

We asked similar questions about equipment needs. We were originally confounded by the data because we saw an increase in the number of unmet needs as the client progressed through the program. Actually this was showing an improvement, because when we got into what the needs were we were finding that very basic needs were being met--for example, the need for basic medical care and basic equipment. A lot of the clients in these programs did not even have wheelchairs or other basic pieces of equipment they needed. We found that when those needs were met, a number of other types of needs emerged. We found needs for specially equipped automobiles, for example, on the rise. The need for typewriters for blind people increased, while basic mobility training needs decreased, making progress. While the number of unmet service needs was increasing, it was actually reflecting great improvement. (The project did not continue long enough to see if, over time, all unmet needs decreased, but they probably would.) It was very simple to collect that information and it was very powerful in showing the dynamics of independent living. It not only showed improvement, it showed that clients have diverse and changing needs, and that there is almost a developmental sequence. As one set of needs were met, another set of "higher level" needs emerged. There is some very interesting data on this area which made a good argument for expanding

independent living services.

Another measure I alluded to earlier was client satisfaction. Who knows better whether there is improvement or whether services are effective than the person himself. These are just a few ideas. I could add other examples, but because you all have different needs, you will have to tailor your improvement indicators to your program. Obviously, if you are living in an area where there is already an accessible transportation system, you may not want to spend a lot of time evaluating improvement in transportation in the community. Focus on areas which you most want to impact.

There are a few cautions you should be aware of when using such data. First of all, do not depend too heavily on "scores"--this is a trap we often fall into. For example, scores on severity can often show severity increasing over time when working with persons with progressive conditions. Scores are simply not applicable to that type of population. Clients vary greatly. One type of client may have a great potential to capitalize on transportation; for example, you may simply have to provide a specially equipped van. For another type of client, you may have to create a very extensive system of transportation service to meet needs of that client. In another situation you might just need to provide driver's education. So whenever you compare those types of scores you are comparing very different things and the scores do not mean all that much.

What we can do is show whether improvement is occurring in certain areas. For example, in social interaction, if we collect information on how often a person was involved in various types of social activities in the past thirty days and we see that it is on the rise, we know that we are doing something. If we can determine what types of activities they are engaging in we can find out what types of things we are getting the clients into and what other types of things they are not getting into. It may show us

areas we need focus on; for example, we may find we have to go out and make recreation facilities more accessible.

We are able to take that kind of information to those who are designing independent living programs, and to the center staff, and say, "We're doing well in these areas, we aren't doing so well in others." The information can lead you into an exploration of your program. If you determine you are not doing so well in an area, you can start to analyze why.

Another thing you make use of, of course, is the percentages. You can determine if a certain percent of clients increased in a given area, or if a certain percent decreased. It is very easy to use for going to funding sources when trying to secure funds; they understand percentages, and they are meaningful.

I have talked about quite a few things you can include; I want to back up and say again, we want to keep our information collection to a minimum. For example, we might want to use client files we already have available to collect a lot of basic information. Keep down the amount of information you have to collect on a special evaluation form. Keep both the number of items and the time necessary to fill the forms out as low as possible. It has to be simple and it has to be clear. One of the best ways of insuring that the data is reliable and that the forms will not take too much time to fill out, is to keep the form clear.

There are a lot of other types of information we need, but a lot of those information needs can be filled through special studies. We do not have to collect everything through an evaluation system. Use special studies or let other researchers come in and do a special study on an area if you are interested in particular problems.

Concerning your evaluation system, I would encourage you to do a "mock-up" of the report you are going to produce. If you are going to have an annual report for example, lay

out your tables ahead of time. Lay out what will go into the text under each of those table headings. If you do this, analyzing data, tallying it, putting it into the tables and writing the text become relatively simple tasks. For a small center, producing a report might mean a person going through the data annually and constructing some tallies or a few analyses. If you have a very large center, you might want to tap into some of the state resources like statisticians, evaluation experts, and computers. The point is, have those things done ahead of time. It takes a little time up front, but is well worth it. Make use of the state rehabilitation agency people. They have a lot of experience in evaluation and you should capitalize on that resource.

