POLICY

Planning and Development in Independent Living

workshop proceedings June 1980

University Center for International Rehabilitation/USA

Michigan State University

Policy Planning and Development in Independent Living

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UCIR Donald E. Galvin, Ph.D., Director
proceedings by Susan J. Sigman

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Steering Committee

Burt Danovitz, Workshop Coordinator
UCIR

George Frassa, Graduate Assistant
UCIR

Donald E. Galvin, Ph.D., Director
UCIR

Michael Moore, Ph.D., Professor
School of Labor and Industrial Relations
Michigan State University

Robert McConnell, Supervisor
Program Development
Michigan Bureau of Rehabilitation

Kathy Miller, Administrative Assistant
UCIR

Bill Powaser, Coordinator
Planning and Budget
Michigan Bureau of Rehabilitation

Denise Tate, Ph.D., Coordinator
Research Evaluation
UCIR

Consultants/Trainers

Jean Cole, Ph.D., Director of Training
The Institute for Rehabilitation & Research
Houston, Texas

Gerben DeJong, MPA, MSW, Director of Research
Tufts University Medical R&T Center
Boston, Massachusetts

Kent Hull, LLB,
UCIR

Kathy Miller, Administrative Assistant
UCIR

Michael Moore, Ph.D., Professor
School of Labor and Industrial Relations
Michigan State University

Stanley E. Portny, President
Stanley E. Portny & Associates, Inc.
Alexandria, Virginia

Len Sawisch, Ph.D., Coordinator
Consumer Development
Michigan Bureau of Rehabilitation

Miriam M. Stubbs, Director
Policy Development and Legislative Relations
Rehabilitation Services Administration
Washington, DC

A biographical sketch of workshop consultants/trainers appears in Section IV, Independent Living Policy Planning Resources, of this report.

introduction

A policy may be thought of as a statement which structures courses of action intended to accomplish some basic purpose or intent. Enlightened and effective policies can serve to translate what are frequently, and understandably, ambiguous and general statements of Congressional intent, i.e., legislation deliberated upon in the conference rooms on Capitol Hill, into appropriate decisions and actions on the part of administrators, counselors and consumers in Indianapolis, Springfield, Madison, Minneapolis, Lansing... Such policies are crucial to success in independent living and challenge state rehabilitation agencies with the task of designing consumer involved service programs which are appropriately sensitive and cost-effective while also being consistent with the individual beliefs and values that are at the basis of the I.L. movement and P.L. 95-602.

This short-term training program in Policy Planning and Development for Independent Living Rehabilitation was designed to meet this challenge by addressing two high priority training needs of the Region V state rehabilitation agencies: 1) policy analysis as a dimension of program and financial management, and 2) development of independent living services as specified in Title VII - Comprehensive Services for Independent Living, of the 1978 Rehabilitation Act.

The overall goal of the 2½ day program was to assist states in the development of appropriate and effective independent living rehabilitation programs by increasing participants' abilities in policy planning and development. Lectures and group activities were formatted around the following training objectives:

- To provide knowledge about the current status, future directions and critical issues in independent living.
- To supply the knowledge and skills necessary to enable participants to utilize the six phases of policy development and implementation.
- To provide participants with a policy planning and development model for use in their agencies.
- To teach conferees how to effectively elicit input from individuals and groups participating in the policy process.
- To furnish individualized technical assistance to states regarding policy planning and development for I.L. services.
- To assist each state in evaluating its current policy planning and development capabilities.
- To provide instruction in the dissemination and operationalization of policy.
- To create an atomosphere in which state experiences in policy development and planning for I.L. services can be shared.
- To provide written training materials for trainees to use in the areas of policy planning and development, and independent living.

Approximately 40 persons attended the training, including representatives from the RSA Regional Office in Chicago. Five participants were selected by each agency based on their involvement in policy planning and development, and/or independent living services.

Four major thematic issues prevailed throughout the workshop and have been incorporated into this report as 1) The Relationship Between Title I and Title VII, 2) Parts A and B of Title VII, 3) Independent Living Centers and Consumer Involvement, and 4) the Agency's Scope of Services (Part A). Consultants from around the country with expertise in these areas and in the field of policy analysis served as facilitator/technical assistant teams. Materials in this document are arranged in a sequential manner which simulates the actual training process which participants experienced.

It is hoped that these proceedings will serve as a valuable resource to the entire Region by presenting a model for implementing policy planning and development in the design of programs which will be harmonious with the historical perspectives of the independent living movement.

UCIR ....about UCIR

The University Center for International Rehabilitation (UCIR) is funded by the National Institute of Handicapped Research in order to provide an international perspective in responding to domestic needs in rehabilitation and special education. In this role, UCIR acts as an international facilitator in developing effective channels and strategies for the identification of innovative programs, policies, methods and technological devices that demonstrate the potential for positively affecting domestic service delivery and thereby enhancing the lives of persons who experience handicaps.

UCIR's Research Division currently pursues eight specific areas of emphasis, two of which are directly related to this regional workshop in policy planning and development. These two areas are independent living practices in selected countries, and consumer participation. Other major research areas at UCIR are disincentives to employment for disabled individuals, coping with disability, functional assessment systems for disability classification, barriers to importation of technological devices for handicapped persons, educational resource alliance, and information exchange and communication.

Selected foreign and domestic research activities in these areas are assessed in terms of their relevance, accuracy and potential for immediate utilization in the field. Practical knowledge of high quality is disseminated by UCIR's Information and Education/Training Divisions through publications, formal training of graduate students, and informal training via seminars and workshops such as this. A listing of publications currently available from UCIR appears in the back of this document. Persons interested in obtaining additional information on UCIR's goals and activities are invited to contact the center.

Donald E. Galvin

Donald E. Galvin, Ph.D., Director
University Center for International Rehabilitation
Michigan State University
D-201 W. Fee Hall
East Lansing, Michigan 48824

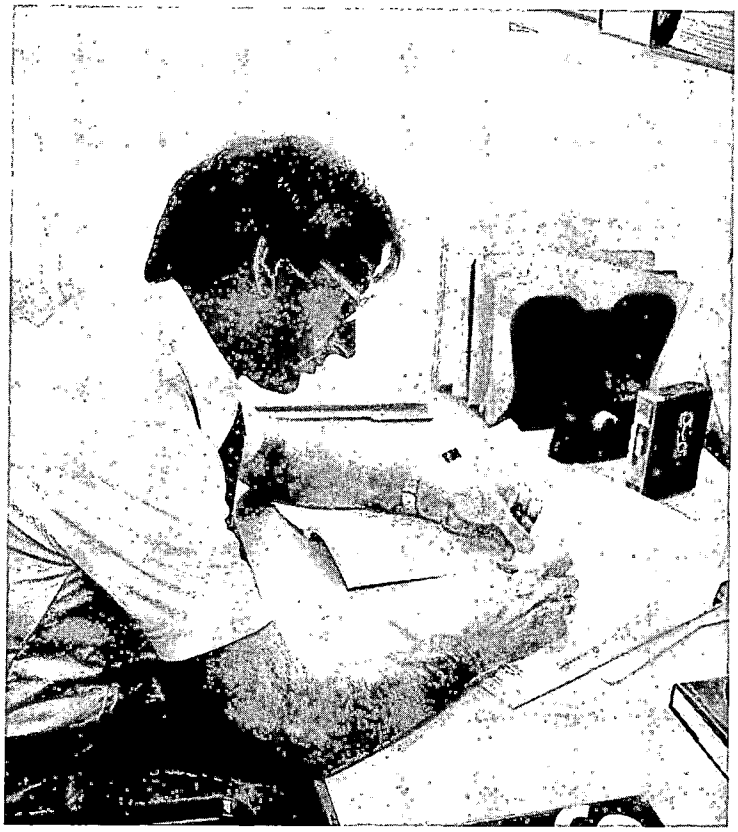
contents

1.

Independent Living: Past and Present

An initial lecture session provided participants with a foundation for I.L. policy planning and development through an understanding of the evolution of the independent living movement, its present concepts (both consumer and professional), and the challenges and controversies which the new legislation appears to be sparking.

As a result of obtaining an increased knowledge of the intent of the movement and the content of the legislation, greater policy planning capabilities can be developed, thus promoting more sensitive, relevant and realistic policies which will maximize both the scope and quality of I.L. services provided through agencies.



Gerben DeJong
Tufts-New England Medical Center
Boston, Massachusetts

The Historical and Current Reality of Independent Living: Implications for Administrative Planning

Introduction

My thesis this morning is that historically there have been two different conceptions of independent living. These two conceptions overlap a great deal---both are reflected in Title VII of P.L. 95-602 and both have major implications for administrative planning, the subject of this conference. For lack of better terms, I will refer to these different conceptions of independent living as (1) the "professional conception" of independent living and (2) the "consumer conception" of independent living. This dichotomy may appear a bit artificial and perhaps a bit unfair, but I believe it can be especially helpful in sorting out the language found in Title VII of P.L. 95-602 for future planning.

The Professional Conception of Independent Living

In the professional or rehabilitation conception, independent living has been viewed as a competing policy goal---a goal that competes with the traditional goal of vocational rehabilitation. For many vocational rehabilitation professionals, independent living services are for those for whom a vocational goal is thought to be impossible. Independent living is seen as an alternative to the vocational goal---thus, the term "independent living rehabilitation" is distinct from "vocational rehabilitation". Independent living rehabilitation services are often implied to be those medical and social services that enable a disabled person to live in the community short of being gainfully employed.

This conception of independent living is abundantly evident in the 20 years of independent living legislation introduced prior to P.L. 95-602. For example, H.R. 369 in 1959 and H.R. 8395 in 1972 both included language to extend independent living services to individuals "for whom

a vocational goal is not possible or feasible." The Senate version of H.R. 8395, which was later vetoed by the President, had an even more narrow conception of independent living. It viewed independent living services as those that would bring disabled persons "up to the point of having vocational potential." In the Senate's view then, the independent living goal was subsidiary to the vocational rehabilitation goal.

The Consumer Conception of Independent Living

The consumer conception of independent living has historically been a broader one. It has not viewed independent living and vocational rehabilitation as competing policy goals. Rather it sees vocational rehabilitation as subsidiary to the independent living goal: gainful employment is one of several ways a person can become independent. This conception is the reverse of the Senate view in 1972---mentioned a moment ago---where independent living was considered subsidiary to the vocational goal.

To gain a fuller appreciation of the consumer conception one has to consider the relationship of independent living to five other social movements of our time: (1) the civil rights movement, (2) the consumer movement, (3) the self-help movement, (4) the demedicalization/self-care movement, and (5) the deinstitutionalization/mainstreaming/normalization movements. A discussion of these movements may appear to be a diversion of sorts, but I believe that these movements are fundamental to the consumer conception of independent living. Moreover, the language of Title VII and its implications for administrative planning can be better understood once the impact of these five movements is brought into sharper focus.

The material I'm about to present may be familiar to some of you since it draws heavily from some of my previous writings. My apologies to those who have "heard it all before," but I think this material will strengthen the thrust of my presentation.

The Civil Rights Movement. This movement has helped many disadvantaged groups become aware of their rights. The movement often distinguishes between civil rights and benefit rights or entitlements. Civil rights are rights such as the right to vote, right to hold elective office, right to trial by jury, etc. Benefit rights are entitlements such as income benefits, medical benefits, educational benefits, etc. Benefit rights are sometimes elevated to civil rights in the sense that often without the benefit of entitlements, one cannot fully exercise one's civil rights.

It is also helpful to contrast "serices" with "entitlements." In referring to services, particularly human services, one often thinks about the ongoing intervention of professionals. However, when a service is elevated to an entitlement, professional judgment is considerably diminished beyond the initial eligibility determination process. I think it is fair to say that consumers view services more as entitlements than as services. In short, the civil rights movement has instilled an attitude toward human services as those services to which persons are entitled as a matter of statutory, if not constitutional, right.

The Consumer Movement. This movement is harder to define. Consumerism as an ideology is easier to define. As an ideology, consumerism means that the consumer has the responsibility to become informed about product reliability and service adequacy, an idea that is closely aligned with the concept of "consumer sovereignty," namely that the consumer is the only person who should decide what is best for him or her.

The Self-Help Movement. Today, there is a self-help solution for every problem or crisis in our society: alcoholism, drugs, gambling, death, homosexuality, child abuse, women's health, aging, smoking, childbirth, etc., etc. A number of mutual aid groups have developed not only as support groups, but also as alternatives to mainline human service organizations. In this country, centers for independent living often serve as the primary self-help unit for disabled persons and often try to serve as alternatives to traditional human service organizations.

The Demedicalization or Self-Care Movement. In Western society an increasing number of behaviors and social problems are being medicalized. Alcoholism, mental

problems, and even child abuse are often termed as "diseases." As the medical model expands into new areas, some are beginning to question whether certain life problems or conditions should be "demedicalized." Two of the most visible examples of the demedicalization perspective are the natural childbirth and death-with-dignity movements.

Central to the demedicalization argument is that people can and should take greater responsibility for their own health care. The demedicalization/self-care movement goes beyond the keep-fit, watch-your-weight, stop-smoking, and drink-less campaigns of the recent past. It encourages people to administer their own treatment for minor health problems. In the case of persons with chronic health conditions or disabilities, the movement asserts that disabled persons can avert many potential complications arising from such conditions through their own efforts.

Thus, the movement for independent living has been a partisan in the demedicalization debate. At issue is the extent to which the management of disability should remain under the aegis of the medical care system once medical stability has been substanstially obtained. Today, public policy with respect to disability involves an almost constant medical presence: in determining eligibility for income benefits, in the certification of need for special auto licenses, etc. The movement for independent living asserts that a constant medical presence in the lives of disabled persons fosters behaviors on the part of both medical practitioners and disabled persons that are in conflict with independent living goals. Specifically, a disabled person is expected to assume the "patient role" which, among other things, exempts a person from "normal" activities and responsibilities, and requires a disabled person to defer to the technical competence of the physician. From the perspective of the independent living movement, disabled persons want neither to be exempted from normal activities and responsibilities, nor do disabled persons want to become dependent by surrendering decision making responsibility to the physician.[1]

The Deinstitutionalization Movement. This movement is one that cuts across several human service areas. The best known efforts are in the areas of mental illness, mental retardation, juvenile corrections, and more recently, physical disability. The adverse consequences of prolonged institutionalization are known to most of us. One of the most succinct critiques of institutionalization is one rendered by my mentor and colleague at Tufts-New England Medical Center, Dr. Paul Corcoran, a physician in rehabilitation medicine:

> Patients are encouraged to follow instructions, rules and regulations. Compliance is highly valued, and individualistic behavior is discouraged. The "good" patient is the individual who respectfully follows instructions and does not disagree with staff. On the other hand, the patient who constantly asks for a dime for the pay phone, a postage stamp, or a pass to leave the institution on personal business tends to be treated as a nuisance or labeled "manipulative." Patients do not make their own appointments, keep their own medical charts, or take their own medications. Responsibility for these things is legally vested in the institution. Yet on the day of discharge, the patient is expected suddenly to assume control of his own health care and life decision making.

Consumer Conception Summarized

By taking our cues from these various social movements, we are now in a better position to summarize the consumer conception of independent living. According to the consumer conception, the central problem is not one of inadequate ADL skills or vocational skills but rather the inordinate dependence our system fosters---dependence on professionals, relatives, and others. Moreover, there are the problems of architectural barriers, inadequate support services such as attendant care, economic disincentives and others. The problem is not located so much in the individual as it is in the environment. The solution to the problems of disability are not through traditional rehabilitation as much as through peer counseling, advocacy, self-help, consumer control, barrier removal, etc. According to the consumer conception, then, a disabled person should not simply accept the patient or client role, but aggressively assume the consumer role. The consumer conception is not preoccupied with vocational goals, but is concerned about the ability to become more self-directed in one's

affairs; the ability to live in the least restrictive environment; and finally the ability to become productive, not only in gainful employment, but also in making other contributions to family and community life.

Interpreting Title VII

Having said all of this, I think we can more adequately interpret the language found in Title VII. The analytic approach I am using here is not altogether different than what a theologian would do in interpreting the Scriptures. One has to consider the larger social and historical context to adequately understand the meaning of the written word, whether in Scripture or in law.

I would argue that both conceptions of independent living can be found in Title VII ---both the narrower professional conception and the broader consumer conception. While both conceptions are present, I believe that Title VII is more heavily weighted toward the consumer point of view, particularly in Part B. To the extent to which Part A is intended to parallel the Title I program, i.e., vocational rehabilitation, it is more consistent with the professional perspective.

However, if one looks closely to the language of Parts A and B, one will find many references to concepts and ideas made popular by the social movements I have discussed. Consider the following:

Civil rights - Title VII authorizes services such as "advocacy services with respect to economic rights and benefits."

Consumerism - Title VII provides that "handicapped individuals will be substantially involved in policy direction and management of independent living centers;" and that "handicapped individuals have a substantial role in developing the state plan."

Self-Help - Title VII provides a grant program for independent living centers, the principal self-help vehicle of the independent living movement.

Demedicalization - Title VII provides for independent living-based health maintenance programs and attendant care.

Deinstitutionalization - Title VII views services as a way of fostering alternatives to institutionalization.

One could go further, especially by looking at the laundry list of services authorized under Title VII and see many items consonant with the independent living philosophy, e.g., peer counseling, independent living skills training, and others.

If my argument is correct that Title VII is weighted toward the consumer conception of independent living, then the President's veto of earlier legislation, we noted, was heavily laced with a professional perspective which viewed independent living as a competing policy goal. In the 5-year interval from 1973 to 1978, a more clearly articulated consumer perspective took hold. This perspective made its way into the language of P.L. 95-602, an accomplishment that might not have been possible 5 years earlier. This, I believe, is a historical reality that should have a material bearing on our interpretation and implementation of Title VII.

Current Reality

I have also been asked to say a few things about "the current reality." Because time is short, I will merely list them:

- Money is tight and appropriations for Title VII will remain modest during the foreseeable future. Thus, Title VII is in some ways more symbolic than substantive. However, even symbolic gestures should not be underestimated.
- There is competition from many different disability groups (particularly from the mental health community) to stretch the conception of independent living to meet the needs of their particular constituency. While this may be desirable in some respects, this competition is likely to dilute the special meaning of independent living as we have come to understand it in the recent past.
- The law requires that Part B grants be filtered through state vocational rehabilitation agencies. This undoubtedly puts state agencies in the driver's seat and also risks diluting the consumer conception of independent living.
- There are varying degrees of enthusiasm for independent living among state vocational rehabilitation agencies--- from enthusiasm to outright apprehension.

The progress independent living will make in a given state will not only depend on the assertiveness of consumers but also the support from state agency heads.

Implications for Administrative Planning

Again, the shortness of time requires that I merely list some of the implications of this discussion for administrative planning.

- Administrative planning must take into account the broader definition of independent living. The justification for this broader view is both historical and statutory.
- Consumers must have a vital and substantive role in the planning and administration of Title VII services.
- Granted that there is not much money for independent living services, we must not think of independent living merely as a program. It is a consciousness, a way of viewing the world of disability. Thus, even in the absence of substantial funding, independent living is a perspective that should guide all planning for disability related programs, under Title VII or otherwise.
- Thus, independent living is not rehab "warmed over a few degrees." Independent living is not just another box on a form to be checked off when deciding whether to charge services to Title I or Title VII. If this is all that independent living is, then we will have missed the point.
- By the same token, we should not automatically model the provision of independent living services after the 26-closure system now used in vocational rehabilitation. The 26-closure system presumes an end point, a point in time at which a goal is obtained and services can be terminated. Independent living services may need to be provided indefinitely in order to sustain independent living goals. The need for attendant care does not disappear once one is living independently.
- The broad conception of independent living embodied in the statute will make planning for accountability difficult. However, it will be important to develop and operationalize accountability measures that are consonant with the goals and philosophy of independent living. I believe such measures can be developed. To date, I've been distressed by the glorified ADL (activities of daily living) measures being passed off in the name of independent living.
- The diverse nature of independent living services will force state vocational rehabilitation agencies to become more involved with other state-level human service organizations. The historical isolation of state vocational rehabilitation agencies will have to diminish, especially when the absence of any substantial funding for Title VII services will require cooperation from other state human service organizations.
- The broader conception of independent living will make administrative planning difficult. On the one hand, a broader view will permit more flexibility. On the other hand, a broader view will generate more uncertainty---uncertainty as to (a) who should be served, (b) what services should be provided, and (c) how services should be evaluated. The more narrow conception of independent living embodied in earlier legislation would have narrowed these choices considerably.

In short, the language of Title VII is vague on many points which will make administrative planning more difficult but also will provide more latitude. However, the historical analysis provided here should provide some guidance both as to what independent living should be and what it is not. Staying tuned to what persons with disabilities are saying and have said over the last several years, offers the best guidance that we can have as we go about the task of planning for independent living services.

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[1] For an expanded discussion see: Gerben DeJong, The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research, Occasional Paper. (UCIR: Michigan State University, 1978), pp. 29-37.

Miriam M. Stubbs, Director
Policy Development and Legislative Relations
Rehabilitation Services Administration
Washington, DC

Independent Living and its Policy Status within RSA

Introduction

In addressing independent living and its policy status in RSA, this presentation lists a collection of synthesized issues related to the subject which are considered of a priority nature on the RSA federal level. Extracts from this list are put into the following themes:

1. The policy decisions related to independent living which are made within "current realities" must be seen as evolving, changing and growing.
2. Independent living and vocational rehabilitation share legitimately certain commonalities and differences. These may or may not be continuing and permanent. Therefore, rehabilitation, if it is to be responsive, must pay attention under Title I and Title VII headings to how I.L. is going to influence vocational rehabilitation and vice versa as long as the two are kept on separate tracks.
3. Independent living needs definition. As a result of a recent announcement made by the President at the 1980 annual meeting of the President's Committee on Employment of the Handicapped, there is a design phase for a White House initiative in independent living which is intended to pull together resources. This effort confirms the fact that different people using the term independent living mean different things --- residential, community, consumer dominated, or anything that is conceivable.
4. When issues relating to independent living are addressed, such issues are multilevel issues. Most issues which presently preoccupy the minds of people in rehabilitation are operational issues. However, it is important that issues on a strategic level which will shape the future (of Title VII, for example) not be forgotten.

Issues Relating to Current Policy Status

1. There is a need to define what I.L. is, how it is to be accomplished, and its scale. A major question now is what the role of Part A should be in terms of shaping the future and defining what ILR is under Title VII. A dichotomy is developing between those who are making a concerted push for funding Part A and another group which feels temporarily content with building Part B in order to gain experience or have broader and larger research and demonstration.
2. How much linkage and how much independence could exist between I.L. rehabilitation and established lines, programs and patterns? For example, can or should an I.L. rehabilitation operation stay apart from the education community or from rehabilitation facilities of various kinds?
3. How can policy and linkages between I.L. rehabilitation and vocational rehabilitation be made consistent at all levels? A need exists to stay abreast of I.L. policy decisions running in concurrent streams with VR and thereby understand why there are legitimate differences. Policy determinations that are made now will be based on today's realities. Two years hence, the decisions could be justifiably opposite. This situation will no doubt arise increasingly until I.L. is funded on perhaps the same level as V.R., however far away that seems now. Someday, the question of a merger between the two programs may even arise and it is therefore very important to maintain the outcome and related data on both programs in a consistent manner (e.g., measures of functional limitations).

The nonmandatory services in Part A are an area of persistent confusion. Should we be moving toward a core of mandatory services that coexist with options? Such are questions that can only be concluded in the "reality context."

4. How do we settle the issue of inclusiveness of Part B projects as related to multidisability, and particularly to inclusion of the mentally ill?
5. How will states relate to the subject of who within a state gets to apply for a Part B project (e.g., laissez-faire, open competition, hand-picked by state agencies, etc.)
6. How will I.L. accomplishments, outcomes and gaps in services be measured and reported? It must be remembered that when asking the legislature for either money or program authority, data is essential. Our society demands accountability, the need for measurement, and this demand is not going to diminish.
7. There will no doubt be a whole segment of effort on both the federal and state level to develop an ability to recognize the contributions of I.L.R. projects to policy change: their ability to influence state laws, their success in capturing other funds or service resources, their success in coalition building, their networking capabilities, their ability to build some component of self-sufficiency in relation to federal support, etc.

Issues Stemming from Recent Legislation

1. What impact will the new Social Security Amendments of 1980 have on I.L.? If the new amendments provide the needed relief from disincentives and more disabled people return to work, won't these people also remain as persons needing assistance under the broader I.L. authority, as well as help for continuing physical assistance?
2. What effect will Section 482 of the Higher Education Authorization have in the area of increased I.L. rehabilitation centered in educational settings? The section would "allow any expense to a handicapped student including special services, transportation, equipment, and supplies needed by the student" which can be taken into consideration in computing student financial aid awards.

Conclusion

Because of the allotted time frame, this presentation was unable to underscore all the correlations and differences which exist between the historical perspective and current reality of independent living and RSA's current policy status for independent living. It was noted, however, that what happened with respect to independent living legislation between 1959 and 1972 was due, among a great many other things, to a failure on the part of the various principal parties in rehabilitation to do sufficient policy planning on independent living, thus underscoring the need for this and similar training experiences.

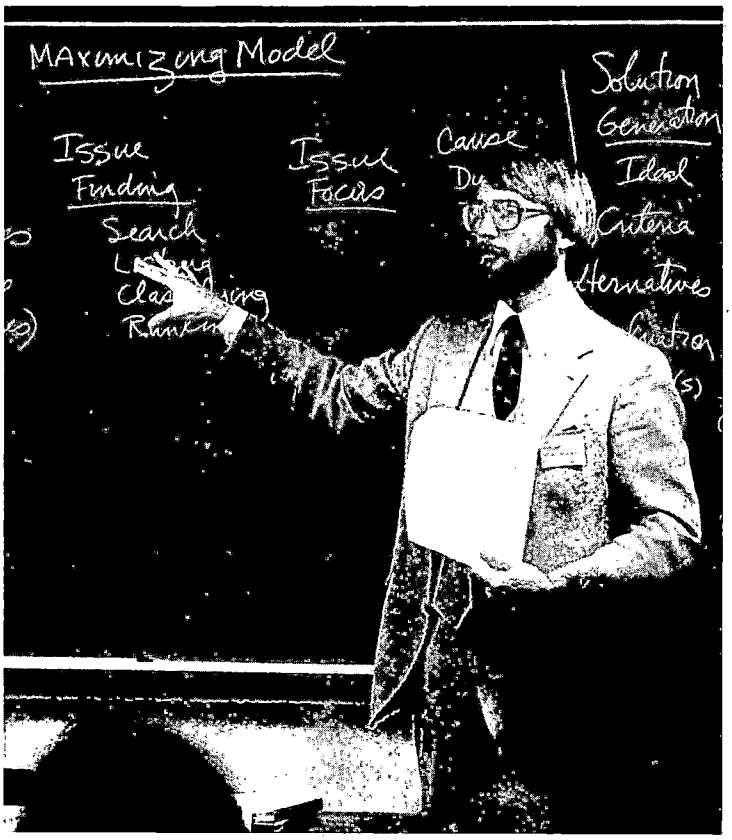
2.

Policy Planning and Development in Independent Living

Since the passage of P.L. 95-602 in November 1978, state rehabilitation agencies have been expected to respond rapidly to major program changes, particularly in the area of independent living. With these new priorities there is an increased need for improved work in policy planning and development. Procedures in this area must be identified clearly, explained and incorporated into agency planning if agencies are to be successful in implementing the legislation.

This section summarizes two major presentations and provides agencies with a model for future policy planning and development. This "maximizing" model represents an efficient system for identifying and analyzing issues, making policy decisions, implementing plans, and monitoring/evaluating a program's effectiveness.

Participants demonstrated their ability to apply this model through three related activities which are reported as subparts within this section.



Michael L. Moore, Ph.D., Professor
School of Labor and Industrial Relations
Michigan State University

The Rationale for Planning

Introduction

One crucial factor about independent living (I.L.) is that it is an issue large enough to illustrate virtually all the key factors in any attempt toward administrative problem solving. Independent living both challenges and enhances the basic missions, values, and heritage of rehabilitation. It changes definitions of needs and consumer populations. Very rarely are decision makers confronted with an issue this big. I.L. is at the core of what agencies are, what they have done, what they value, and where they are going. In fact, I.L. is bigger than rehabilitation itself. It can be viewed as either a fundamental shift in terms of traditional rehabilitation, or perhaps it need not be viewed as rehabilitation at all, but may come through other agencies.

All agencies, including rehab, were at one time solutions to problems that existed. Programs have grown up out of these agencies to provide certain services to solve certain problems. Therefore, the agencies are generally configured to group together specialists in solving certain types of problems that fill the needs of our society. With different definitions of those needs, numerous people are organized in various ways to solve differing needs. Organizations also require a sense of having ways to search and tap the environment for resources, i.e. "similar benefits" and innovations outside their agency in order to determine what is actually going on inside and thereby judge when something is new. In this "issue sensing," one very important element is to avoid making a guess at what the crisis is and then lunging in to just "do something." This is where policy analysis really starts. In policy planning and development for independent living, rehabilitation agencies must answer the questions: Who are we? Why are we that way? What needs do we meet in society? What new needs are being annunciated?

The Rationale for Planning

When designing, operationalizing and delivering services, most agencies would work beautifully if clients needed only one service. Then, specialists could be brought to bear and could get the problem solved, people would flow back out of the system, and case loads would turn over. When agencies get into more complex human problems where people need more than one particular service to function fully, the nightmare begins.

A single system will not necessarily have all the answers, but it may have access to a host of outside resources that could impact on various people's needs. Yet, it is often difficult to look at just some of the issues in I.L. in terms of the core set of services that hopefully a center would be able to provide and then relate this to all other social services provided by other federal and state agencies (housing, medical, architectural, traditional V.R.), to education through university centers, to mental health, public health, social services, CETA, etc., in the many ways necessary to operationalize all of the resources that appear in demand as part of a "good program." Such a program involves a range of services, and not necessarily all provided by public agencies. Unfortunately, each of these potential resources has a different delivery system. Some have federal laws, enabling legislation, and coordination, and others do not. Some are primarily local and locally run, and others are not. The administrative complexity of pulling together services and resources is not a simple linear matter where one can say exactly what is needed and be able to have it provided. On the contrary, meeting new or even existing needs may demand a fresh delivery model entirely, which often involves new policy development.

In terms of policy development, there are two different models which should be considered: the crisis model and the reality model.

The Crisis Model for Policy Development

The crisis model is a very general model designed to explain many day-to-day behaviors within an organization. It begins with a person or a bureaucrat sitting in what may be called a "resting state." The resting state does not imply alert; it could be the person in one's normal activity trap (writing themselves little messages or "to do" lists at the beginning of the day and then having that immediately thrown out as people interrupt, phone lines light up, or casts of peers wait outside the office). From here the day begins to disintegrate as usual. But for many people this is considered normal behavior, something they have been doing for years. The person cranks along, works hard, feels frustrated and full of tension at the end of the day, but she or he is accustomed to this work style and senses it as normal.

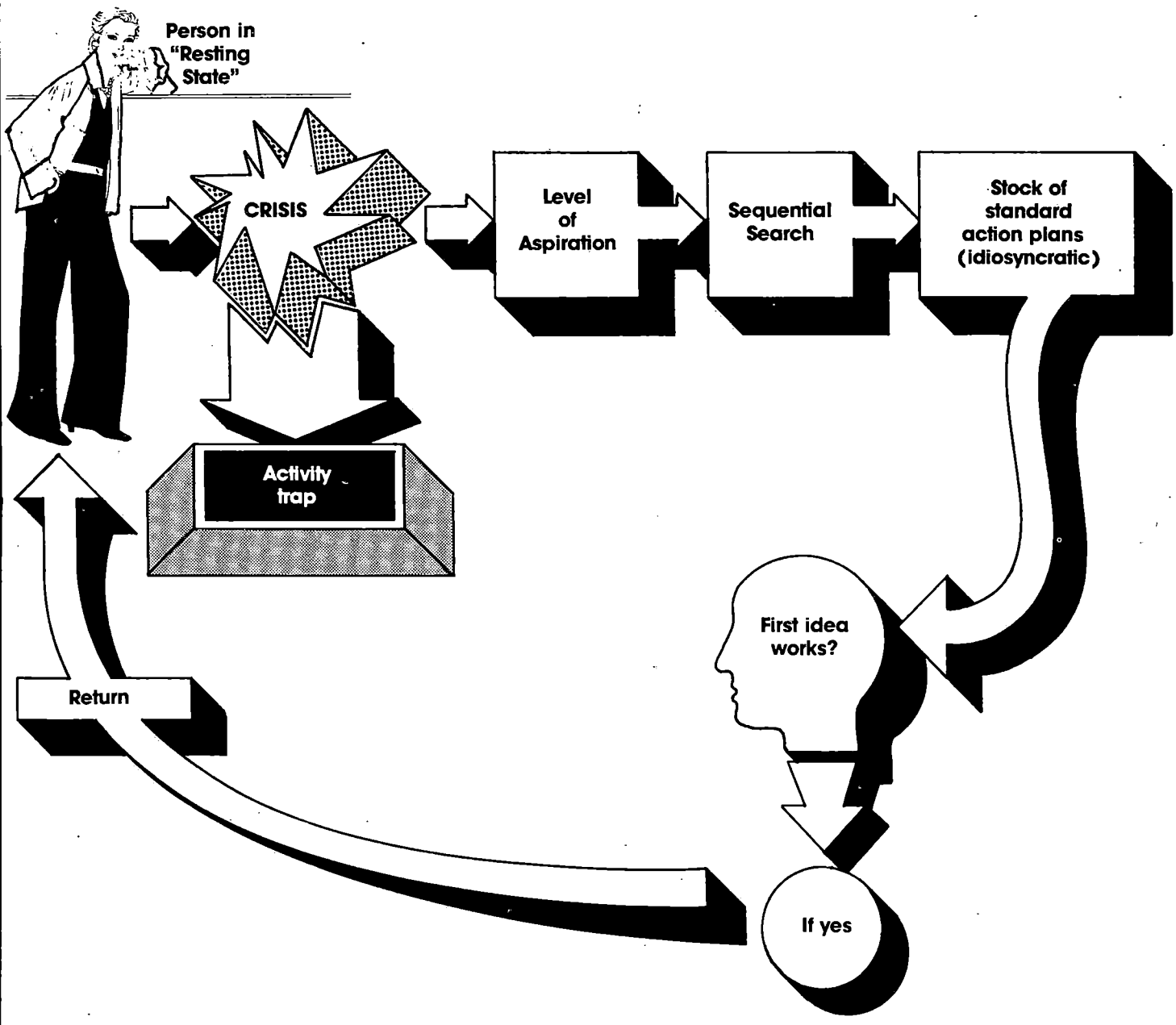
What does it take to start the policy development model in this instance? It takes a crisis intervention. The word crisis is not operationally defined very well. To some people it may mean a deadlin a report due, a meeting, being called to speak or just being asked to react. But something has to happen to make the person perceive a crisis, in which case he or she must do something. Most bureaucratic syste are set up so that crises happen several times daily.

How do such people get out of the crisis? Do they carefully consider what they are up to and how to handle it with a sense of quality? No, not really. Research points out that persons in the crisis model generally have a simple level of aspiration typified by, "How can I get in less of a crisis than my present situation?" Such people do not "make" decisions; they put off decisions and move away from problems. For example, "How do I get these people out of my office? They are embarrassing the age cy. How can I temporarily placate them?"

Most people who work in large organizations have action plans stored up that tend to be idiosyncratic or unique to themselves, or in some cases the agency will have a store of action plans. Some typical action plans are to form a committee, deman a written analysis, stall, do nothing, coordinate with the federal government, etc. Other people have personal coping plans such as terrorizing staff or blaming the bos One office may do one thing, and another may do something else, but typically this is what is found to happen in the crisis model: People are forced by a crisis to lunge out in what tend to be "stock" reactions. Thus, numerous studies of administrative management lead to a description of many managers as muddling through, holding committee meetings, and gradually things either go away, get shelved, get resolved, or someone else does the work. Then the cycle repeats itself as depicted in Figure(

Figure 1: "Muddling Thru or Avoiding Problems"

Crisis Model

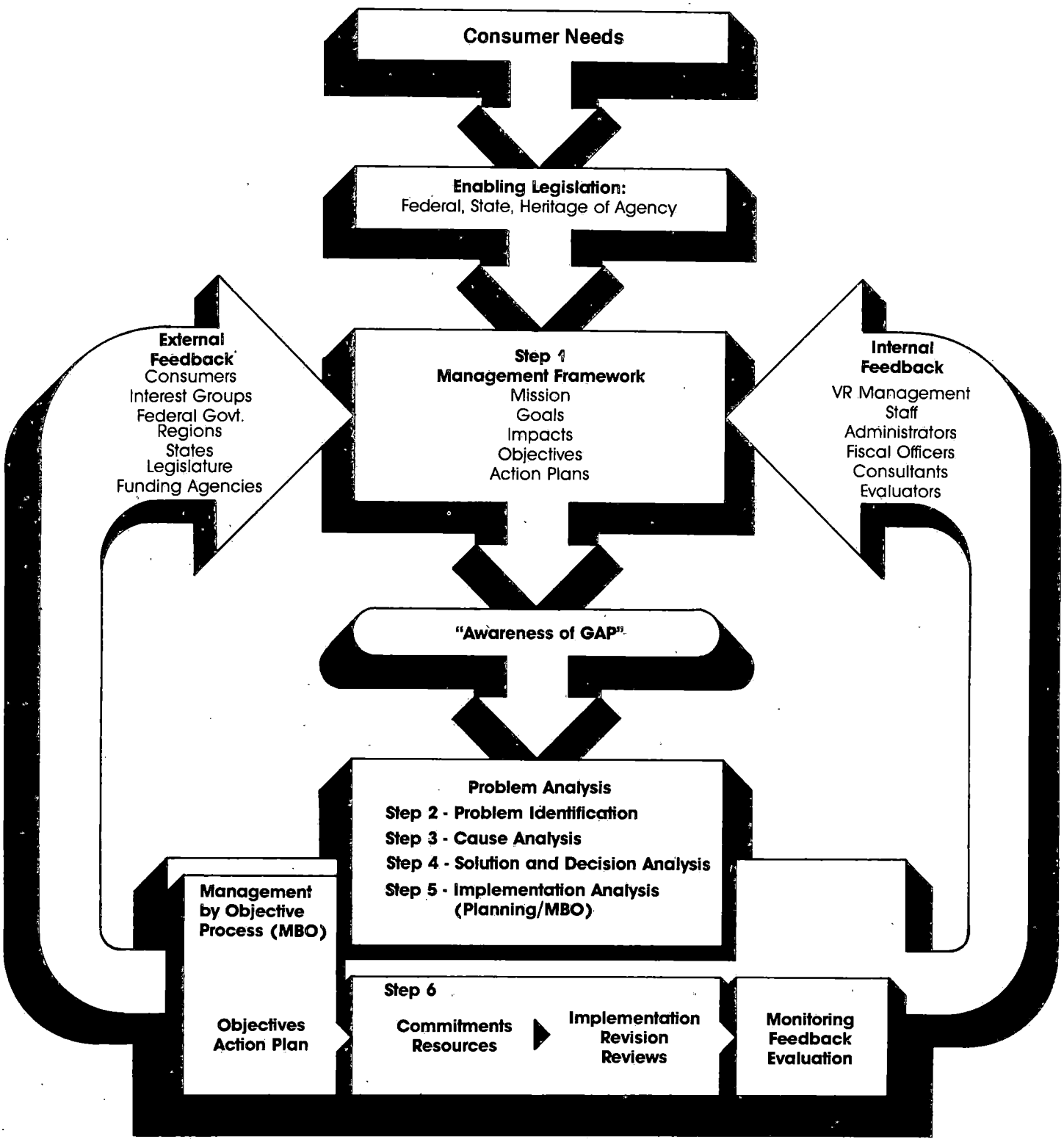


The Reality or "Maximizing" Model for Policy Development

The mechanism for identifying issues and generating good solutions is generally to look toward ideal models. Figure (2) represents a system planning cycle which takes a look at how such a model works in changing the mission of an agency, in sensing gaps, in problem analysis and policy analysis, and in problem solving. This cycle can serve as a reminder of how to touch base on certain critical factors relating to policy planning and development without simply "churning ahead." The system planning cycle is a good method for moving from an agency's ideals to its present realities, to its plans for the future, and finally into new models for service.

In applying the system planning cycle there may be many alternatives. There will be a need to experiment and discover the contingencies that can provide for multiple successes, as well as to try things that really do not work, sound impossible, or "didn't go before." The latter explains why it is so important to be able to get relevent data on which to base informed choices which can then be implemented.

Figure 2: **System Planning Cycle**



With a clear understanding of its enabling legislation and basic management framework, an organization can move forward in the planning cycle from sensing gaps to analyzing problems. In this "problem analysis" stage of such a model, it is important to understand that most human problems, such as those faced in rehabilitation, fit into the category of "wicked" problems which refer to their ethical wrongness (i.e., malnutrition or energy waste) and also to their complexity. Defining a wicked problem is difficult and can "box in" the decision maker so that only certain solutions may seem appropriate. Possible solutions are numberless, however, making it impossible to analyze them all. No single solution, no matter how good, can solve the whole problem because no wicked problem is a single problem. Rather, each one is a symptom of another problem. Due to all these factors, many problems in human services tend to be attacked again and again without ever being solved.

The Problem Analysis Process

The solution to facing such problems is problem analysis, which gives the decision maker something more than just past experience or sheer activity to use in attacking problems that have no clear definitions or boundaries. Problem analysis is a method of defining and categorizing problems so they can be dealt with systematically and creatively. It gives a framework for making decisions and plans and ensures efficient use of resources.

As indicated earlier in Figure (2), once the first step of mission and goal setting is complete, there are five subsequent steps in problem analysis: (1) situation analysis and problem identification, (2) analysis and specification, (3) decision analysis and solution choice, (4) planning, and (5) commitment and implementation.

Step 1, Mission and Goal Setting, is a very necessary prerequisite to this process because it gives the organization a reason for existing and sets the organization's direction by defining purpose, clients to be served, and key organizational values. Specific goals and objectives are derived from the mission statement. Each goal is a single purpose statement of an ideal condition to work towards. For each goal, key result areas are specified which pinpoint major concerns which the organization's work should affect and also break down a goal into areas that relate directly to organizational activity. If a unified effort toward policy analysis approaches is to be achieved, basic accord must exist in different subunits on the missions, goals, delivery systems and evaluation methods.

Once an agency defines the ideal conditions, it can look at the existing situation and determine, not just that there are problems, but where and how much existing conditions differ from ideal ones.

Sept 2, Situation Analysis and Problem Identification, compares ongoing results with desired results to determine how improvements can be made. The stages of this process include situation analysis, problem analysis, priority analysis and problem specification.

Initially, the agency must look at the overall situation and determine where gaps exist between goals and reality. This information can usually be learned through feedback from external evaluators and internal pressures. When gaps or problems are found, they should be analyzed by placing them into categories. Problems can be divided into two levels: 1) strategic concerns, and 2) operational concerns. There are seven interrelated categories of problems within these levels, listed from the most important and hardest to change to the least important and easiest to change. Considering each of these categories listed in Figure (3) provides insights into other aspects of a problem broader than those which first drew attention to it.