In short, gear evaluation toward your own specific needs to identify areas of strength and weakness in your program. Work together with state people; they can provide a lot of technical expertise. While it will take some time up front to develop the system, you will develop a good system and a functional system, one that is responsive to your needs.

EXAMPLES OF EVALUATION SYSTEMS

I'd like to briefly mention a few examples of evaluation systems in place. Although they were developed for different uses, their systems provide us with good operational models. The Hospital Utilization Project of Western Pennsylvania is something you might want to check into. It centers basically on medical rehabilitation facilities, but they have some very interesting things on their form that independent living centers should note. The program is a national program, one that hospitals and medical rehabilitation facilities use to help them develop their required evaluation reports. The Hospital Utilization Program sends out a packet of forms, including an intake form, a discharge form, and a follow-up form. They have different sets of forms for different types of facilities. Each one of these forms is one page

in length and is computerized. They collect basic demographic information and collect functional indicators, which are fairly simple, but very effective for their needs. They have five or six functional items from which they calculate a crude score of functioning and it seems to demonstrate improvement rather well. While it is aimed at a slightly different target population, the layout of the form collects a great deal of information in a very simple fashion, and provides us with a real life model for evaluation systems. I think it is very useful to look at this as just one way of collecting information. After they get their information, it is fed into a computer which can provide such things as scores on individual clients, on the entire programs, comparison of their program efforts to past years, comparisons of their program to other programs, or compilation of all the data of programs together to find out what is going on generally in rehabilitation facilities.

Although such a system is a little too aggressive and a little too large for CILs, it might be interesting to entertain the idea of doing something on a much smaller scale on a regional basis. If the region can work together and collect common data elements, it would be a very simple matter to put some of that information together for comparing one program to another. As I said, there will be problems in doing that, but it can be done within a region, for looking at selective characteristics in special studies, and for use as a data base from which special studies can be initiated. Centers may not be ready to work on something that comprehensive just yet. It might be better to start getting basic information on an individual basis and then later, as centers find out more about their programs and gain more experience, to start working with other programs to develop some sort of common information system.

SPECIAL PROBLEMS

A large percentage of some program activities will be referrals. One cannot conduct an extensive interview over

the phone when someone is calling for information on accessible housing, transportation, or other informational requests. In that circumstance, centers might want to set up some alternatives which simply collect the number of phone contacts and information requested. My point is, different things are going to happen in different centers and you are going to have to look at those special problems yourself.

Another thing to look at is the client who only wants or needs one service. Are you going to make them go through this whole form? I doubt that you really want to do that. You might want to use an abbreviated form just to collect a few pieces of information on someone who comes in for a single service. So, there are all sorts of unique problems in developing systems. The best persons to define these problems and determine how to cope with them are the center staff, relying on the resources of the state evaluation expert, university faculty, or others who can provide technical assistance. These are things that centers are going to have to work out for themselves.

In summary, centers have a very good opportunity to develop an evaluation system that is meaningful to the center, and that could be used at the center to improve its effectiveness. If centers wait for a standard reporting system to come down the pike, it is very likely that that system will be very useful to the federal and state governments, but not as useful to centers. That is not because the federal and the state people are not concerned with center needs; it is because they are seeing things from their perspective and they do not have enough center input. If, on the other hand, federal and state planners can look at good evaluation systems that are responsive to center needs, they can use some of those elements in developing a common reporting system. It is very important to develop effective evaluation systems and demonstrate that it can be done efficiently. Then, when a common evaluation system does come, centers will be able to show ways of doing evaluations

that maintain responsiveness to Centers for Independent Living.

WASHINGTON UPDATE

Bill Bean

Dr. Bean administrates the Indepenedent Living Program
in Washington, D.C.

WASHINGTON UPDATE

Good evening. I notice on the agenda that immediately following this session tonight is scheduled time for you to interact and get acquainted with people from other states and programs. I know that this is something you are looking forward to and realize you are probably tired from a day of travel, so I will keep this brief and informal.