Categorizing problems is a special feature of problem analysis. It allows a focus on types of problems and what can be done about them, rather than just leaving the manager stuck with the idea that "a problem is a deviation from a specified objective." It is definitely possible to see aspects of all seven types in any one problem, which indicates a need for priority analysis before the problem can be clearly specified or defined.

Priority analysis sifts out the important factors in a problem. As indicated in Figure (4), each aspect of a problem (structure, mission, delivery, etc.) is evaluated on its seriousness, urgency and growth to determine which aspects are crucial and must be dealt with.

Figure 3: Problem Identification Categories

Level 1 - Strategic Concerns

1. Mission and Goal Problems
   - undefined scope and magnitude of the problem area you are here to solve
   - change in market needs
2. Measurement Problems
   - undefined measuring stick/monitoring effect of your efforts in problem area
3. Effectiveness Problems
   - undefined relationship between what outputs produce and how they achieve impacts

Level 2 - Operational Concerns

1. Delivery System Problems
   - determining best way to produce chosen outputs
2. Efficiency Problems
   - determining most cost-effective resource allocations and combinations for outputs
3. Structural Problems
   - organization and policies impeding targeted achievement
4. People Problems
   - group or individual performance impeding targeted achievement due to:
     - Won't do problems (motivational)
     - Can't do problems (inabilities)

Figure 4: Priority Analysis Factors in Situation Analysis

Seriousness
of problem area

- who does it affect? (scope)
- how much does it affect? (magnitude)
  - impact
  - costs
  - legal aspects

Urgency
of problem area

- time availibility constraints
- consequences of delay

Growth
of problem area

- trend: past, present, and likely future

Finally, when a problem has been categorized and all aspects of it evaluated and compared, problem specification is possible -- the problem can be defined. This means summarizing the problem in specific terms; identifying the goals, impact indicators and targets it affects directly or indirectly; and showing how the problem relates to achievement of the desired goals. Only after problem specification can one start to look for the problem's cause.

Step 3, Cause Analysis and Specification, sifts through possible causes of the problem to separate causal factors from irrelevant ones. It includes five sequential stages:

Structuring the problem	Look at the problem and determine just what it is, what it is not, and the relevant difference between these.
Generating & identifying possible causes	Relate each cause to a particular problem level or type.
Verifying possible causes	Test each possible cause and evaluate the strength of the evidence that any particular condition led to the observed result.
Determining most likely causes	Examine the causes that pass the test to determine which are most likely.
Specifying the most important cause	Settle on one cause or complex of causes as the specified cause of a problem.

Step 4, Decision Analysis and Solution Choice, helps managers determine just what they want a solution to accomplish. This step also keeps managers "in focus" as they generate, evaluate and settle on a solution. The five sequential stages to this process are:

Describing the ideal solution	Do not try to come up with the actual solution in this stage, but try to describe what it should include and what it should accomplish. List the factors that are "musts," the factors that are "wants," and the consequences to avoid.
Generating alternatives	Alternative solution ideas should aim at reducing or changing either the causes of the problem or their effects.
Evaluating alternatives	Evaluate each possible solution. Criteria for rating solutions should include effectiveness, cost, impact, adverse consequences, and any other factors important to the organization.
Choosing the best alternative	Choose one alternative on the basis of how well its advantages and disadvantages balance out.
Giving rationale for choice	Explain the key factors in the choice in a rationale. This phase helps in obtaining resources and in gaining support for the solution.

Step 5, Planning , is the process in problem analysis of operational planning and management by objective (MBO). Here, plans are made for action and for analyzing potential problems. The solution developed in Step 4 is turned into statements of objectives which include the desired results and the method(s) by which these results will be measured. These are then developed into an action plan which includes key steps, expected deadlines, analysis of potential problems and analysis of time management.

Step 6, Commitment and Implementation, is where a mutual understanding, agreement and shared ownership of plans is expressed between administration and staff. The plan is implemented. As action gets underway and feedback becomes available, the six steps of problem analysis are repeated again and again.

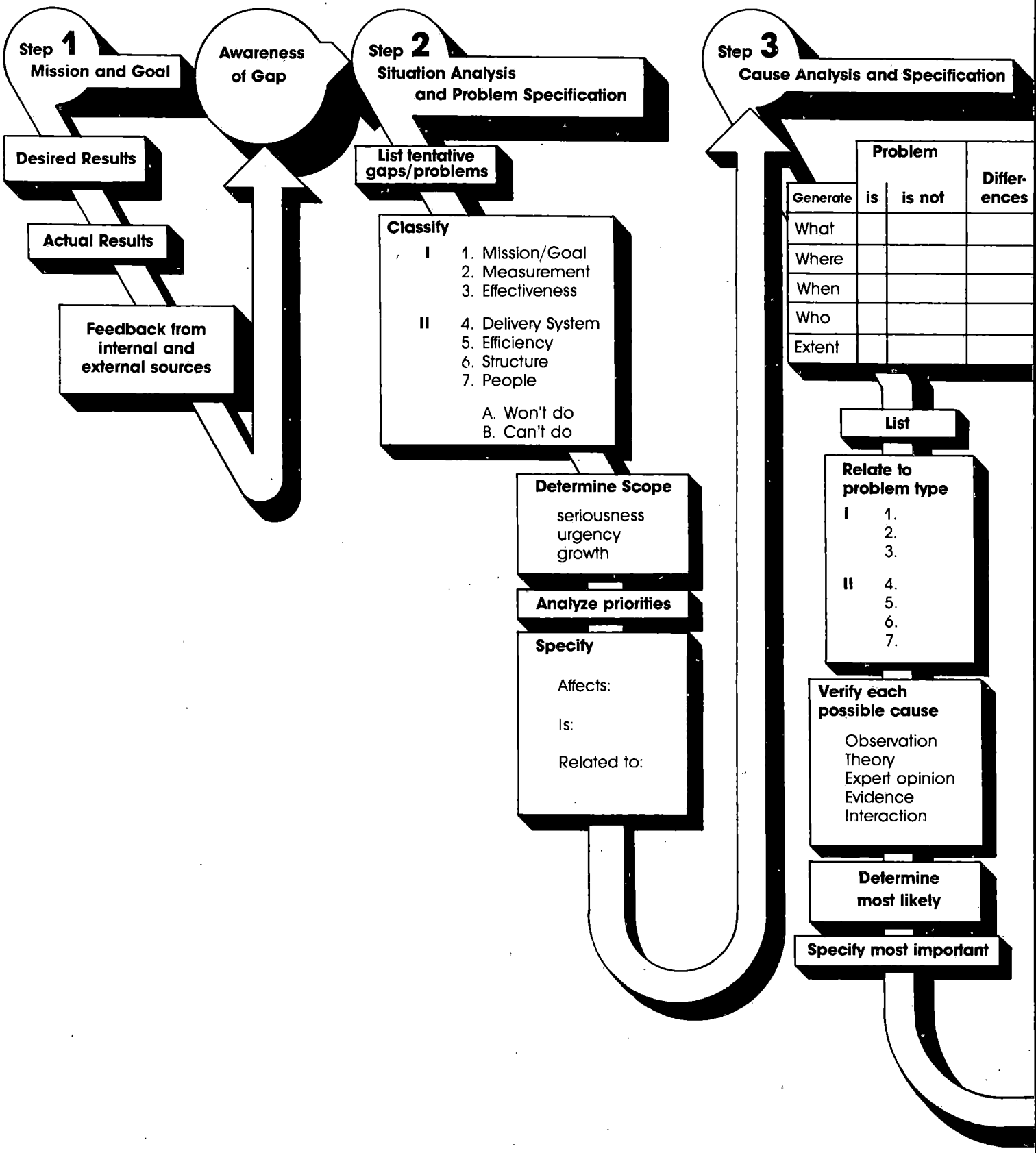
A flow chart of the entire process of problem analysis appears in Figure (5), and a detailed outline of strategic planning systems in governments using this approach is presented in Figure (6).

Conclusion

The preceding discussion on problem analysis via the system planning cycle

(con't to page 22)

Figure 5: **Problem Analysis Flow Chart**



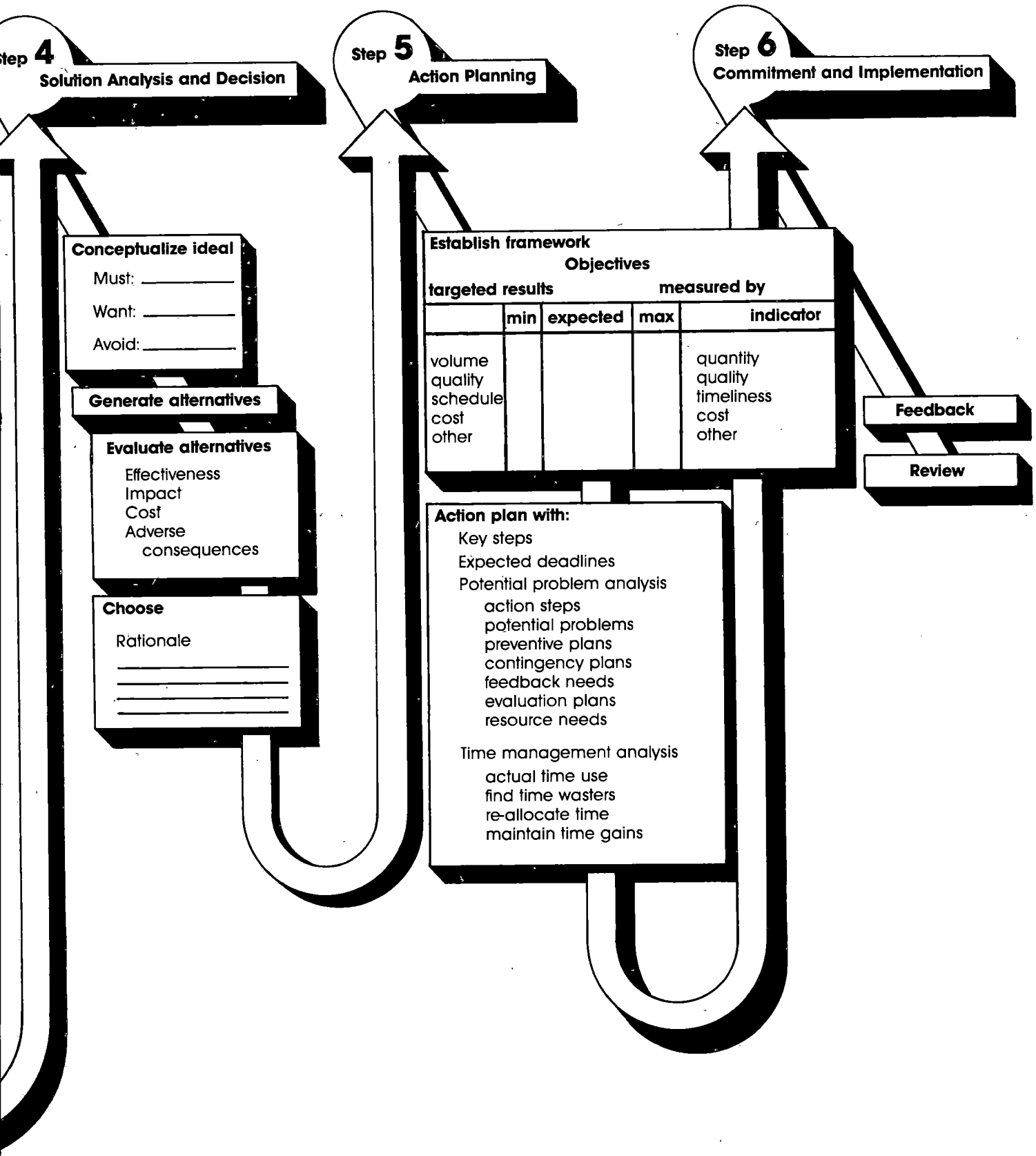

Step 4
Solution Analysis and Decision
Step 5
Action Planning
Step 6
Commitment and Implementation
Conceptualize ideal
Must: _____
Want: _____
Avoid: _____
Generate alternatives
Evaluate alternatives
Effectiveness
Impact
Cost
Adverse consequences
Choose
Rationale
_____
_____
_____
_____
Establish framework
Objectives
targeted results
measured by
min
expected
max
indicator
volume
quality
schedule
cost
other
quantity
quality
timeliness
cost
other
Feedback
Review
Action plan with:
Key steps
Expected deadlines
Potential problem analysis
action steps
potential problems
preventive plans
contingency plans
feedback needs
evaluation plans
resource needs
Time management analysis
actual time use
find time wasters
re-allocate time
maintain time gains

Figure 6 : STRATEGIC PLANNING SYSTEMS IN GOVERNMENT

POLICY ANALYSIS ACTIVITY CHECKLIST

1 DEVELOP MISSION STATEMENTS

A. Identify Purpose

1. Why was this Department/Bureau/Division/Section/Unit created?
   a. What was the Legislature's intention in creating this Department
      (1) Was it expressed in the enabling legislation?
      (2) Was it expressed in the Constitution?
      (3) Was it expressed in the initial or subsequent appropriations legislation?
      (4) Has it changed over the years through:
         ° Legislative action?
         ° Judicial rulings?
         ° Executive order?
         ° Public outcry?
         ° Media outcry?
         ° Internal reorganization?
   b. What was the Commissioner/Director's intention in creating this Bureau/Division/Section or Unit?
2. Is there an expressed National Public Policy with respect to product, service, or impact we supply to public?

B. Identify Consumer Needs

1. What products, services, impacts or benefits do our existing or potential consumers require?
   a. Have these needs been researched or studied during the past 5 years?
   b. Have these needs changed materially in the last 5 years?
   c. Have our operational assumptions (Operational Philosophies) about our clients, changed in the last 5 years?
      (1) Have they been seriously challenged by authorities, the media, the public or our own clients?
   d. Have we reported these changes the Director/Commissioner/Governor/Legislature?

C. Identify Clientele

1. Who are our clients?
2. What segments of the general population do they come from?
   a. Economic and social strata, educational level, age, sex, geographical residence, occupation, employment status, their total number, etc.

D. Identify Values

1. What are the Department's values?
   a. Productivity, product or service volume, program effectiveness, public image, product or service quality, product or service cost effectiveness, equal treatment of clientele, employee development, clientele satisfaction, innovation, etc.
2. What rank or priorities do the above values hold in our organization?
3. Will our value system be challenged by our clientele, the general public, the legislature or the governor?

2 PLANNING ASSUMPTIONS

A. Evaluate Present Condition

1. Where are we now?
   a. What are our strengths, weaknesses, major problems

B. Evaluate Future Conditions

1. Where will we be in 1, 2, and 5 years if we do nothing differently?
   a. What trends, risks and threats do we face?
      (1) Political, economic, social, demographic and technological trends, risks, and threats
2. Do we like the answers to the above?
3. If not, what options do we have?
   a. Do nothing - enlarge - combine - eliminate - modify - magnify - rear-

range - put to other uses - reorganize

(1) "Everything that doesn't change, remains the same."

4. What new opportunities exist?

3 STRATEGIC PLANNING

A. Review Current Programs

1. Will our current programs, program structures, or program priorities fulfill our long-range clientele needs?
2. How could we phase-out our programs/program in 5 years, if all the necessary resources were freely available?
3. How can I phase-out my present position in 5 years and still achieve my Department/Bureau/Division/Section's current objectives
4. Should any new programs be designed, established or implemented to satisfy our clientele's future needs?
5. Should any operational innovations be attempted next year? The year thereafter?
6. Should any existing programs be abandoned?

B. Develop Long-Range Objectives (By Program Category)

1. What do we want to accomplish by 1985? Why? (Is it what we all want? Can we all commit to it?)

C. Develop Long-Range Strategies (Game Plans)

1. How will we accomplish our long-range objectives?
2. At what total costs?
3. What do we have to give up or trade-off?
4. What won't we do anymore? What will we defer for future consideration? What should we abandon?
5. What alternative strategies should we consider?

4 OPERATIONAL PLANNING

A. Develop Operational Objectives (By Program Category)

1. Who will be principally responsible for producing;
2. What specific products, services, impacts or benefits;
3. When will they be produced;
4. How many are going to be produced;
5. How well will they be produced; and
6. How costly will their production be?

B. Develop Work Schedules

1. How many units of service/benefits/work will be delivered or produced during the next fiscal year?
2. How many man-years will this production/delivery level require?

C. Develop Budget

1. What will our unit costs be at the assumed level of production/delivery?
2. What will our general and administrative costs be?
3. What will our total costs be?

D. Develop Management Information System

1. What data will we need to assess and evaluate our progress?
2. How often shall we review our progress?

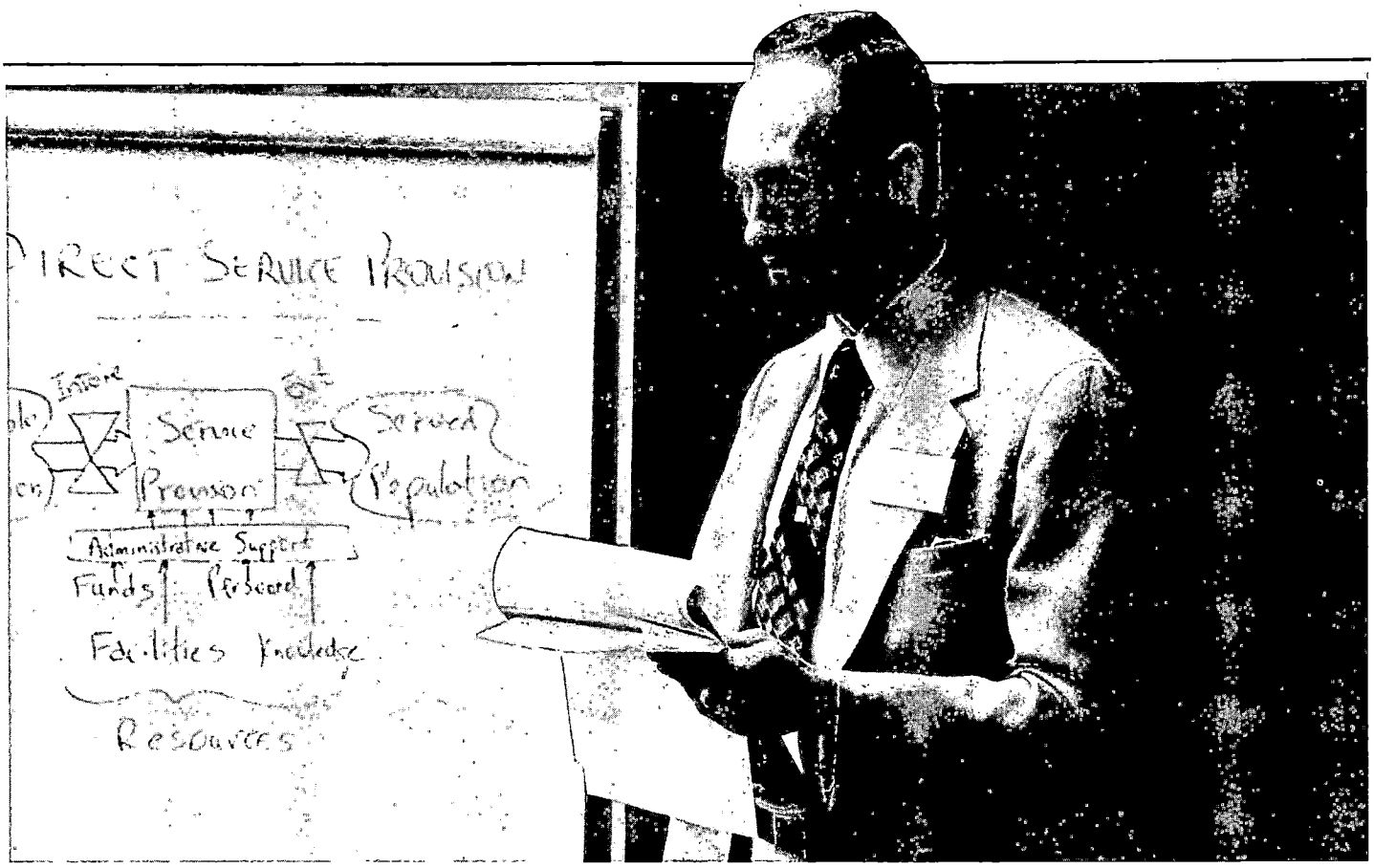
5 EVALUATION

A. Develop an Evaluation Process

1. How did we do against our planned operational objectives?
2. How did we do against our best past performance?
3. How can we do better next fiscal year?
4. What can we learn from this year's experience?
5. What should we abandon?

presents simple but important checkpoints to be considered in developing policy for new programs of service in independent living. In fact, this entire process is policy analysis of the most systematic sort. The phase of this cycle which most state agencies are presently going through in enacting the new legislation is the management framework phase: that is, they are assessing their strengths and weaknesses, reviewing current programs and establishing long-range objectives. Ultimately, agencies will shift into operational strategies where informational systems, evaluation mechanisms and whatever else is needed to appropriately accomplish their objectives will be implemented. The purpose of this workshop is to familiarize and hopefully equip persons with the skills necessary to make these transitions and successfully complete the entire cycle.

This system for sensing gaps and ultimately linking problems with quality action plans cannot always promise success, but it is a fact that if people are good enough to remember they are doing something special, especially when dealing with complex issues such as independent living, and if they stop to say, "Let's really do this right!", then this mechanism will have a positive impact on pooling both internal and external resources to get better solutions, and ultimately improve the ability of rehabilitation agencies to achieve their mission.



Policy Development and Implementation for Independent Living Programs

Stanley E. Portny, President
Stanley E. Portny & Associates, Inc.
Alexandria, Virginia

Introduction

The charge for this segment of the conference is to analyze the I.L. issues identified through the previous day's nominal group process and begin to identify certain basic major concerns that each participant and facilitator feel are important in starting action within their respective programs. Basic thoughts must be "talked through" in order that a reasonable plan of action will emerge. Then steps can be designed to determine how one might begin to take action.

Perspectives on Issue Identification/Analysis

Two often overlooked perspectives are offered which may aid in guiding persons or groups through the issue identification and analysis stages of planning policy for an independent living program.

First, one must consider the possible levels of intervention in dealing with independent living issues, where the problem emanates from, and at what level the problem is most realized. While each person brings his or her own perspective(s) to independent living issues and services, it is essential to recognize that there is a coordinated series of actors all the way from the Congress and federal governmental branches, through central and regional offices, to the state level and local service delivery systems, all of which need to work together if I.L. is to be implemented. Legislation must be enacted, policy must then be developed, plans must be generated to implement the policy, action must be taken to implement the plans, and finally some evaluation must be made to determine how effective agencies are in accomplishing what they plan.

Second, the individual service provider needs to know whether his or her personal efforts have been successful. Determining effective ways to report this information is also a crucial factor in the planning and implementation of a program.

A Model for Policy Development and Implementation

Successful design and implementation of a Title VII program requires that the following four steps be taken:

- .Develop policy
- .Plan
- .Implement
- .Monitor and evaluate

The interrelationships between these activities are illustrated in Figure (7).

Policy consists of the body of information which specifies program purpose and the specific actions that will constitute its achievement. In order to facilitate an accurate understanding of the types of program behavior which are to occur, it is necessary to develop policy statements with increasing specificity, to translate general program interest (program mission or purpose) into actual guidelines for action (program procedures). This policy continuum is illustrated in Figure (8).

It is often difficult to reach a consensus on what the mission of a program is; and, frequently, a formal statement of the program's mission is never drafted at all. When consensus does not exist regarding a program's mission, it is possible for other external parties to formulate statements which represent that mission which they would like to see pursued rather than that which the program was originally designed to achieve. In such cases, program evaluations frequently assess the extent to which a program has achieved this new mission and set of expectations, rather than the original one which guides a good portion of program operations.

After specifying clearly the program mission, a detailed series of plans must be formulated to facilitate the achievement of this mission. Critical components of these plans include detailed statements of actions to be performed, as well as the specification of a time frame for the completion of all tasks and the identification of all resources required.

Often in the development of a program, either procedures are established which have little or no specific relationship to achieving the program mission, or a specific mission statement has been drafted and no procedures have been developed to operationalize it. Lack of planning increases the likelihood that, despite the quality of the initial program intent, little or no positive action toward that intent will occur.

A Title VII program will entail two basic types of activities:

- .Direct service provision
- .Indirect service provision

Figure 7: Program Development and Implementation Model

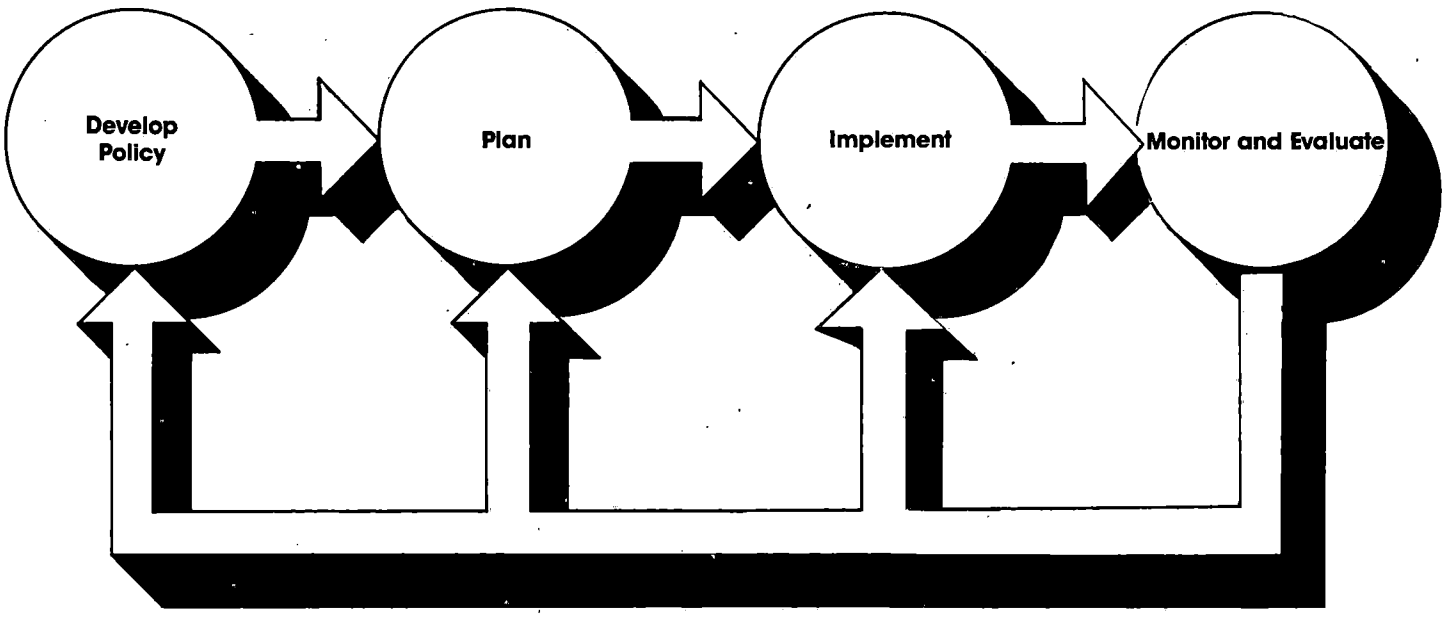
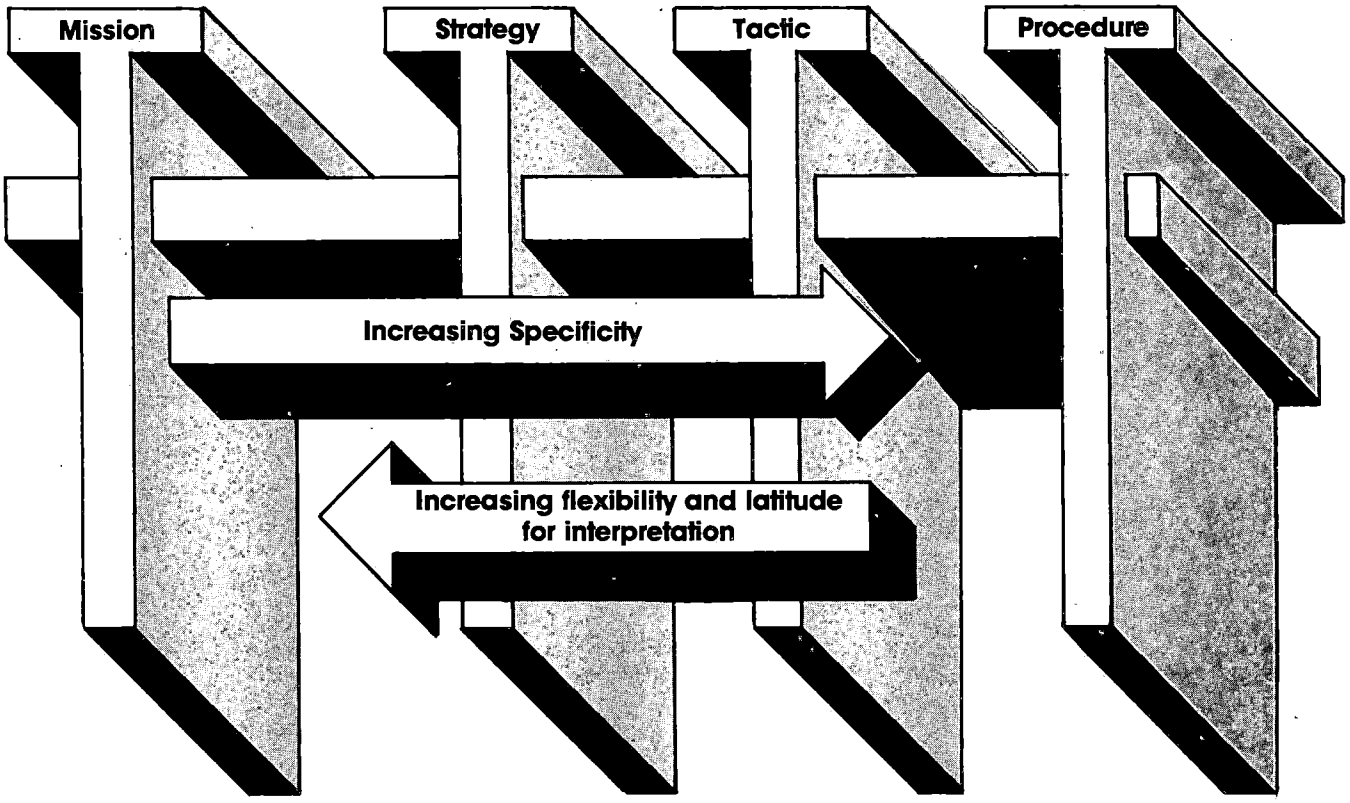


Figure 8: The Policy Continuum



A primary component of activities in a Title VII program entails the coordination of money, facilities, knowledge of technology and personnel in order to provide selected services directly to severely disabled people. A diagram of the relationships between these direct service provision activities is illustrated in Figure (9). In addition to the resources indicated, a service delivery system also requires an effective administrative support network to insure the coordination of all resources and program activities. Particular questions to be addressed when designing an organization and associated procedures for providing independent living services directly to eligible severely disabled people include:

.Who is to be served?
.How are these people to be identified?
.What services are to be provided?
.How and when is their participation in the program to be ended?
.Once they leave the program, can they ever return?

In addition to providing services directly to severely disabled people, an independent living program can serve in the following capacities to assist the target population:

.Provider of funds for the purchase of services;
.facilitator and coordinator of services;
.regulator of services, that sets service standards or credentials service providers; and
.capacity builder, that develops training programs, funds research, builds facilities and so forth.

Finally, an effective system of monitoring and evaluation should be established to assess the extent to which the program mission goals and objectives are being successfully achieved. The evaluation process entails four steps:

.Select criteria with respect to which program performance will be assessed;
.Develop a procedure for collecting and

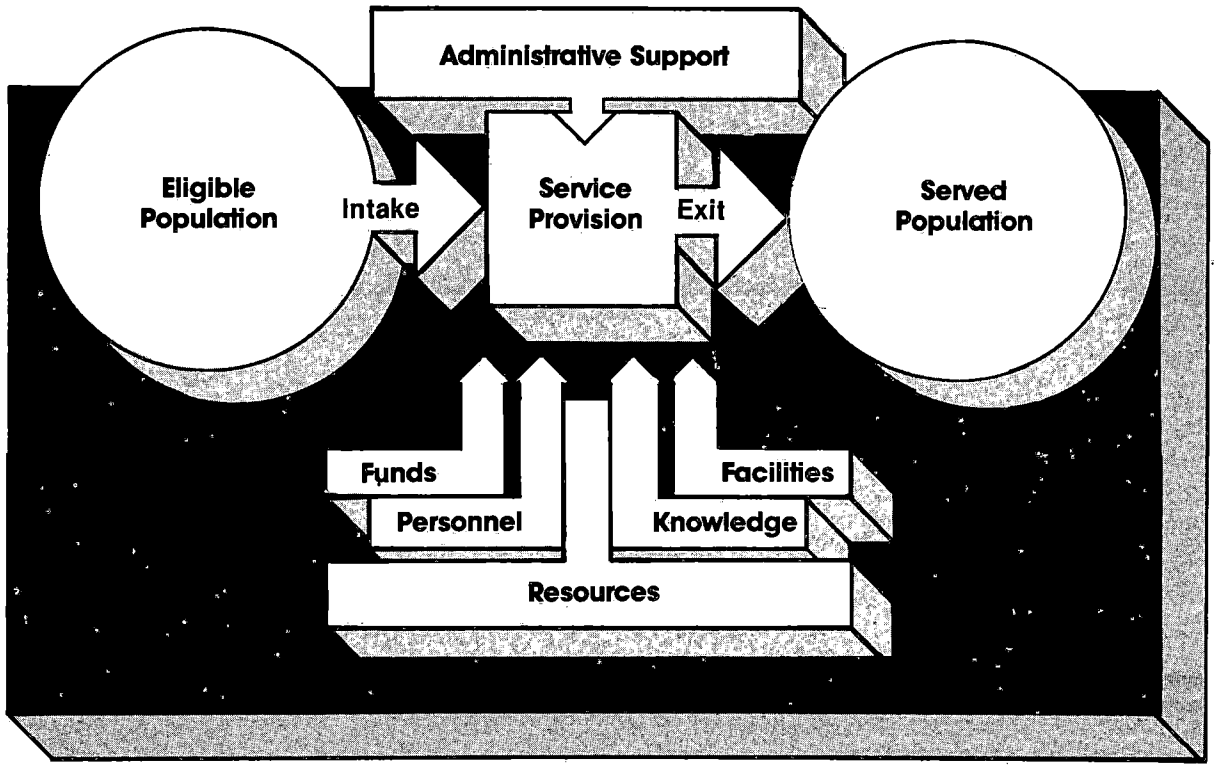
reporting data on program performance (such as, for example, through case records, periodic sample studies of the target population or applications for continued funding);

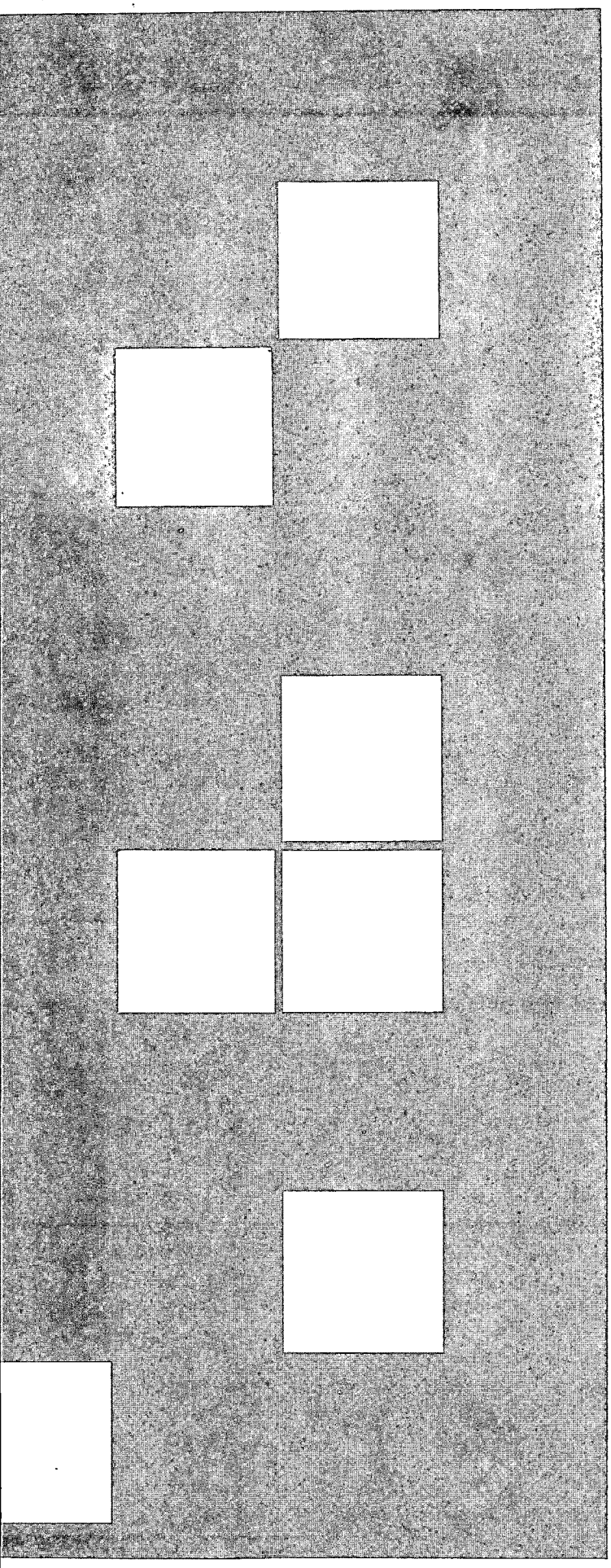
- Develop procedures for examining the data collected and comparing it with the mission, goals and objectives to be achieved; and
- Feed back the evaluation results to the program personnel. At a minimum, this information should be provided to a) the service providers who work directly with the consumers; b) the manager who is responsible for acquiring and coordinating program resources and activities; and c) the policy maker who determines the general mission and goals which the program is designed to accomplish.

Conclusion

This presentation is concluded with a statement of concern that participants actively seek to find answers to two issues raised during this conference when they return to their state programs. It is recognized that existing independent living legislation and funding will enable program initiatives to be established which only partially conform with the most desirable conceptual approach to independent living. However, the fact is underscored that agencies will be able to establish successful independent living programs, only if they are able NOT to focus on activities which never result in action. Rather, thoughts on the concept of independent living, where it should go, and what it reasonably should do must be translated into any and every mechanism possible for providing the needed services. Admittedly, this is a difficult charge, particularly in the present environment where the Part B grant is under minimal control by state agencies. But at the same time, minimal funds for agencies' services can and should be interpreted as a need and opportunity for more creativity in determining ways to interject new ideas and philosophies.

Figure 9: Direct Service Delivery Components



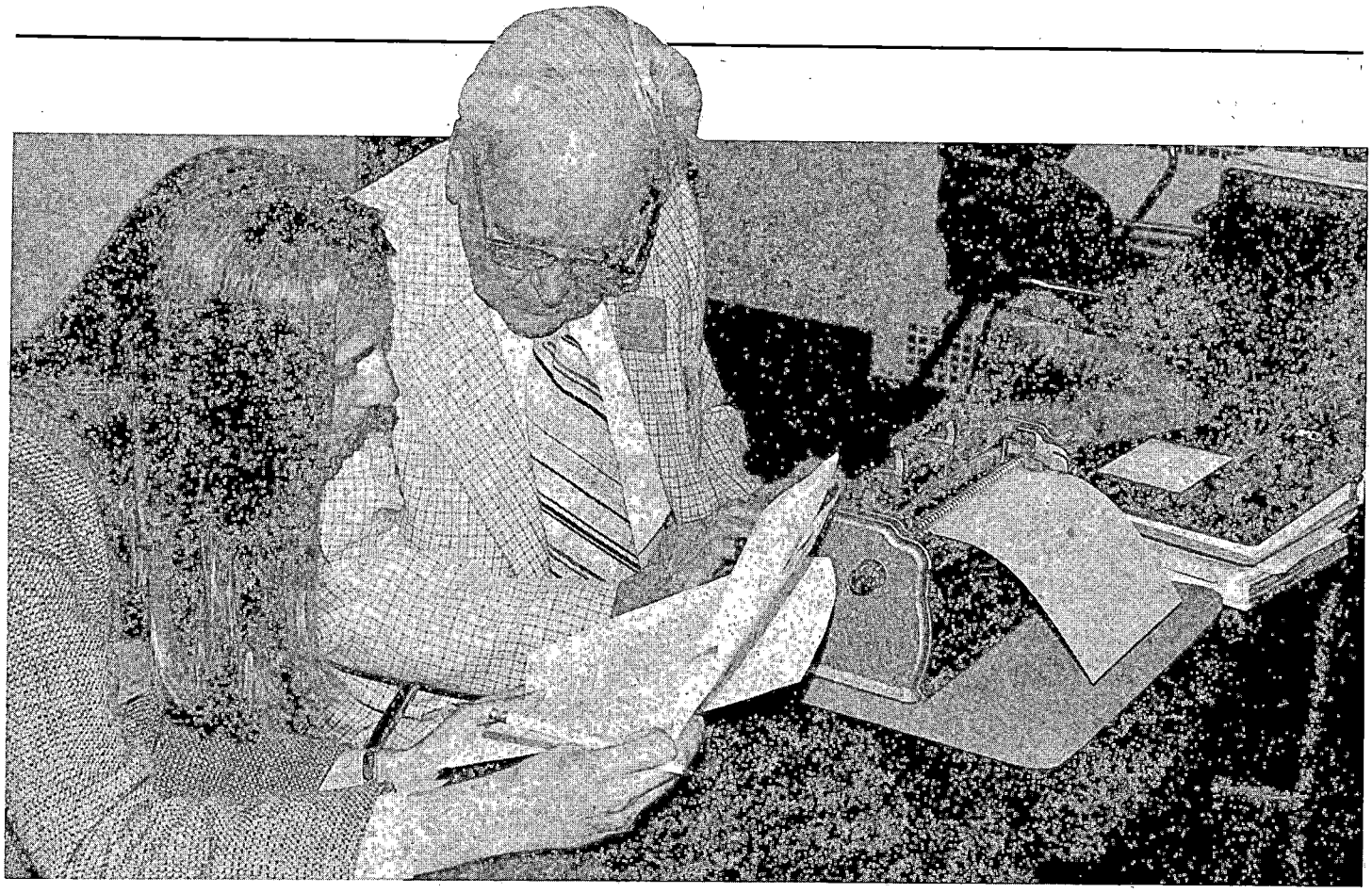


2a.

Issue Identification

Two carefully structured group exercises exposed workshop participants to some of the skills required in effectively eliciting input from individuals and groups included in the policy process. These activities were 1) an independent living values exercise, and 2) the nominal group process.

As a result of these exercises, conferees identified many of the primary and secondary I.L. issues confronting agencies. The "team approach" used in both exercises was designed to stimulate future agency efforts in this area, which no doubt will involve input from consumers, ancillary agencies, consultants, counselors, federal/state administrators, and a host of others.