The thing most people want to know about first is the status of the application reviews we received for 1980. As you know, money was made available in Part B of Title VII of the Rehabilitation Act for grants to establish and operate centers in independent living. The appropriation was for \$15 million. We awarded ten projects totaling \$2 million last year, which meant that we had \$13 million left this year for starting new projects. We had two competitions this year, the first ending March 15 and the second on July 15.

The Act makes the designated state unit administering the rehabilitation plan the principle eligible applicant. If a state agency has not applied within six months, any local public or private non-profit organization in that state may apply. The first competition was limited therefore to state agencies only. From that competition we awarded 31 or 32 grants. In the second competition we awarded about 30 more, so we now have 59 grantees. In addition, 22 grantees received supplemental awards.

The priority for funding applications for the second competition was for states who had not applied before, states which had applied earlier but had been turned down, and then those local organizations in which the designated state unit did not apply. Projects which had been funded in 1979 and were applying for supplemental grants were the second priority. The third priority was for supplemental grants to those projects funded in the first half of 1980.

Through this process, we now have projects in this region in New Mexico, Texas, Louisiana, and Arkansas.

I would like to address the grant review process briefly and tell you about some of the things we encountered.

In conducting grant reviews, the people in the driver's seat are the peer reviewers. The Central and Regional Office people also review, but we generally join the train after it is already out of the station. We look at what the peer reviewers have said and if we have information that is not available to them or if it looks like the peer reviewers have made a gross mistake, we can make our own recommendations to the Commissioner.

Another thing that complicated the review process was the legislation. The continuing resolution we got last year was very specific in funding Section 711 only. We had no latitude; the money had to go for Part B discretionary grants. But Part B money had to go to a state unit which was administering a plan under Part A, even though there was no money in Part A. I think it is a very strong statement of interest among states that even though there is no Part A money, many have developed a Part A plan in order to be eligible for Part B money. The problem was in sorting out which applications for Part B money were really proposing to fund a Part A program, which has much more latitude and flexibility, from those which really proposed a Part B center.

Another thing that gave the reviewers a great deal of difficulty relates to the announcement that came out in the Federal Register, which is the basic structure on which an evaluation has to occur. A phrase in Part B says that there shall be substantial involvement of handicapped individuals in the administration and direction of these centers and that handicapped individuals shall be employed by the centers. The problem was in defining how much involvement and how many handicapped persons constituted "substantial."

Another thing that caused a lot of problem and grief in reviewing applications is whether a program is attempting to address itself to all disabilities, most disabilities, or whether it is single disability in focus. Nothing in Part B, or Title VII as far as that goes, has made reference to a disability except Part C, Independent Living Services for Older Blind Individuals. Since Part C is not funded and it is the only part that has reference to disability or age, that means that Parts A and B are for all disabilities and for all ages.

Having said that, we see we have a small program. Our basic grant unit was \$200,000, and that was the amount for which people were applying. With that small amount of money, how are you going to get a viable program serving all disabilities? The fact is that you don't try to do everything for everybody. You sort out what you do have available, and it should be available to persons with all disabilities. If you are developing a housing roster, or finding landlords who are willing to accept a Section 8 grant subsidy, or otherwise deal with disabled people, that information should be available to any disabled person, regardless of their disability.

To get a program going, you have to have support. You are not going to serve many people with \$200,000, meaning you have to get other programs on board, or develop a strategy for getting other programs on board. We did put in the announcement this time that one of the special criteria for funding was that you have to have the involvement of other programs. The idea of using this small amount of money is to leverage other resources. The problem is, how do you get support before you are started, and then how can you leverage other programs' support when everybody else is trying to do this too?

That is the process and outcome of this year's grant cycle. We have learned from the peer review. There is some question about whether depending heavily on peer reviews

is an adequate way to go, but we will just have to wait and see how it works out next time. And I am optimistic there will be a next time.

The administration has asked for \$18 million for next year. So far this figure has held firm, and has not been chopped. Right now, the administration is going to ask for continued growth of this program, even though it is new. We've jumped from \$2 million to \$15 million even though the administration only asked for \$10 million. The Congress, in a continuing resolution last year, raised it to \$15 million. Now the figure is up to \$18 million so there is still constant growth. We will probably continue to talk about \$200,000 grants and will probably still have a priority for funding states that are not yet funded. I'm hoping that in the process of application/reapplication whatever problems there are can be resolved.