The Independent Living Values Exercise: Procedures and Outcomes

Purpose: The purposes of the independent living values exercise were to introduce participants to each other, to initiate conversation, to elicit thoughts relating to individual values, and to highlight the need for listening skills in a group process.

Procedure: In conducting this exercise participants were asked to individually study identical lists of 23 issues relating to independent living. Issues varied in size, complexity and level, and were predetermined by workshop coordinators through a needs analysis study and steering committee review. Participants were requested to individually reflect upon the importance of each issue based upon their own job, interests, and personal values and to then record their choices of the five least important and the five most important issues on a values exercise worksheet.

Participants were later assigned to one of seven small work groups of approximately six members per group. Here, members were encouraged to discuss their previous selections with others in the group and hopefully convince the group to concur on those issues which they personally felt were of primary importance. Following a 30-minute discussion period, group votes were taken to determine the top five issues within each group. Participants then re-

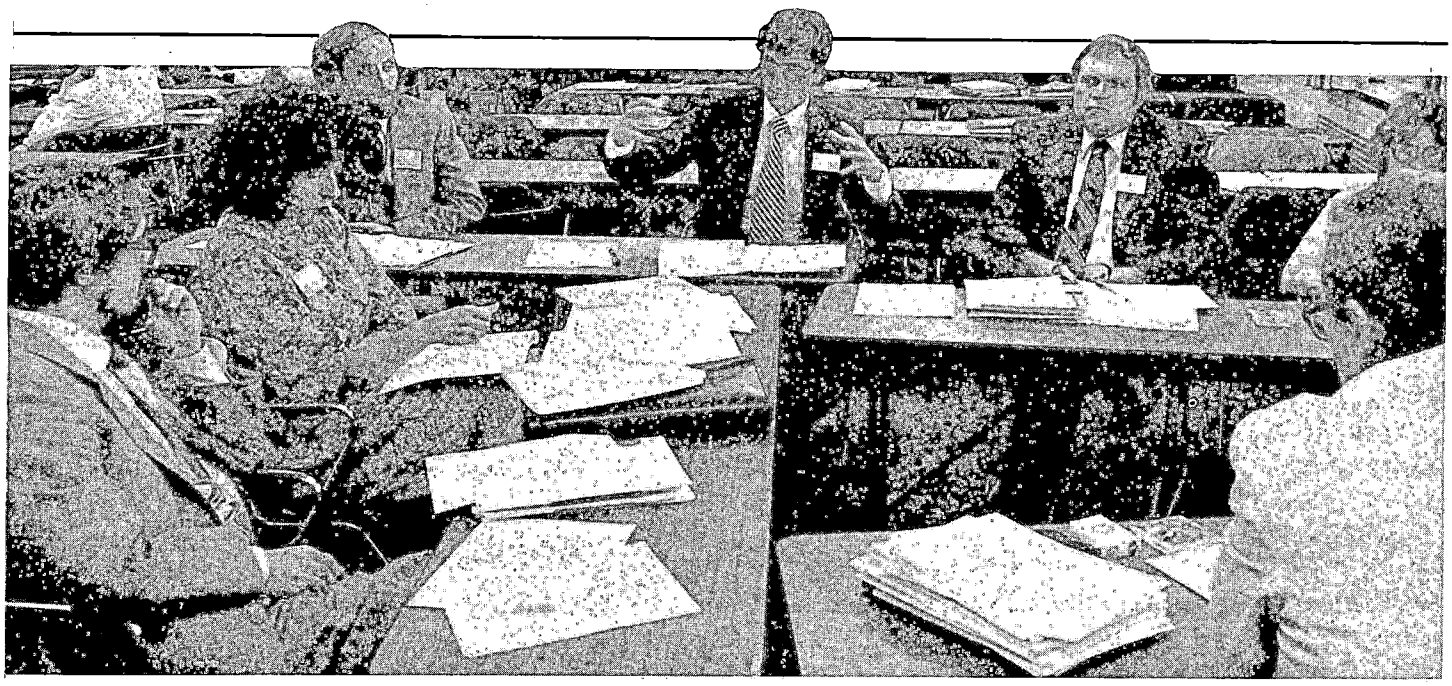
convened into a plenary session where all group results were pooled to determine a weighted average of where the entire delegation stood on major issues.

Results: Listed below are the original 23 issues. Asterisks (*) to the left of numerals indicate the number of group votes which a particular issue received.

*****1. Clarifying the relationship between Title I and Title VII
2. Placing independent living services in the state agency
****3. Operationalizing the administrative requirements of Part A and Part B
4. Staff development related to independent living
5. Staffing patterns
****6. Interagency planning and cooperation
*7. Program effectiveness
****8. How to best utilize scarce resources
*9. Clarifying accountability for independent living results
***10. Consumer involvement
11. Consumer satisfaction
*12. Outreach to new consumers
****13. Role of consumer in program design and management
14. Increasing programmatic legitimacy of independent living as a state VR function
15. Developing an order of selection
16. Tight administrative controls on independent living services provided
17. Control of all independent living administration by program consumers
**18. Full entitlement of consumers (receiving all services to which they are conceivably entitled)
*19. Determining eligibility criteria
*20. Lobbying for more funds for independent living
21. Specifying duration of services
****22. Developing measures of program success
23. Developing standards for independent living centers

Conclusions: The total conference consensus on the top issues from this list clearly focused on issues number 1,3,6,8, 13, and 22. An important outcome of this activity was that each group appeared to recognize that they were dealing with "clusters" rather than just single issues. For example, there is a cluster of items above related to the issue of legal clarifications, or to group planning. From this exercise a recognition began to emerge that issue identification is not something that any single individual will successfully accomplish. Rather, the need for issue identification is something which forces individuals to recognize the effectiveness of total agency planning.

Furthermore, through the process of being constrained to deal with a given list of 23 issues, most participants identified the fact that these were not comprehensive issues and that there are other equally important I.L. issues which should be addressed in policy planning and development.



The Nominal Group Process: Procedures and Outcomes

Purpose: The nominal group process is a problem-finding exercise. It represents a method of running a meeting which gives the meeting a purpose and structure with which to achieve that purpose. The goals of the process are 1) to identify and list as many issues as possible (problems, opportunities, gaps, challenges, etc.) which confront the group, 2) to obtain a list of the top issues and their relative importance, and 3) to increase awareness and understanding of the issues within the group. It is the most efficient and effective means of collecting and defining the greatest possible number of issues or problems. It is <u>not</u> an attempt to come up with solutions.

Procedure: In participating in the nominal group process, participants were separated into four teams. Teams were given ten minutes in silence during which members were asked to write down all the issues, seen as problems or opportunities, which he or she associates with the independent living concept and its implementation in the next two years. Individuals were asked to consider societal, organizational, financial, geographical, legal, personnel, or any other types of issues which came to mind.

When time expired, a round-robin process began, during which each team member in turn specified one issue from his or her list. Team members were permitted to "pass" at any time. Team facilitators numbered the issues and recorded them. When a team ran out of issues, the list was discussed, issues were changed and combined, and new ones were then added.

After discussion, issues were voted on the basis of relative importance. First, team members individually listed the issues they saw as the top ten in order of importance. Scores were recorded and added to find the team's top ten choices. Discussion followed and a second vote took place in which members listed and weighted their top five issues in order of importance. These were tallied to determine the team's top five issues and their importance. Each team reported back to the larger group and more discussion followed.

Results: Lists of top issues and the complete lists of issues were collected from the teams for review and synthesis by workshop facilitators. From this data the following issue classification was performed and returned to all conference participants. This summary represents a total synthesis of all of the issues that were identified in each of the groups --- not just the top five. While many of these issues could be classified into several different categories, an effort was made to collect issues around the major themes of the conference, 1) Title I vs. Title VII, 2) independent living centers, 3) agency scope of services, and 4) Parts A and B. Issues marked with an asterisk (*) were noted as being especially important by conference participants.

Policy Planning and Development in the Independent Living

Issues from the Nominal Group Sessions

June 11, 1980

Issue Category: Title I vs. Title VII

This issue category was largely operationalized as "issues which participants would like to have resolved by the federal policymakers."

Definitions
*Definition of IL: *Operational definition of IL
*Distinguish between IL & ILR
Basic definitional clarification

Big Questions
Is IL just the tip of the welfare reform movement (i.e. compile various maintenance programs)
National & international - Cross fertilization of IL service models
National policy on independent living
NIHR prioritization of IL research
Where does client dependence end and independence start
Work disincentives
*Disincentives

General Issues
Title I/Title VII
Maintaining fiscal accountability between Titles I & VII
Dual eligibility relationship between Title I/Title VII
Is this really new or just I&E money in disguise?
Use of Title I funds for IL services
Rehab. facility jealousy toward CILs
Leadership for new program
Divergence in policy and training conferences

Public Awareness
Expectations exceed resources (especially consumers and groups who see IL as a panacea)
Public and state agency acceptance/awareness of needs & benefits of IL
Selling IL concept to the public (taxpayers)
Sensitizes non-DVR professionals in principles of ILR
Deal with perception that IL is all things to all people
Public decision making with dissemination of results

Miscellaneous
Effects of RSA move into Dept. of Education

Lack of Definition
*"Consumer satisfaction" not operationalized clearly
Meaning of "client motivation" (ILR)
Ages to be served
Mandatory standardized core services
Dichotomy of system orientation
Ongoing vs long-term needs
Defining outcomes
What is duration (rehab. or maintenance)
*Where to draw the line for unending ILR services (range, duration, cost)

Funding
Continued funding (any source)
Lobby coalition
*How to stimulate increased funding to get to the entitlement level
Cross-disability vs categorical funding
Campaign strategy to secure public and legislative support

Payment for Services
Service voucher system (clients given vouchers for services)
Purchase vs provide
Client contribution to costs of IL

Issue Category: IL "Centers"

Issues related to independent living centers (ILC) are grouped here as are many consumer issues. Many issues in this section also could have been grouped as issues related to scope of services provided by state agencies.

Center Philosophy
Change title "Independent Living" to "Choice of Lifestyle"
Problem of over-dependence on established ILC models (such as Berkeley I.L.C.)
Is IL imposing middle-class values
Medical model as a barrier to IL
Who runs I.L.C. (community handicappers vs VR handicappers)
Flexibility to respond to changing needs and community differences
Network of ILCs
Identify funding sources - private to public - future

Role of Consumer
How to organize a board for a center (private-nonprofit) composed of 60% severely disabled
Working formula between consumers & VR related to authority issues
What is role of able-bodied in consumer movement
When is consumer no longer a consumer? Are handicapped employed professionals still consumers?
Role of consumers
More sophisticated consumer orientation techniques (particularly IL programs)
Consumer expectations
Minority movement in IL
Greater coordination and cooperation among consumer groups
Mobilizing consumers in geographic areas where they aren't organized
Must consumers be organized to be involved
*Identify mechanism for consumer involvement at all stages
Consumer backlash to RFP process
Radical consumers are frustrated because implemented programs aren't consistent with legislative intent
Lobby coalitions

Training and Development
To prepare consumers without imposing professional values on them
Management training for consumers operating IL centers
Development of reliable attendant care program
Attendant education pool and financing

Legal Issues
Legal assistance for advocacy
Legal liability regarding services provided by care givers

Barrier Elimination
Eliminating architectural, transportation and communication barriers
Transportation and housing

Issue Category: Agency Scope of Services

This section is the largest single category of issues and reflects seminar participant characteristics in that the greatest number were from VR agencies in Region V. Issues related to the need to operationalize independent living concepts were evident.

Agency Scope Role Definition
*Delineating scope of services
Effective role of state VR agency in IL
Public awareness of IL
*Duplication of services: How to utilize existing programs
Extent of client self-determination allowed
*What is (should be) VR role in IL with respect to:
a) consumer involvement
b) planning
c) program development
d) program operation
e) accountability
f) funding resource development
g) service resource development
h) advocacy resource development

Delivery System
Inability to provide state-wide services
State-wideness
Providing timely service in most desired consumer environment
Should this be a county level program with county board administration
*Responsibility of local community in development of IL
State-of-the-art of other state and local service providers
Should VR have a specialist within agency

and an ILC in same regional area
*Prioritizing services with limited resources
Range of services to be offered
Client's rights and appeals
Third party grievance process (for consumers)
Define the appeals process
Service delivery problems for rural consumers
Identification of client performance inhibitors
Control by consumer of plan
Identify major similar benefits
Case management/payment methods for IL services
Delivery of IL services to rural areas/states
Accessibility of services in rural regions
Linkage and/or obligation of private rehabilitation in IL
Lack of national leadership

Eligibility - Order of Selection

IL and needs of older Americans
Services to children
Eligibility considerations/order of selection
Eligibility criteria
Prioritization of recipients for IL services
Scarce resources - order of selection
Identify casework priorities and intake criteria
Prioritizing disability type populations vs existing eligibility
Operationalizing concepts -- services for all disabilities
Identify target population

Staffing and Personnel Issues

Professionalization in VR
Staffing: Existing VR staff or new staffing
Development of standards for service providers
Is there a need for a new professional
Recruitment, hiring, training of agency staff
*Staff competencies (recruit and train)

Training and Development

Staff training to think functionally rather than categorically
VR counselors/professionals attitudes toward non-vocational objectives
Adequate pre-service/in-service curriculum for providing IL services
What implications for higher education related to IL
Existing staff orientation to IL
Reducing resistance to change and reluctance of governmental agency staff from traditional work-ethic values
Who trains state agency staff
Impact of IL concept/philosophy on training of professionals
Curriculum level for IL workers
Provision of adequate staff training

Research - Program Evaluation - Outcome Measures

Program evaluation, data collection, and reporting requirements
Evaluation of program effectiveness
Measurement of consumer's success
Development of evaluation outcome criteria
*Program evaluation and accountability
Who sets measurement standards for ILC's
Establish outcome expectations for IL services
Assuring quality with low financing
Criteria for case closure
Insuring unobtrusive accountability
Establish data base
What difference do IL services really make

Energy

Impact of energy scarcity on IL
Reconciling concerns of energy conservation with IL

Interagency

Interagency planning and cooperation
Turf protection - distinguishing between vocational and social services
Considering cooperative agreements regarding our getting money rather than giving it
Where to place ILC with other agencies (location)
Autonomy and cooperation in ILR
Establish cooperative working relationships with other agencies
Need models of interagency cooperation
Interagency agreements, contracts, use of similar benefits
Lack of service delivery - coordination
*Integration of IL with social service systems
Jurisdictional problems (cross programs)
Create cooperation between VR & D.D. program planning and implementation
*Influence other major institutions to provide services to the disabled

Legislative Issues

State legislative commitment (i.e., getting

permission to implement
Authorization for using funds
Securing legislative appropriations

Public Awareness
Public information and support of IL movement
Selling IL concept to the public (taxpayers)

Issue Category: Parts A and B

Issues related to Parts A and B reflect concern with the broad IL program defined by the legislation, and most especially the interface between traditional rehabilitation services and grants to independent living centers.

General Issues
How to select best candidates for ILC grants
*Operating policies and procedures, Parts A, B, and C

Interface Issues
Content of IWRP
IWRP/IEP interface
IWIL RP should be seen as more important than the IWRP
State agency Part A - staffing pattern of ILR
Peer counselors vs agency counselor
ILR program in state agency not being perceived as a single resource providing IL services
Purchasing services from Part B centers with Part A funds - How to do it?

Funding
Establishing Part A funds
Stabilized funding for maintenance of effort
ILC existence after Part B funds, i.e. what happens if no new Part B is available after three years
Who controls budget decision; state VR or centers' boards of directors

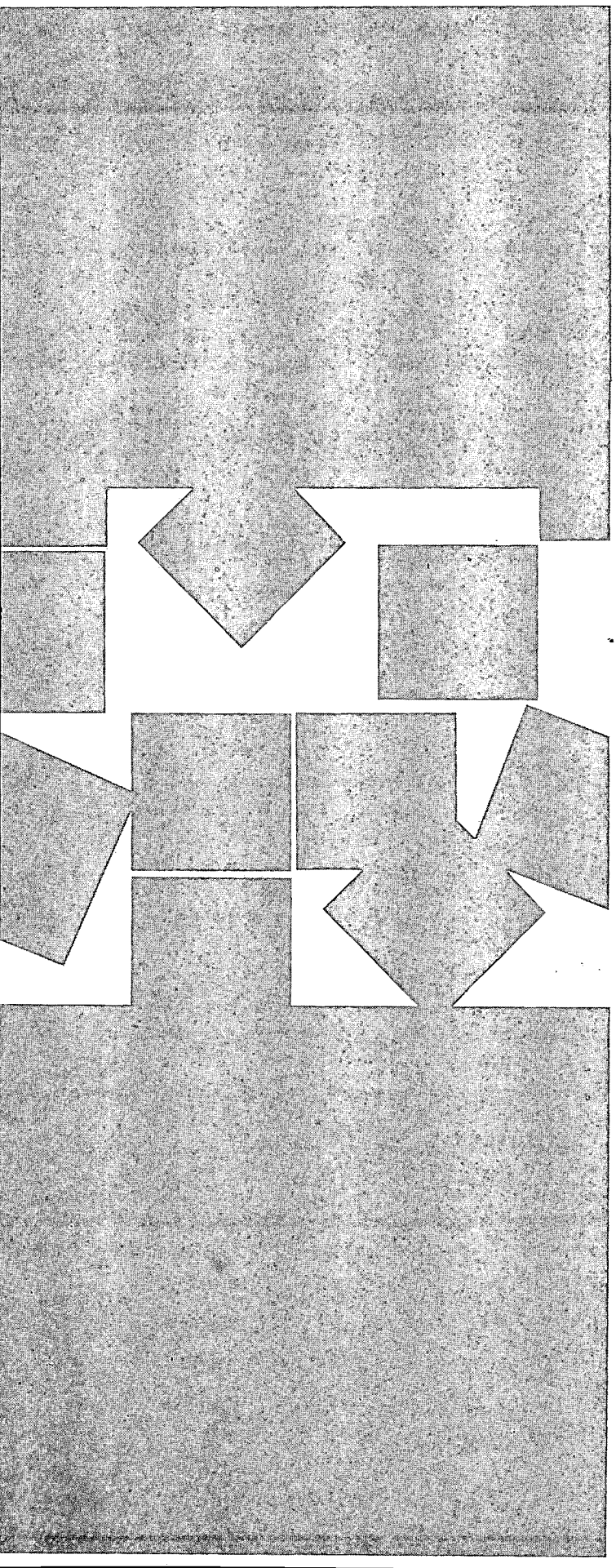
Planning
Opportunities to serve new constituency
Determination of need for IL services
Assessment of what is needed and what is available
Look at overall needs
Long range planning in IL
Concepts vs programs

Budget and Funding Issues
Money: How to plan with inflation and recessions
*Adequate money
Long term budgeting of dollars required to serve each individual client accepted

Conclusions: The emphasis of this activity was on demonstrating what various members of a team can accomplish together. There are really two benefits which can be seen through this issue identification activity. The specific charge was to identify the top five issues which groups felt were most important and had the greatest consensus of importance to people right now. These are the important "major" issues. But equally important are the "secondary" issues that were identified as team members were encouraged to be more creative and go beyond where they normally go by identifying new issues related to the "potential effectiveness" of I.L. While these secondary issues may not be dealt with initially in policy planning for I.L., it is suggested that these may be concerns which will have to be addressed later if programs in I.L. are going to be successful.

From this standpoint, an issue classification list such as the one that evolved from this nominal group process can be a tremendously valuable resource for use in stimulating people, making sure all the right questions are asked, and in avoiding crises. This type of information can serve as a framework from which an agency or group can come up with a focused approach to the concerns raised under the general headings and begin to develop action plans and requirements. However, in no way should one feel constrained to have to deal with every issue on such a list. The success of this process is measured by the extent to which participants are able to take this information and use it as a springboard.

Issue classification performed by
Michael L. Moore, Ph.D. and Valerie Ellien



2b.

Issue Analysis

The charge for this segment of the workshop was to analyze the I.L. issues identified through the earlier nominal group process in order to bring forth certain basic major concerns that each participant and facilitator felt were critical in policy planning within their respective programs. Basic thoughts were "talked through" in analysis group sessions which corresponded with the four major themes of the conference: Title I vs. Title VII, Parts A & B, independent living centers/consumer participation, and agency scope of services.

Consultants' perceptions of these sessions revealed that participants had, in fact, acquired a "policy state-of-mind," which was demonstrated through their successful initiation of a causal analysis in many issues confronting their agencies.

Issue Analysis Group Sessions

By the mid-point of the conference, participants had each received and reviewed copies of the issue classification report resulting from the previous day's nominal group process. The fact that approximately 180 separate issues were identified in this report highlights the fact that independent living is in a very fluid and initial state: there may be much that is known, but evidently there is a lot more which still remains unknown.

During the remainder of this session participants proceeded in teams through a series of four issue analysis groups. Policy analysis and independent living consultants aided teams in collectively interpreting various issues. The activities of these 45-minute sessions all centered around issue analysis with the ultimate goal of developing a "policy state-of-mind" within participants.

Issue analysis groups corresponded with the major themes of the conference and paralleled the categories into which issues were placed in the classification report. Consultants for the groups were:

Issue Analysis Group	Consultants
Title I vs. Title VII	Stanley E. Portny Miriam M. Stubbs
Parts A & B	Jean Cole Gerben DeJong
Independent Living Centers and Consumer Participation	Kathleen Miller Kent Hull
Agency Scope of Services	Len Sawisch Michael Moore

After teams had the opportunity to meet in each of the four issue analysis groups, a plenary session convened during which a consultant panel revealed many of the perceptions which had been gleaned during team efforts to analyze various I.L. issues confronting their agencies. The following is a brief summary of the major points expressed during this informal discussion.

Title I vs. Title VII

.In trying to focus on either Title I or Title VII, it becomes apparent that everything is related to everything else and therefore people dealing with I.L. legislation generally begin by focusing on whatever their particular area of interest is.

.In the issue of relating Title I and Title VII, two possible structures were analyzed: 1) the conception of Title VII programs as a new link in the service delivery system, another service availability which can be used to respond to a client's overall view of needs; and 2) that Title I is not simply a parallel to Title VII or something separate from it, but perhaps the Title VII philosophy on I.L. can actually be used to guide the whole nature of the Title I service delivery structure through the concept of a comprehensive continuum of services.

.The issue of how to structure the service delivery system was analyzed in two ways: 1) Some participants feared the separation of Title I and Title VII because of a potential loss in the ability to coordinate services. Here it was noted that parts of Title VII services are an effective and necessary adjunct to some Title I services and, in fact, a person who might not be successfully rehabilitated with the current profile of services might well achieve a successful Title I closure through long-term I.L. services. 2) On the other hand, many participants felt there was really no need to inconvenience clients with the bureaucratic reality of having to be placed into either a category I or VII status, but rather that the intake process should simply be a large "funnel" after which a detailed individual assessment can take place focusing on two aspects, a) the vocational aspects of the person's functioning, and b) everything else involved in his or her life.

.The issue of a need to limit services in the Title VII program was analyzed from the perspective that without clearly

defining what the program is able to do it may become a catch-all or "dumping post" and thus be drained of its resources without actually becoming responsive to the needs of society. This issue was particularly difficult to analyze due to the fact that the whole present emphasis on providing services is on "expansion," not limitations. However, it was agreed that it is important that programs determine ways to be responsive to whole groups, not just benefit individuals.

.The need for definitions for some aspects of the Title VII program was an issue which was analyzed from a "survival" point of view. Title I is fairly well defined and identifies which services money can be directed towards, but as Title VII funds become available every other department in the state will begin taking action to determine where such funds can be used. The less clearly definitions have been framed, the greater the chance that rehabilitation services may lose some very scarce resources.

.In analyzing the issue of terminology, it was brought out that a dichotomy exists when one used the word "rehabilitation." The word rehabilitation does not simply mean "fixing up" a client, it may mean improving the environment (i.e., barrier removal, new technological devices for transportation, etc.). The latter is implied when the phrase "independent living rehabilitation" is used.

Parts A & B

.A need exists for further analysis of the issue of targeting services under Part A and Part B. For example, should such services be set up statewide? Should a series of demonstrations be set up? Should the system try to serve all the needs of a few people or a few needs for all people?

.In analyzing the issue of needs assessments, there appear to be conflicting points of view: some feel it is a very necessary step; others disagree and feel it is needless...After all, ask any disabled person what his or her needs are and he or she can usually respond.

.Three interpretations were presented in an analysis of the nature of the Part A program: 1) Part A as becoming the I.L. version of the Title I program, 2) Part A taking on some of the characteristics of Part B in purchasing services and other forms of contracting, and 3) Part A as a completely new model for service.

.In analyzing the issue of new models of service under Part A, the term "VR frame of reference" surfaced. Here it was noted that a purely VR frame of mind can often cause persons engaged in policy analysis to ask the wrong types of questions and to think of I.L. issues in the context of a purely VR model. When this occurs people are often torn between developing truly new options versus trying to reduce the dissonance by redefining an issue which confronts an organization in a way which is more familiar to the establishment.

.Discussion focused on the issue of whether first year dollars, especially under Part A, should go towards enhancing the capacity of state agencies for future years' delivery of I.L. services or be targeted more for direct services through existing rather than new mechanisms. Concern was expressed that in many instances one could not even begin to talk in terms of "enhancement" simply because there is presently no capacity whatsoever and therefore, developing capacity should be the first requirement.

.A need exists for further analysis on an entire potpourri of issues related to Parts A & B (i.e., identifying needs, setting priorities, forming task forces, interagency committees, cooperation, establishing terms, administrative decision making...)

Independent Living Centers

.In addressing issues related to independent living centers, persons tended to focus heavily on the subject of consumer involvement in matters such as consumer input and training.

.When persons from traditional rehabilitation agencies are asked to discuss issues relating to ILCs there is often a reluctance to focus on any single issue because 1) they are unaccustomed to addressing this subject matter, and

2) there are so many issues that it is often difficult to select one single problem to analyze.

.The issue of who should provide training to ILC personnel was analyzed taking into consideration the mistrust that lies in the traditional rehabilitation agency as the provider of service training and the influences that this could bring to bear.

.In analyzing the issue of provision of technical assistance, it was decided that VR agencies have the resources to provide technical assistance in the areas of grant writing and facilitation of cooperative agreements, and that other community resources should be brought in to provide other areas of technical assistance such as educational classes, etc. It was noted that existing rehabilitation facilities could be tapped for their expertise in administration.

.After analysis, it was strongly felt that cooperative agreements should be initiated at the local level and that such agreements could not be effectively implemented at the state level.

.In analyzing the issue of program effectiveness, client satisfaction was weighted as the primary consideration. But it was also noted that often client satisfaction is contingent upon certain environmental factors which enable the delivery of services.

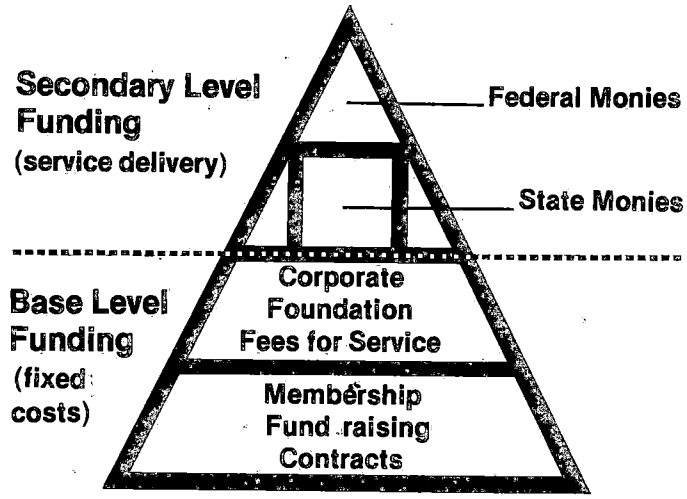
.Members of various issue analysis groups concurred on the importance of the issue of advocacy, stating that it is primary to what an ILC philosophy is about and to the effectiveness of the whole center.

.In discussing the issue of obtaining a stabilized funding base, public relations within an agency and its outreach efforts toward clients were considered critical evolutionary links.

The "pyramid" was used as an example of one possible funding model.

NOTE: In using this model it is important to realize that there is a direct correlation between the scale of pyramid funding components and the actual time required to establish these resources.

Figure 10: Pyramid Funding Model



.In further analysis of the funding issue, it was suggested centers use program service areas as the basis for requesting supplemental funding or support in advocacy efforts. Example: If a lack of accessible housing restricts ILC efforts in referral, the center can capitalize upon this situation through an application for supplemental funds for advocacy in this area.

.It was agreed that ILC proposals should be designed to meet state/community needs while responding to the specific criteria of the RFP.

Agency Scope of Services

.In discussing this overall issue it became apparent that the scope of agency services is really quite clear. The real questions are: Who has the authority, and consequently how can agencies maximize services and interagency cooperation to effectively pool resources? These questions point to the need for a process which addresses basic issues first.

.In trying to confront I.L. issues within an agency, the endorsement or "blessing" of the concept by the whole top management team is a critical prerequisite to successful planning.

.It must be remembered that persons in top management are representatives of their function or agency background and therefore live within two organizations: their functional organization that

delivers the service, and as part of a top management team of experts. When such individuals work cooperatively they are expected to step out of their organizational role and become a team to bring about innovation or develop policy. Such a team is not required to deliver any services, rather, it is required to handle innovation.

.In order to accomplish change, agencies must structure a path for obtaining input and making decisions about I.L. concepts. Ideally, this would involve interaction between internal change agents, outsiders, people from within the organization, special task forces, committees, top management expertise, consultants, etc., in order to formulate and analyze all the issues. The following "VR Tracks for Change" were recommended by group consultants.

Figure 11: VR Tracks for Change

Obtain "blessing" of top management by using existing consumer committees, dollars, authority and a credible change agent

▼

Strengthen the above

▼

Demand formal reports with deliverable dates

▼

Initiate preplanning

- **Invite other agencies to participate**
- **Establish task forces within various committees**
- **Present drafts**
- **Develop an "agency built" plan**

▼

Initiate planning

- **Review task force reports**
- **Obtain input from overall advisory council**

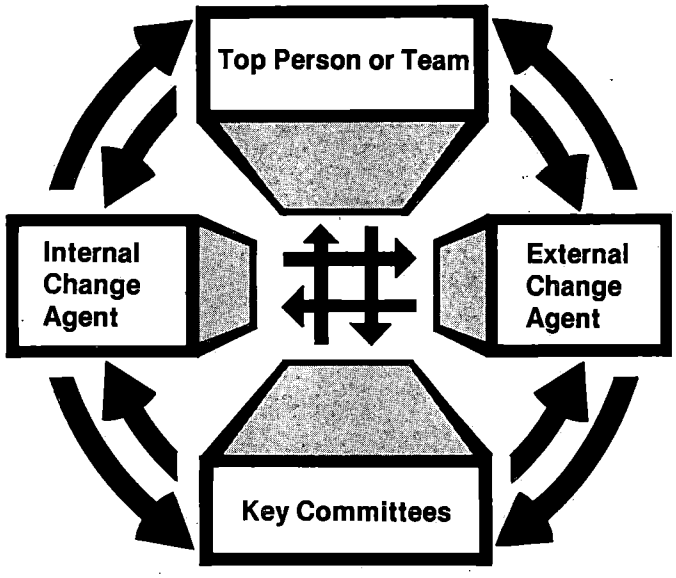
▼

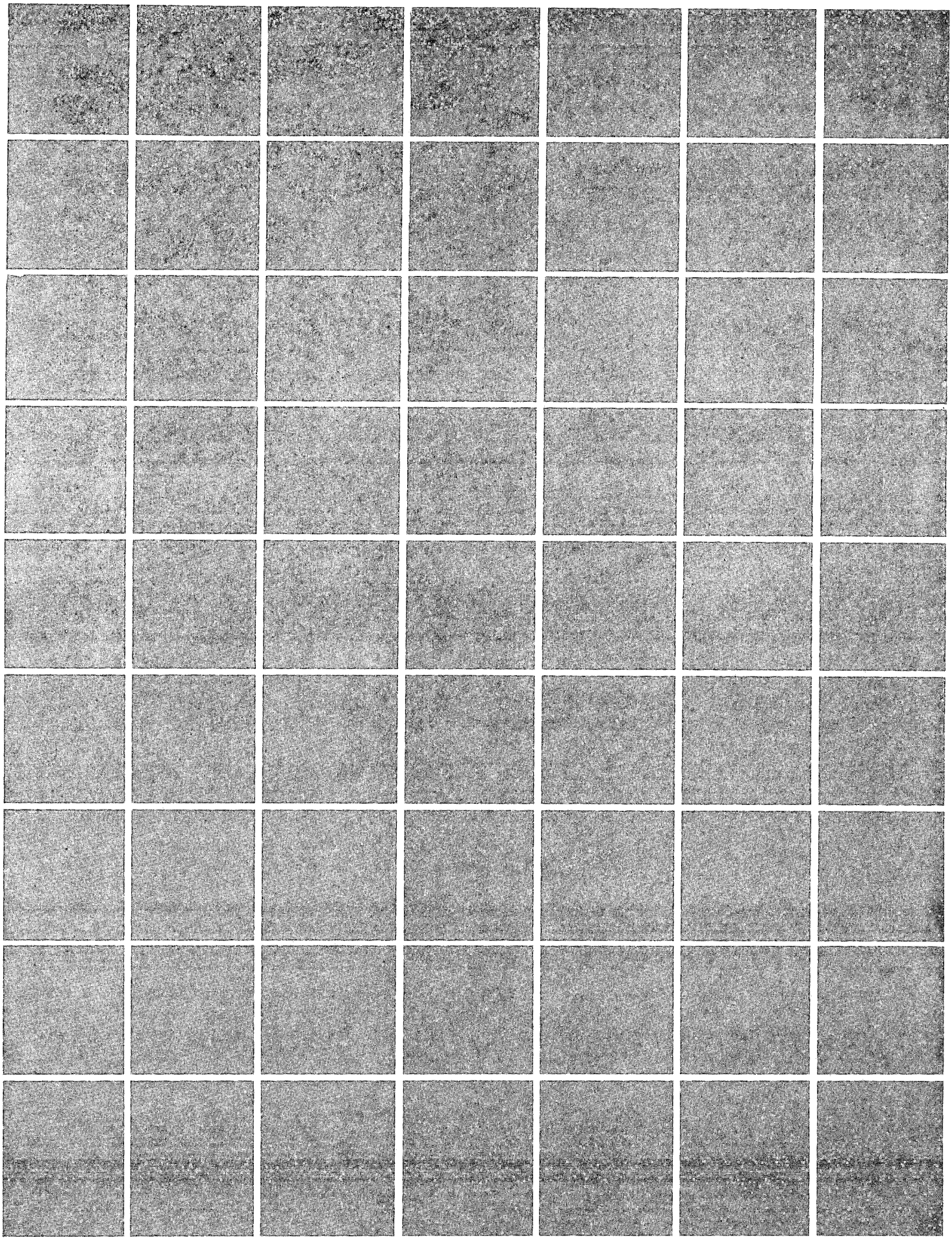
Implement

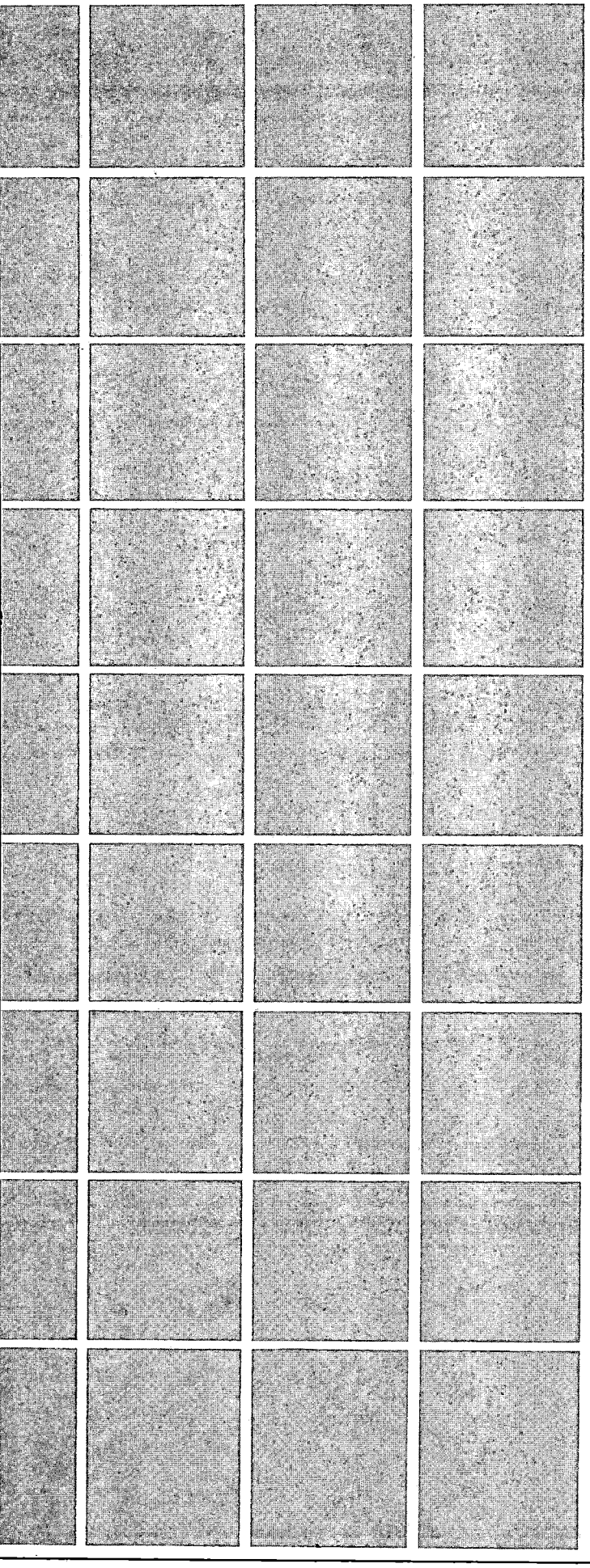
- **Ask consumer representatives to oversee**

.In discussing matters related to implementation, it was noted by consultants that independent living specialists and others attending to policy planning and development must be sensitive to the processes by which they can effectively plan reentry into their system in order to maximize the experiences they've gained from a workshop experience such as this. To do this, he or she must carefully plan reports, document intentions, develop formal and written recommendations and then determine which committees should receive information. This process is termed the "art of reentry." By mastering this art one can determine where he or she fits into the following model.

Figure 12: Maximum Leverage Model







2c.

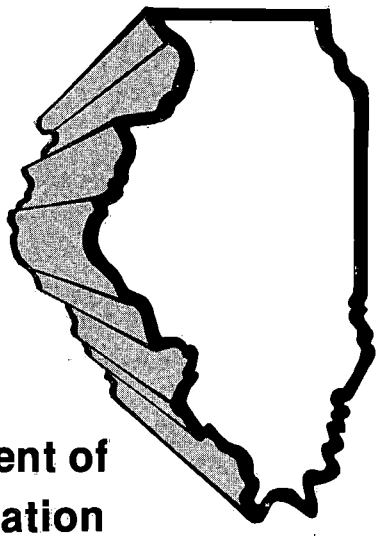
Decision Analysis, Planning & Implementation

The 2½ day workshop culminated in the assembly of state implementation sessions during which members met with others from their respective agencies to begin to apply new team skills in the area of policy planning and development in I.L. rehabilitation. Workshop consultants were made available to each team to serve as technical assistants.

Following these one-hour sessions, accomplishments related to state plans were shared with the entire group by representatives from each agency. Subsequent information obtained from agencies through a follow-up evaluation conducted by UCIR in early September 1980 has been incorporated into these state reports. Hopefully, these reports will not only demonstrate the policy planning and development process in action, but will also serve as a resource to state/regional decision makers by providing up-to-date feedback on issues of major concern in relation to the current planning and implementation activities within various agencies.

Decision Analysis, Planning and Implementation

Independent Living in Region V: State Implementation Reports



Illinois Department of Rehabilitation Services

The state of Illinois, as described in their earlier presentation, "Experiences of the Illinois Department of Rehabilitation Services" (see Section 3), has been involved in a variety of programs and services to provide independent living services to severely disabled persons. However, representatives of the Illinois Department were unable to attend the implementation workshop report session due to conflicting flight schedules. Consequently, the information reported below was obtained totally through subsequent telephone interviews.

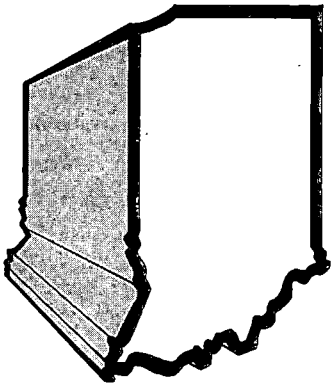
Post-workshop follow up:

More recently two other proposals have been submitted for Part B centers; one in Rockford and another in Peoria. Although located in metropolitan areas, these centers, especially the one in Peoria, may also serve rural communities.

During earlier presentations, the Illinois group expressed concern regarding two specific issues: the provision of attendant care services and the development of shared responsibilities with other agencies such as the Developmental Disabilities Office within the Department of Mental Health. With respect to the first concern, information obtained after the training revealed that the Division of Comprehensive Rehabilitation Services is assisting the Department of Aging with their attendant care services, and the Association of Rehabilitation Facilities with programs to train mildly mentally retarded individuals to become employed as attendants. The agency has also applied for a Section 305 Comprehensive Rehabilitation Center grant which involves a cooperative arrangement with five facilities to develop and coordinate services that are not being provided.

With respect to the second concern, an interagency consumer effort which includes the Governor's Planning Council on Developmental Disabilities has been initiated to organize housing alternatives in Illinois. The Division of Comprehensive Rehabilitation Services is also considering becoming involved in some joint federal funding arrangements with the Developmental Disabilities Office to expand their services available currently under the Supportive Living Arrangements Program. The program would be increased to include physically disabled persons.

Other concerns, described during phone interviews, relate to the need for specific policy planning on interagency cooperation issues, such as determining the role of different agencies, defining the role of consumer groups and defining the parameters of programs and of various target populations to be served. A technical assistance seminar involving facility directors, state agency personnel and consumer groups is being designed to address the issue of interagency cooperation in developing an independent living plan for Illinois.



Indiana Rehabilitation Services

Workshop summary:

A large portion of the Indiana workshop session consisted of discussion on specific problems the agency has encountered in its planning thus far. Three major issues arose which this group feels merit their further analysis and, hopefully, their resolution before missions, goals or action strategies can be formalized.

1. Given the fact that there is not a "state-wideness" requirement in Part A, what is the effect of that on the principle of order of selection or the absence of an order of selection? To what extent do conflicts arise in serving potential rehabilitation clients as opposed to serving those who are not capable of achieving the traditional vocational goal?
2. Do the statute and regulations permit a highly selective geographical restriction of I.L. programs? Is it feasible to situate the principal program in just one city?
3. Is it possible to restrict certain types of I.L. programs to serve only certain disabilities and specify certain other programs in other cities which will be aimed at other problems?

A fundamental problem which emerged from this session, and one that may need to be remedied by means of legislation, is that there appear to be two basic priorities in the Act which are not yet clearly worked out as being consistent in terms of what each means for I.L. One is the initial purpose of the legislation, which is to serve severely disabled people, and the second larger thrust is for providing participation by consumers in the I.L. movement.