I always get questions about Part A. Right now, it looks like the prospects for getting Part A money in 1981 are nil. It would require at least an additional \$10 million + program, which just does not seem to be in the cards at this time. 1982, of course, is another year.

There will be a Research and Training Center in Independent Living and the announcement should be coming out soon. The existing RT Centers were not eligible to apply, which was a matter of some sorrow because among other things Arkansas, Massachusetts, and Texas have considerable skills and interest. I wish they could have competed.

There will also be grants to conduct some national training in independent living this year. The training focus will be on about 65 trainees. The training will be devoted to the type of skills needed to manage independent living programs.

We hope to also develop some training materials from this conference here in Arkansas. We recognize that there are a tremendous amount of training needs and that Title VII does not provide for training, technical assistance,

evaluation research, etc., so we are working with other on-going programs to sponsor the training.

Right now, we do not have a mechanism in place to answer questions like: "How many people are being served?", "What kind are they?", "What kind of services are being provided?" I've got a real good staff person, Bob Jones, working on the whole question of reporting and accountability for Independent Living Centers. I wish I could take him off everything else to finish this and he would like to also, but he has a third of the load in dealing with states.

We realize that initially we are only going to be skimming the top, but we are going to get something in place to answer these kinds of questions and then try to get a sounder evaluation system in place. The vocational rehabilitation system has realized for some time that the R-300 reporting system does not provide for the many gains that people may make as a result of services even though they do not end up a "26." Measuring gains is a complex task, but something that we all are working on.

I could talk for some time about philosophies and the excitement this program generates, but I am going to stop and give you a chance to ask questions.

IMPLEMENTATION ISSUES

The course participants divided into small groups by job titles (e.g., vocational rehabilitation agency independent living coordinators, independent living center directors, etc.) and identified a list of issues and other topics of concern to them in implementing independent living centers. These issues were recorded, combined where they overlapped, and addressed by a panel of persons representing various vantage points in independent living. Panel members included:

Bill Bean - Federal Representative

Beverly Chapman - Independent Living
Center Director

Lex Frieden - Consultant and Researcher
for Independent Living

Tim Muzzio - Program Evaluator

Ted Thayer - State VR Agency Coordinator
of Independent Living

Tim Milligan - Panel Chairman

The following comments were drawn from the panel presentation addressing the issues and topics of concern.

The issues developed included the following:

1. Staffing the Center for Independent Living
2. Technical Assistance
3. Organizational Structure
4. The Board of Directors
5. Linkages with State Agencies
6. Alternative Funding Sources

Panel Presentation - Summary

ISSUE: Staffing the Center for Independent Living

1) Recruiting -

The focus in recruiting staff should be on finding and hiring qualified disabled persons. Degrees and experience, which are often listed as prerequisites to employment, are frequently irrelevant to the actual job requirements. Directors are encouraged to look for disabled persons with strong potential regardless of vocational experience.

An extensive outreach program is necessary to locate qualified persons. Suggested recruiting sources include the vocational rehabilitation agency and other independent living centers.

Recruiting both nationally and locally is desirable to maintain a balance between "new blood" coming in and knowledge of the existing community.

Many potential recruits are SSI recipients. In many cases, the widely held notion that these persons cannot or will not risk working is a myth. It is important for the SSI recipient to get clarification of regulations in case they are not able to work after trying it, however.

2) Training the Staff -

Staff development is an important but too often an under-addressed aspect of management. It is common for programs to get busy with meeting existing needs and never find time for upgrading staff skills.

Finding resources for training is a problem for many programs. State rehabilitation agency staff development sections are a good resource for finding out about available training and in many cases will make openings in agency-sponsored training for independent living center personnel.

Community colleges are another good source for acquiring needed training, and in most cases are very responsive to community training needs.

ISSUE: Technical Assistance

Within most communities there is a wealth of untapped resources able to provide technical assistance on many aspects of Independent Living Center Operation.