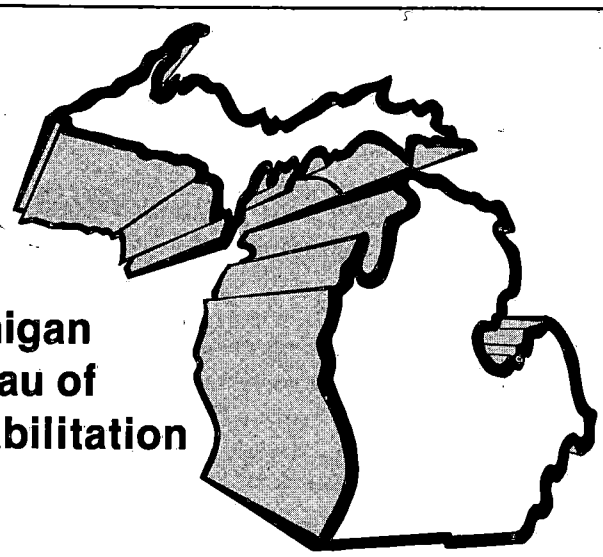
The Indiana group determined that it would consider the use of outside consultants in dealing with technical problems that develop in the implementation of I.L. plans in cases where the agency has no experienced staff to advise in such matters.

Post-workshop follow up:

It is noted above that during their state implementation workshop, Indiana representatives discussed specific problems that their agency has encountered in planning for independent living. From phone interviews it was reported that these problems, which seem to be both administrative and financial in nature, are still a reality for that state.

Indiana has submitted a proposal for the establishment of an independent living center under Part B. Although the proposal had been partially approved, the state felt that it could not assume responsibilities for the continuation of the proposed center activities after three years, since there was no Part A funding guaranteed or at least appropriated at the federal level. A $200,000 grant awarded was, then, returned to the federal government.

As explained by one of the state's workshop representatives, Indiana has no formalized independent living programs at the moment, however, federal regulations do not mandate state participation in Title VII activities. It was also indicated that if independent living services were funded under Title I instead of Title VII, thus providing a continuum of services from traditional VR to independent living, the state might then take a different attitude as far as supporting these programs.



Michigan Bureau of Rehabilitation

Workshop summary:

The Michigan Bureau primarily addressed two broad areas of concern, 1) recognition of a need to develop a pilot program in Part A, and the possible structure of a service delivery system to implement that pilot, and 2) I.L. versus I.L. rehabilitation and the Bureau's role in relation to each.

Michigan has approximately three years experience with ILCs and therefore expressed some degree of comfort concerning the location of centers and their roles within the Part B program. There are, however, some new assumptions which the bureau foresees a need to test and which validate its proposal for a Part A pilot program. These were identified as the relationship between Parts A and B, the interface between Title I and Title VII, and the relationship between the rehabilitation agency and its centers regarding I.L. provisions.

In conceptualizing a service delivery system for this pilot which attempts to sort out the relationship between Titles I and VII, the bureau perceives a "no fail system" in which the only failures would be due to client dropouts. This conceptual model focuses on client entry through an assessment pool which allows the client to provide direct input into determining the stream which he or she will enter. Such a comprehensive assessment process assumes that everyone can fit into the system in one way or another, either through the severance track or Title I. The model identifies client needs and provides a service delivery track without limiting the services available to an individual. Flexibility is provided between services in that individuals who meet the test of the traditional VR program would fall into the Title I track but still receive some services under the Title VII group. Other individuals would flow into the Title VII track. Heavy movement could occur between the two tracks, based on subsequent assessments coupled with candidates' needs and objectives.

In addressing the issues of the extent of services which the state agency will provide in Title VII, the Michigan team identified two options, 1) those services that may bring an individual to a point of readiness to benefit from another maintenance program in the service delivery system, or 2) certain services that have a maintenance function and will help the individual with fees and I.L. outcome.

It was noted that the Part B program plays a key role in terms of both the I.L. rehabilitation concept and the I.L. program concept. Part B is looked upon as the facilitator of Title VII rehabilitation objectives in terms of the tracks and support services needed to effectively service a client. Advocacy and civil rights activities were identified as two functions a center could clearly provide that would support the I.L. philosophy and also enable an individual to integrate. The bureau expressed a sensitivity to the fact that true commitment to the I.L. philosophy must be implemented on a statewide basis with "many actors," the state agency being only one. While the agency representatives feel it is important to affirm a commitment to that philosophy, they also feel a greater need to develop a more comprehensive approach to I.L. as a philosophy throughout the entire state of Michigan by enhancing statewide planning efforts.

A concluding observation concerning the bureau's plans is that, based on the assumption that the federal government is not likely to authorize states to use Title I funds to support Title VII programs in the near future, this proposal for a pilot project can be viewed as a very creative interpretation of federal policy.

Post-workshop follow up:

In subsequent phone conversations with Michigan bureau representatives it was reported that:

(1) Regarding the proposal for a Part A pilot program, because of budget cutbacks, the bureau has decided not to commit any funds to its implementation.

(2) The philosophical differences in conceptualizing both I.L. and I.L.R. have implications both in policy and administrative decision. For example, in negotiation between the Michigan Bureau and another state agency to provide supportive services for a housing program, the Michigan Bureau decided not to fund these services since they are not in line with the I.L.R. philosophy of developing specific skills to allow disabled people to improve their situation.

Michigan Commission for the Blind

Workshop summary:

Historically, blind programs across the country are somewhat advantaged in terms of planning and implementation in the whole I.L. arena because these programs have traditionally had components in which I.L. concepts have been and are being utilized. For example, most agencies serving the blind not only have a rehabilitation framework consistent with Title I, but also have been involved in the extension of the Title I program through their outreach work with clients in their homes in terms of I.L. skills. However, representatives from this group recognized that this does not mean that a panacea exists for all problems because new I.L. issues and constraints have been and will be identified, thus creating a need for both short-term and long-term planning.

One of the major concerns which the Michigan Blind Commission feels it faces in policy analysis and development is the question of incorporating Title VII into its total programming. The issue which must be addressed here appears to be the role of Part B following initial demonstration phases. Will Part B become the umbrella for the future? The commission senses the need to be able to relate on a continuum its clients' needs, particularly the multiply handicapped, to potential resources and facilities, and their expected impact on the provision of services.

Other considerations include the continuation of long-term resources and the art of accessing similar benefits. For example, once programming is underway, what happens if those resources under Part A which are complemented by the rehabilitation program under Title I are no longer available to facilitate what has been initiated in working with the full range of I.L. services? Here, the need for built-in program contingencies, particularly in the first two or three years of funding, was recognized. The movement towards accessing similar benefits and knowing the resources that are available on behalf of clients is also a strong component to be considered in developing Title I programming and will be a continuing component of Title VII programs. Most general and blind rehabilitation agencies have written policies on similar benefits, but the commission participants feel these may need to be reviewed further in terms of how to access other agencies and resources to their fullest.

A changing role is perceived in terms of the rehabilitation counselor or teacher and what is referred to as an I.L. specialist. The relationship between types of services and potential staff restructuring is a major issue confronting the commission. Although an integration has historically taken place between the role of rehabilitation teachers serving the blind and I.L. concepts, the perceived role change here is that I.L. specialists will not only be able to serve individuals, but will be expected to be aggressive in outreach efforts to secure continuing services for clients and access other available resources. I.L. specialists are going to become the catalysts for identifying long-range problems and will also serve as initiators in the development of formalized agreements that do not currently exist with other agencies and services. This component must be underscored in Title VII programming in the future and will probably be addressed through in-service and

formal training for commission staff.

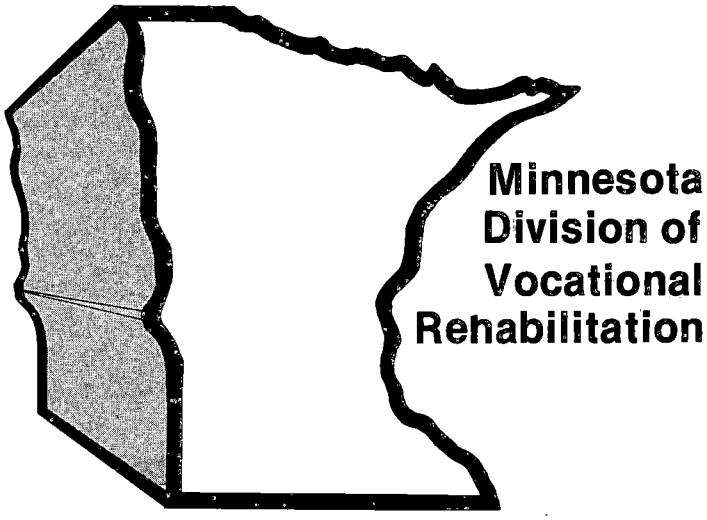
In terms of providing an equitable base of service within individual local communities, it is thought that Title VII must also address this issue in order to reach some accord with the consumers which the commission is serving and intends to serve.

In conclusion, it was noted that blind programs across the country see I.L. as an opportunity not only to build upon their history, but also to be creative in their outreach efforts.

NOTE: The Michigan Commission for the Blind has been awarded grants for the establishment of two I.L. centers: a rural model to be located in Gaylord and an urban center to be established in Lansing. These centers are exclusively for the blind who are not served through the traditional VR program and are both funded under Part B of the legislation. It is hoped that once Part A moneys are available, these centers can be expanded. A more detailed report on these efforts appears in Section 3 of these proceedings.

Post-workshop follow up:

No additional data was reported through later telephone interviews.



Workshop summary:

Minnesota's report addressed three areas of policy analysis and development which were approached in its implementation session: 1) the need for establishing conceptual consistency for the I.L. program within all levels of the state agency, 2) the importance of a mission statement, and 3) the further development of its plan and input mechanisms.

It was pointed out that Minnesota is somewhat ahead of other Region V states in that the division has $809,000 of state appropriated funds to invest in I.L. services in the coming year. Working with that figure and with "new perspectives provided through this workshop," the division conceives a Model A program which is illustrated by the following:

Figure 13: Minnesota Model "A" Program

Mechanics	Federal	State	Input	Possible Missions(s)
ILCs Part B	$200,000	$100,000	I.L. Task Force	Advocacy Coordination Information/Referral
Part A Program		309,000	"	Person-to-person (hands on delivery)
Grants		200,000	"	Capacity building
Total	$200,000	$609,000		
	Pre-conference Plan →		Post-conference Plan →	

An I.L. Advisory Committee was established in Spring 1980 in accord with guidelines specified in the federal regulations. The Committee's fifteen members have unanimously volunteered to serve on subcommittees which will provide advice on the three "mechanics" of the state's program. In this way, the committee, supplemented by input from other related programs, will become the division's basic input mechanism in its planning. Consequently, much of the implementation session was devoted to a discussion of types of representation, areas of interest, and programmatic and geographic concerns relative to the establishment of these subcommittees. It is estimated that twelve to twenty persons will serve on each subcommittee.

Post-workshop follow up:

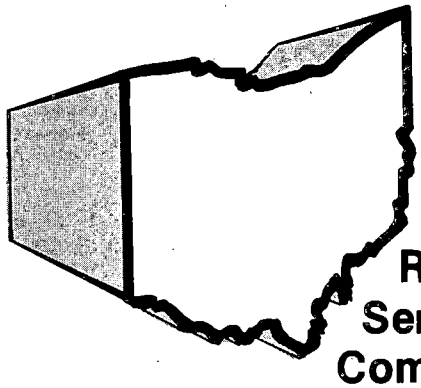
Subsequent telephone interviews revealed no additional data to report.

Minnesota Services for the Blind and Visually Handicapped

Minnesota Service for the Blind had one representative at the workshop, and therefore an implementation "group" report at the time of the conference was not given. A brief overview of the status of I.L. developments within the agency was related through a later telephone interview.

Post-workshop follow up:

Minnesota Service for the Blind and Visually Handicapped is currently writing its state plan. The plan, if approved, will serve persons who are blind and have at least one additional major disability. The plan also attempts to develop new procedures to coordinate its independent living program with special education units around the state.



Ohio Rehabilitation Services Commission

Workshop summary:

Team input during the Ohio session resulted in the identification of a need for establishing a more formalized "tracking mechanism" (i.e., "laying down tracks for VR change"). In this case those tracks were identified as a task force approach through the establishment of an I.L. Advisory Committee with consumer, administrative and field service representation. The committee will focus its efforts on building mission and goal statements, designing a delivery system, and seeking resources for the program.

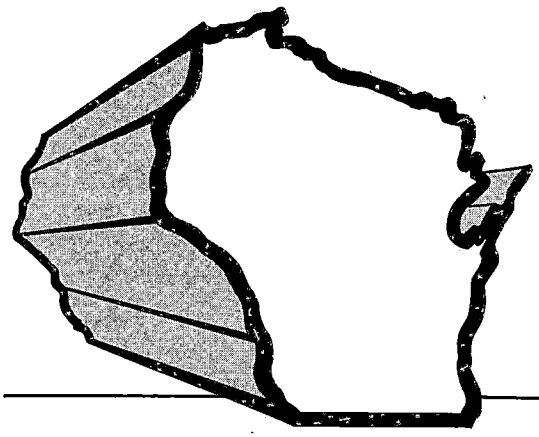
It was noted that commission activities prior to this workshop have been focused on developing plans for ILCs on a competitive basis by identifying eight to sixteen different areas in the state where centers are desired.

Post-workshop follow up:

Through the efforts of its I.L. Advisory Committee, the Ohio Rehabilitation Service Commission and the Office of Consumer Affairs have put together state and local workshops on attendant care and related legislation for representatives from consumer groups, administration and field services. Another workshop is being planned on a campus setting for student clients. This activity will be designed to benefit clients through a greater awareness of various educational opportunities.

In addition, Ohio representatives who participated in the I.L. policy planning and development training are presently involved in developing a long-range plan for the state's independent living activities. Some planning has been done in terms of special projects for indepen-

dent living, for example the group is developing a proposal to include, as part of their 1981/82 biannual state request for funds, additional activities that are outside the scope of the federal grant received to start an independent living center in Cleveland. A proposal has been submitted for a center in the Mansfield area. This center is to be a demonstration model for services in rural areas.



Wisconsin Division of Vocational Rehabilitation

Workshop summary:

As detailed in an earlier workshop report, "The Experiences of the Wisconsin DVR" (see Section 3), the division is funding four ILCs, two with state appropriations and two under Part B. The four centers have their own administrative structure and methodology to provide independent living services. Services have been subcontracted to private vendors. Emphasis is being given to the uniqueness and autonomy of each of these centers so that opportunity will occur to experiment with diversified models responding to different community needs.

Wisconsin's implementation workshop focused attention on the value of further analysis in several sequential areas: mission development, input mechanisms, evaluation strategies, and information transfer. Specifically, this group perceives a need for devoting substantial time in the evaluation of how its new centers are performing in order to determine to what extent each model is adequately beginning to address not only specific local concerns, but also the degree to which each is resolving problems related to the overall concept of I.L.

In terms of general efforts in the area of I.L., it was noted that there is a need to provide basic information on recent developments in I.L. to the entire division in order to establish the critical linkages between field services personnel and ILCs, and that a need also exists for better understanding of funds to be obtained under Parts A and B of Title VII as well as the implications for funds allocated under Title I. Members of the group supported the motion for greater involvement of top level management in the entire process of defining missions and goals in order to develop more effective solutions.

Post-workshop follow up:

Information obtained through telephone interviews indicates that the four centers are currently in operation and that proposals have been submitted for two additional centers; one to be funded by federal and the other by state dollars.

3.

Independent Living Experiences

One specific objective of this workshop was to create a training atmosphere within which various experiences in policy development and planning for IL services could be shared. The Steering Committee supported the idea that presenting a few program models from a variety of settings would be informative for participants. As a result, program planning personnel from UCIR surveyed various IL activities within the region through extended phone conversations and personal visits to ascertain which current efforts could be presented to reflect several varying approaches. Four presentations, including programs from both VR and blind agencies plus an overview of the Michigan State University Office of Programs for Handicappers, comprised this session.

Judy Taylor, Director
Office of Programs for Handicappers (OPH)
Michigan State University

Independent Living within a University Environment

Introduction

Michigan State University resembles a mid-size community in which the total population exceeds 40,000. MSU has its own physical plant and postal, fire and police departments. The university is dedicated to making its campus an independent living lifestyle community and in this effort has supported an Office of Programs for Handicappers since 1972. The director of this program, Judy Taylor, has responsibility for services as well as technical assistance and consultation to university administration and faculty in working with approximately 450 handicapper students. Many of her efforts have spilled over into community and statewide activism and have impacted upon the entire state's approach to I.L.

Persons in state rehabilitation agencies are concerned about these higher education students and often share a joint responsibility with the university for their programs. Ms. Taylor's presentation provided a demonstration of the I.L. environment which prevails at MSU so that, hopefully, this information can be brought to the attention of higher education officials in other states in Region V.

Summary

The Office of Programs for Handicappers coordinates the many activities necessary to insure that each individual at MSU is free to find and utilize his or her full potentials, regardless of physical characteristics.

After looking at a number of programs in the country, MSU's handicapper services program was founded on the premise that what students need in terms of their purpose for being at MSU is an emphasis on an education/civil rights/responsibilities model rather than a medical rehabilitation model. In other

words, handicappers come to MSU not to be rehabilitated but to be educated. In many cases, however, the handicappers are not just students, but also are clients from various social and rehabilitation agencies which, in the past, have been a financial aid resource for students. This mutual involvement between different agencies and the university has been a concern to OPH in matters relating to jurisdiction over the same population and has thereby strengthened their efforts to work closely with all entities thus insuring that handicappers are not caught in a conflict of interests or programs. The need is recognized for agencies and universities to decide what is important for each to do and not to do. In this way, universities serve as valuable tools in the rehabilitation process and, likewise, rehabilitation resources become useful tools in the education process.

Other concerns facing the office were noted, including enactment of 504 legislation, population definition and terminology as related to the provision of services/priorities of funding sources, and the availability of personal resources to serve special populations.

Since the program is primarily on campus to serve the university and its accommodation of handicappers, most OPH counseling and advising services are provided within various units at MSU to insure that units are meeting their responsibilities in accommodating the handicapper population. This university program, as other university programs accommodating handicappers in higher education, fits into the concept of I.L.

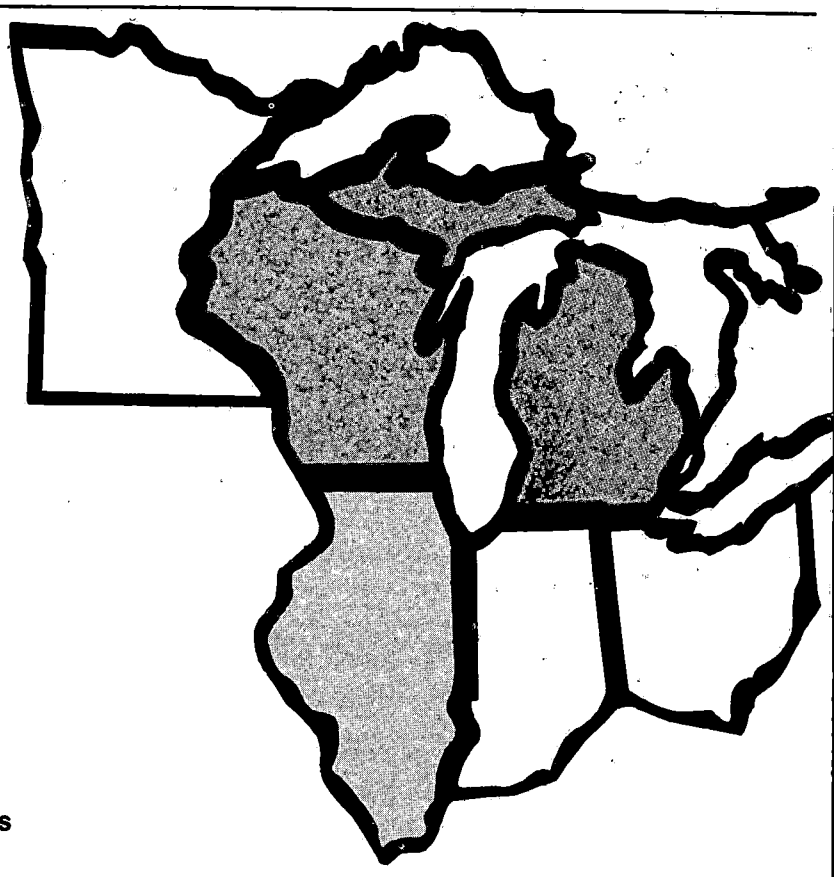
In addition to its long relationship with other units and agencies, the OPH also plays an active role in the lives of individuals who journey toward independent living. The philosophy behind the OPH is to develop services in response to actual demands or needs expressed by individuals. Since access to information is critical for students, OPH meets or helps to meet the information needs of handicappers through alternative equipment and services such as recorded materials, speech compressors for the visual handicapper who uses tapes, typewriters for braille and large print, reading machines, equipment for enlarging braille or print, talking calculators, TV magnifiers, telecaptioning adaptors, a recorded periodical library, interpreter services, and recruiting/training lecturers or note takers.

A personal assistance coordinator aids handicappers in locating qualified assistants in daily personal activities through the OPH program which recruits and trains such assistants. Through this program, the handicapper will be prepared to locate, train and supervise his or her own assistant after leaving the university. The office also operates a special all-weather curb-to-curb transportation service with priority given to handicappers with ambulatory characteristics. Recently, MSU purchased the first vehicle produced and sold which does not involve an elevation or lifting device for wheelchair users, thus making entry and exit much safer.