Proven resources include the following:

1) Vocational Rehabilitation Agencies -

These agencies have extensive experience in operating human-service programs and are able to provide technical assistance in personnel and fiscal management, staff development, identifying potential consumers, grant-application and management, etc.

2) Small Business Administration -

This organization is available to provide technical assistance on managing the center in a business-like manner.

3) Senior Corps of Retired Executives (SCORE) -

This volunteer organization of retired executives can provide invaluable management/consultation.

4) United Way -

These community-based agencies have extensive experience with non-profit human services and are generally available to provide technical assistance.

5) Local Banks -

When requested, many banks are available for assistance with managing financial matters.

6) Law Schools -

These programs are frequently a resource for legal assistance.

ISSUE: Organizational Structure

The overriding consideration in setting up the Center for Independent Living is that the program should be set-up and run on a business-like basis. Specific delineation of authority, staff duties and responsibilities, and lines of communication should be documented and all staff should be aware of the organizational structure.

Sound and clearly understood personnel policies are essential. Staff evaluation criteria should be established and communicated to all personnel. Grievance and disciplinary procedures should be posted and all staff should be trained in these policies.

A valuable resource in developing personnel policies is the state vocational rehabilitation agency.

ISSUE: The Board of Directors

A Board of Directors is a requirement for centers funded with Title VII Part B monies, and can be a vital resource in the operation of independent living programs. The board should be a healthy part of the organization, and should be frequently consulted regarding center operations and directions.

The board function should be included in the by-laws and board members should receive training in their function. The board should not interfere with the day-to-day center operations.

Wide community representation on the board (e.g., minorities, disabilities, etc.) is desirable. Center staff members should not be on the board of directors.

Independent living organizations that fail often do so because of a weak or uninterested board. Leadership is the key to overcoming board apathy. Disabled persons who need the center's services are unlikely to become uninterested board members.

Board members need to understand and agree with the center's goals, and be willing to work to help the center meet its goals. Fund raising and advocacy functions are often assumed by the board, freeing up staff time for providing direct services.

An innovative approach to resource management is to also develop an advisory committee made up of professional persons in the community. This advisory committee need not meet formally as a group, but can be available for assistance in advisory capacity as needed.

ISSUE: Linkages with State Agencies

Although hard data is not available, it seems that those programs which are successful have a solid linkage with a state agency, usually the vocational rehabilitation agency. Of programs that fail, most do not have that solid linkage.

The strongest independent living programs are those which get facilitative support from state agencies, especially in terms of assistance with training, research, developing personnel policies, etc. The state VR agency coordinator for independent living services is a key person in developing this linkage. A contract between the center and the state agency spelling out the obligations and responsibilities of each is important.

Having a liaison person, a rehabilitation counselor for example, in the center part-time is helpful. Caution should be used to clearly spell out lines of communication and authority, however.

The state rehabilitation agency should realize that independent living programs are growing and evolving, and that while the agency has the potential to be of tremendous assistance, it also has the potential for getting in the way.

Centers, too, can be a resource to VR agencies, especially in helping develop vocational goals for disabled persons.

A rehabilitation agency representative should be considered as an ex-officio member for the centers board of directors.

ISSUE: Alternative Funding Sources

Present funding for independent living programs should be considered "seed" money, as funding will probably not be continued on a long-term basis. Concurrently, many sources of federal funds are drying up. The most likely resources are at the community level. Community development grants, and county tax-base funding should be explored.

The Department of Transportation may be a helpful resource for transportation funds. In the past, CETA has been a valuable resource for attendant training programs.

Centers should consider doing contract work for vocational rehabilitation, state employment agencies, and welfare agencies.

A fee-for-service plan with rehabilitation has potential for being a valuable income producer. Centers must develop tangible services to meet specific objectives if rehabilitation is to use their services.

AFTERWORD

This training provided a unique opportunity for persons involved in a dynamic, growing movement to obtain needed information. A valuable side benefit, impossible to document in a Conference Proceedings, was the cross-pollination of ideas and approaches which occurred informally.

We hope that the information we were able to capture will provide a valuable reference to persons operating and starting Centers for Independent Living.