An OPH design program is helping to provide accessibility in all new and reconstructed facilities through a single design balance solution which provides independent, efficient, safe and equal use by as many people as possible. Most of MSU's facilities, including about 60 percent of all academic buildings, are at least partially accessible, and reconstruction of remaining buildings continues. Design balanced apartments and enhanced dormitory residences are also available.

In concluding her remarks, Ms. Taylor noted her concept of I.L. in which she sees a need for programs in independent living, dependent living, or both at various stages in I.L. "In many cases, traditional rehabilitation services tend to best meet the needs of the more dependent population because that's usually where people start...But then there is a whole dimension of needs beyond that starting point and that closure, and these needs must be addressed by a variety of resources."

Independent Living Experiences in Region V:



Illinois Department of Rehabilitation Services

Mike Steinhauer, Manager
Division of Comprehensive Rehabilitation Services
Illinois Department of Rehabilitation Services

Summary:

This report included a brief overview of the Illinois agency, a description of the approach the agency has taken in terms of funding comprehensive rehabilitation services, a discussion of the consumer movement in Illinois and a review of the department's Home Services Program.

Four major service components of the division were outlined: 1) the Bureau of Rehabilitation Services for the Blind which includes VR services, a rehabilitation teacher component, mobility instruction, a visually handicapped institute, the School for the Visually Impaired, and a school for visually impaired children; 2) the Bureau of Rehabilitation Services for Children incorporating the School for the Deaf, and the Children's Hospital School in Chicago; 3) the Division of Comprehensive and Rehabilitation Services which has responsibility for implementing Title VII, for the state-funded attendant care program known as the Home Services Program, and also for the Homebound Employment Initiative which links CETA funding with the Home Services Program; and 4) the Division of Consumer Affairs which has within it the Disabled Individuals' Assistance Line (DIAL), consumer advisory councils in five regions, a Counselor Client Assistance Project, and a section which holds responsibility for implementing Title V. The Access Living Part B Independent Living Center in Chicago is described in a separate presentation.

The department's approach to funding in relation to the change that is occurring in rehabilitation as a result of Title VII and the consumer movement was enhanced by a CETA funded study entitled "Determination of the Need for Comprehensive Rehabilitation Services Among Severely Disabled Persons in Illinois," which was led by Stanley E. Portny. Other CETA funding has recently been used in the Homebound Employment initiative. It was noted that innovation and expansion grant funding (I&E) has been utilized in accordance with Section 130 regulations which have been amended to allow I.L. initiatives under certain conditions. The state presently has one Part B grant and is making a second application in the near future. And finally, much discussion reportedly has centered around the advantages and disadvantages of using Title I dollars, particularly in status 06.

Several recent consumer initiatives in Illinois were recognized, including the statewide Housing Coalition and an effort to establish a consumer information or alert network. The importance of strong relationships between the Department of Rehabilitation Services and consumer groups was emphasized.

The history of the state funded attendant care program revealed that the department received the program through transfer from the Department of Public Aid, and with it received approximately 1,200 active cases. To meet the needs of these cases with limited dollars in the state's services program, experienced VR counselors were selected and assigned responsibility to become either full or part time services counselors, thus affording the opportunity for responsiveness to a large geographical area.

Timely issues which the division noted as concerns are 1) client vs. vendor payment for attendant care and other client services, 2) responsibility/liability as regards the provision of developing resources to provide attendant care, 3) responsibilities to other agencies such as mental health and DD, 4) determination of eligibility for VR or Home Services (Part A, Title VII), and 5) building, coding, reporting, evaluation and justification of the program to the legislature.

Jim deJong
Access Living for Metro Chicago
Chicago, Illinois

Summary:

Access Living is a Part B independent living center which was started in October 1979 with matching funds from the Rehabilitation Institute of Chicago. This organizational relationship was suggested as a future model for other centers because linking with an established organization has fostered respect for the center within the local community, has provided political advantages, and has rendered a source of technical expertise at a minimal cost. However, the institute does not dictate policy to the center. Further, the center is not housed at R.I.C. but operates from a community location.

Access Living is organizationally comprised entirely of disabled people on both the staff and a 13-member board of directors. The center considers the composition of its board a major positive factor, as it includes representatives of existing disabled groups in Chicago, including the blind and deaf communities.

Active programs within the center encompass housing, transportation, personal care assistance, educational courses, peer counseling, information referral, and advocacy. Major efforts in these areas include locating accessible housing and advocating for the creation of more suitable housing, the creation of a communication chain between a state legislative liaison and various consumer groups, and educational courses in housing and money exchange (rights responsibility). In the area of personal care assistance it was noted that the center utilizes the "business relationship" approach by training both the attendants and the clients who will be utilizing attendants. Future attendants are recruited from nine city colleges and participate in 1½ hour sessions during a five week course which sensitizes them to disabilities and the management role of the disabled person. The use of community colleges attendant recruiting was encouraged for large metropolitan areas because it serves to localize needs geographically for all parties.

Other suggestions for implementing new I.L. centers included 1) don't underestimate transportation needs, 2) realistically evaluate the administrative time which will be required, 3) establish good communication linkages with the state agency, 4) look for a director who can relate well to the disabled community in addition to being an effective administrator, and 5) have a proper perspective on the value of utilizing outside technical assistance which may not be familiar with local needs or problems.

In closing, it was stressed that policymakers who advocate the need for establishing standards for I.L. centers should keep in mind that such standards must be kept localized. Each community is different, has localized interests and must tap into community resources. A national standard policy for I.L. centers would not permit the flexibility needed for local successes.

Michigan Commission for the Blind

Phil Peterson, Director
Michigan Commission for the Blind

Summary:

Michigan is one of 27 states which has a separate state agency program for the blind. The Michigan Commission for the Blind has been involved with a variety of I.L. concepts over some period of time. In fact, rehabilitation teachers have been dealing with nonvocational components for approximately 30 years, and this experience now serves as a basis upon which the concept of an I.L. center can be applied through receipt of a grant award to establish a center.

The agency has also operated a rehabilitation center for the blind in Kalamazoo and has served over 1,600 clients in personal adjustment types of programming since 1970. This effort has provided in-service training for field staff in terms of the provision of rehabilitation services and its application to ILC concepts. In addition to blind, the agency also serves multiply handicapped blind individuals.

Most recently, the agency embarked on a two-year pilot project to provide nonvocational services for senior blind citizens by establishing a program in the Saginaw-Bay County area. This program, which really parallels Part C of Title VII, is funded with $150,000 state resources. The upcoming budget specifies $300,000 in general funds for its continuation, which demonstrates the tremendous success this project has received during a period of financial difficulty within the state.

The average age of the clients served in the nonvocational services project is 74.3 years. Approximately 75 percent of the caseloads are female, and 33 percent of the clients are 80 years or older. To date, the referral rate for this particular project is 400% greater than the agency had projected in its original plan to the legislature. This success demonstrates the importance of I.L. concepts, and the agency's experience in this type of Part C pilot program has provided some of the experience necessary to launch an independent living center.

John Crews, supervisor of the nonvocational senior's project, explained the rationale behind the commission's proposal for the establishment of its ILCs.

John E. Crews, Supervisor
Nonvocational Pilot Project for the Senior Blind
Michigan Commission for the Blind

Summary:

In making application for Title VII, Part B funding for centers for independent living, the Michigan Commission for the Blind is attempting to come to terms with some of the realities of its constituencies in a very large and varied state -- a state that is typical in many ways of midwestern states. In this respect, the commission is wrestling with two realities.

First, there are a large number of potential clients in Michigan who have not been or cannot be served through the traditional V.R. program or by other present programs. In studies by the National Center of Health Statistics, the American Foundation for the Blind estimates that the prevalence of severe visual impairment[1] for the general noninstitutionalized population in this country is 6.6 per thousand. Therefore, the foundation projects that there are 1,391,000 noninstitutionalized severely visually impaired people in the U.S. In Michigan that would amount to about 61,000 people. Although solid data is not available regarding the prevalence of blindness, it is estimated that perhaps two thirds of that population is legally blind.

It is known that 50 percent of the people who are severely visually impaired are over the age of 60. While only two children per thousand have severe visual impairment, one out of every five people above the age of 85 has a severe visual impairment. These facts have suggested two things to the Michigan commission: 1) that the commission's nonvocational pilot project for seniors would be successful, and 2) that implementing Part C is very important.

Furthermore, the foundation estimates that of the 1,391,000 noninstitutionalized people with severe visual impairment, 59 percent (826,000 people) have a multihandicapping condition. Estimates suggest that there are an additional 656,000 severely impaired persons who are institutionalized in nursing homes and therefore excluded from the traditional rehabilitation programs. All of these figures point to underserved constituencies, and it is hoped that the issues addressed by the ILC concept will allow the Michigan commission to provide services to its previously underserved and unserved populations.

The second reality is the urban and rural nature of Michigan. Some areas of Wayne County (Detroit) have a population density of well over 6,000 per square mile while in the northern Peninsula the population density is only .5 persons per square mile. Therefore, the commission is proposing two centers for I.L. Both will provide field services, but neither will be actual concrete facilities. One center will be located in Gaylord, a small town in north central Michigan, and the second will serve the metropolitan area of Lansing. Each center will have a staff of two independent living specialists, plus clerical support. The location of these centers will obviously dictate the range of services each provides. The role of the rural Gaylord program will involve more direct service, while the urban population center will become more involved in coordination and advocacy.

The proposal for the nonvocational ILCs closely parallels the VR client caseload in Michigan's underserved and nonserved areas. Outreach mechanisms have been developed to identify clients, and the importance of contact with other agencies serving a variety of populations is recognized as the most effective way to identify the population. The commission anticipates a great deal of cooperation between its programs and the Lansing ILC.

Copies of the commission's grant proposal were made available to workshop participants.

[1]This functional definition of visual impairment uses the inability to read newspaper print as its criterion.

Wisconsin Division of Vocational Rehabilitation

Duane Zimdars, Coordinator
Independent Living Project
Wisconsin Division of Vocational Rehabilitation

Summary:

This section of the Wisconsin report dealt mainly with the process the DVR went through in obtaining state appropriated dollars for I.L. activities.

The state's budget is operated on a biannual system. Therefore, the division began planning its 1979-81 budget request in February 1978, approximately nine months before the 1978 Amendments were signed into law. At this point the division had no real idea what form the I.L. portion of the legislation would take, but there was a strong feeling within the agency that their upcoming budget proposal should have a focus on independent living. In that context, the DVR identified three subprograms for the 1979-81 biennium: an employment related subprogram, an administrative subprogram, and an independent living subprogram. To identify the independent living subprogram, the agency recognized the fact that several of their programs funded through state funds were not strictly vocational, such as a blind social services program and a rehabilitation engineering program.

The proposal was completed by June 1978 and included approximately $600,000 requested for independent living. By December 1978 the request had been received by the Department of Health and Social Services and the Department of Administration. The signing of the new federal legislation (P.L. 95-602) in November 1978 added new life to the request and at this point the agency began considering the distinction between Part A versus Part B. Having the benefit of the law now in hand, the requested funds were targeted as matching funds for a Part A comprehensive program.

In January 1979 the governor's budget was presented to the state legislature, including the $600,000 which had now been targeted primarily as Part A matching funds. The budget was signed approxi-

mately three months later and became effective on July 1, 1979. The division's request for $600,000 was funded conditionally at $220,000. The two conditions were 1) that the funds would be targeted for pilot projects for I.L. as opposed to matching funds for Part A (as it had become apparent that matching federal funds for Part A were presently unrealistic), and 2) that the funds would not automatically go to the division but would be placed in unallocated reserve until a detailed plan had been presented and approved by the state's Joint Committee on Finance.

Presently, the division has developed the plan for utilizing the state's dollars. The plan will be presented to the committee on June 18, 1980. Procedures used in developing this plan are discussed in the following presentation by Bonnie J. McGowan.

Bonnie J. McGowan
Independent Living Specialist
Wisconsin Division of Vocational Rehabilitation

Summary:

In presenting a plan to the state's Joint Committee on Finance, the division developed an RFP which stipulated the need for pilot centers which would serve the physically disabled. This disability group was specifically targeted because studies had indicated that Wisconsin's physically disabled people lack certain services simply because there are no delivery mechanisms or service systems, and no dollars targeted specifically for this audience. This RFP was an effort to insure that such a mechanism, along with other new systems to serve other disability groups, would exist in the future.

The RFP was developed by a committee composed of consumers, service providers and state agency representatives. An announcement of the RFP was sent to over 600 individuals and agencies. The information was also released in newspapers throughout Wisconsin. As a result, approximately 100 copies of the RFP were requested and recipients were afforded 60-90 days to develop proposals.

A total of nine proposals were submitted. While the total response was small it was geographically dispersed within the state, which meant that plans were developed for both rural and urban models. Proposals were reviewed by a new committee with the identical composition as that which had originally developed the RFP. The review panel developed the benchmarks used to score the following criteria specified in the RFP:

1) Evidence that the organization, administration, and methodology to be used for implementing the project is appropriate and feasible for the achievement of the independent living objectives of the project.

2) Evidence that the project will make maximum use of other resources which are potentially available to meet the independent living needs of eligible individuals.

3) Evidence that there will be substantial involvement of severely physically disabled individuals in policy direction and management as well as the employment of severely physically disabled individuals by the center.

4) Evidence that the number and type of staff proposed is sufficient and adequate to carry out the intent of the project.

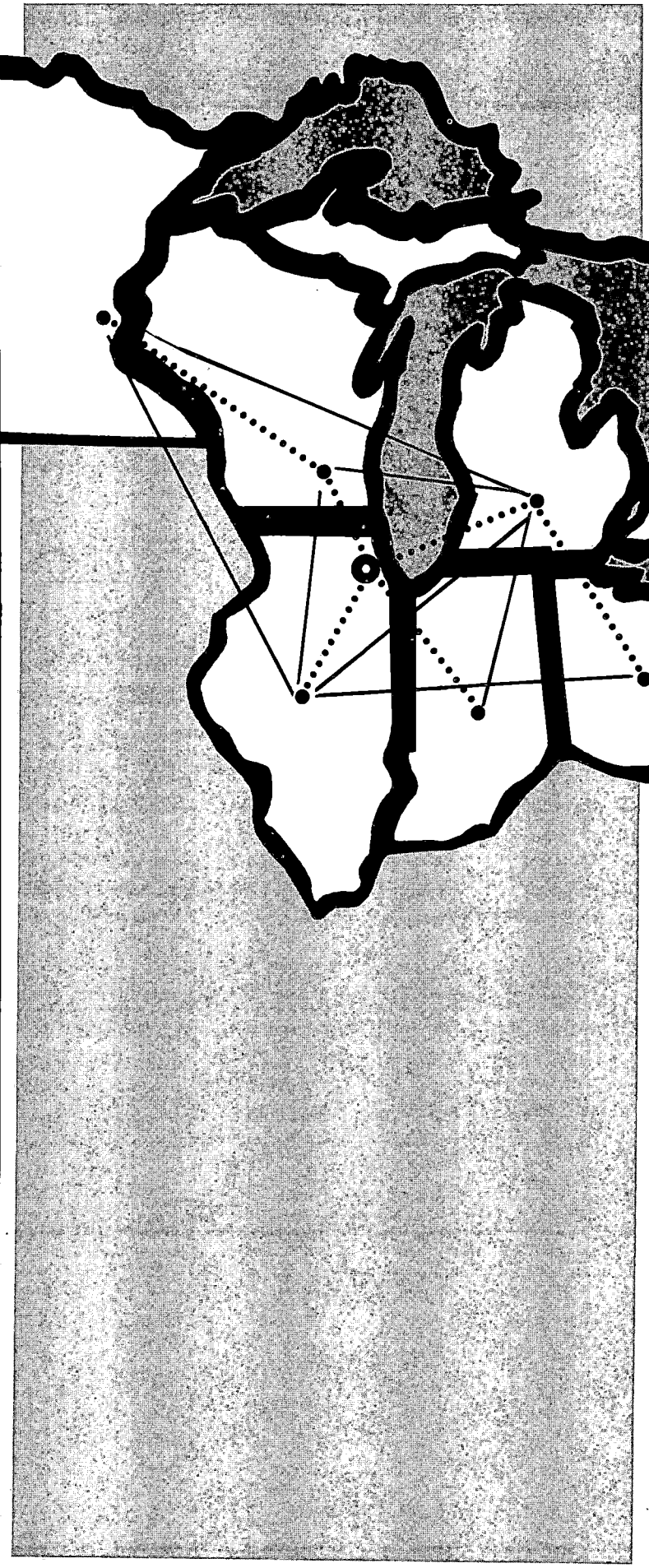
5) Evidence that the evaluation plan to be used will effectively assess the activities of the proposed project.

6) Evidence that the center will have an organized procedure for providing independent living services, including the use of individualized service plans.

7) Evidence that consideration has been given to the future funding of independent living services at such time that project funding is no longer available.

The review panel selected four proposals which the division plans to utilize as the basis of I.L. funding. Each pilot center will have a somewhat different perspective on the problem, which is expected to aid in expanding the service delivery system for I.L. and ultimately result in improved services in the future.

Copies of both the RFP and the benchmarks developed by the review panel were made available to conference participants.



4.

Independent Living Policy Planning Resources

As a result of this workshop, Region V has access to a variety of new resources pertinent to policy planning and development in independent living. Perhaps the most significant outcome of this training experience was the formal identification of representatives who will serve key roles in policy planning and development, and/or independent living services within each agency. Participants' complete names, addresses and telephone numbers are provided in an effort to stimulate interagency communication and collaboration in this area.

Also noteworthy is a bibliography of relevant print materials, many of which were made available to participants during the workshop. Additionally, agencies are encouraged to use UCIR's personnel resources or information service as an ongoing source of technical assistance in I.L. policy planning and development activities.

Region V Independent Living/ Policy Planning Consultant Network: Workshop Participants

Illinois

Jim deJong
Access Living for Metro Chicago
505 North LaSalle
Chicago, IL 60610
(312) 649-7404

Michael Steinhauer, Manager
Div. of Comp. Rehab. Serv.
Dept. of Rehab. Services
622 E. Washington
Springfield, IL 62706
(217) 782-2722

Indiana

Georgianna Garloch
Ind. Consumer Rep.
6015 Alton Ave.
Indianapolis, IN 46208
(317) 293-3245

Kay Heckman, Coordinator
Rehab. Center for the Blind
Indiana Rehab. Services
17 West Market Street
P.O. Box 7070
Indianapolis, IN 46207
(317) 232-1513

Kathy McKimmie
Indiana Rehab. Services
17 West Market Street
P.O. Box 7070
Indianapolis, IN 46207
(317) 232-6504

Dottie Rice
Operations Specialist
Indiana Rehab. Services
17 West Market Street
P.O. Box 7070
Indianapolis, IN 46207
(317) 232-1669

Michigan

Basil Antenucci, Director
of Interagency Services
Bureau of Rehabilitation
P.O. Box 30010
Lansing, MI 48909
(517) 373-3390

Lois L. Bradford
Facility Consultant
Bureau of Rehabilitation
P.O. Box 30010
Lansing, MI 48909
(517) 373-3970

Judith Bufkin
Bureau of Rehabilitation
P.O. Box 30010
Lansing, MI 48909
(517) 373-8595

John E. Crews, Supervisor
Nonvoc. Project
Mich. Comm. for the Blind
310 Johnson
Saginaw, MI 48607
(517) 753-4469

Pat DuFort
Exec. Director
Ann Arbor Ctr. for IL
2385 E. Stadium Blvd.
Ann Arbor, MI 48104
(313) 665-7531

Curt Eaton
Asst. Area Administration
Bureau of Rehabilitation
P.O. Box 30010
Lansing, MI 48909
(517) 373-8595

Paul Glatz, Director
Mich. Rehab. Ctr. for the Blind
1541 Oakland Drive
Kalamazoo, MI 49008
(616) 385-1550

Myrtle L. Gregg, Director
Commission on Handicapped Concerns
309 N. Washington
Lansing, MI 48909
(517) 373-8397

Peter Griswold, Director
Bureau of Rehabilitation
P.O. Box 30010
Lansing, MI 48909
(517) 373-3390

Ray Hinz
Mich. Bureau of Rehab.
P.O. Box 30010
Lansing, MI 48909
(517) 373-3970

John King, Director
Detroit Ctr. for Indep. Living
4E Alexandrine, Suite 104
Detroit, MI 48201
(313) 494-9726

Robert F. Losin
Eastern Area Admin.
Mich. Bureau of Rehab.
P.O. Box 30010
Lansing, MI 48909
(517) 373-3974

Bob McAllister
State Technical Institute and Rehab. Center
Alber Drive
Plainwell, MI
(616) 664-4461

Jim Obranovic
Facilities Dev. Specialist
Mich. Comm. for the Blind
300 N. Washington
Lansing, MI 48909
(517) 373-2062

Phil Peterson, Director
Mich. Comm. for the Blind
300 N. Washington
Lansing, MI 48909
(517) 373-3062

Harry R. Smith
Bureau of Rehabilitation
P.O. Box 30010
Lansing, MI 48909
(517) 373-3390

Mitchell Tomlinson
Director of Services
Peckham Rehab. Center
930 D West Holmes
Lansing, MI 48910
(517) 394-4100

Minnesota

James O'Keefe, Asst. Adm.
Minn. Serv. for the Blind & Visually Handicapped
Dept. of Public Welfare
1745 University Ave.
St. Paul, MN 55104
(612) 296-6084

Dale A. Palton
IL Advisory Committee
Minn. Div. of Voc. Rehab.
717 Third Ave., S.E.
Rochester, MN 55901
(507) 285-7301

David Sherwood
Indep. Living Program Manager
Minn. Div. of Voc. Rehab.
444 Lafayette Rd.
St. Paul, MN 55101
(612) 296-9258

Marv Spears
Director of Rehab. Resources
Minn. Div. of Voc. Rehab.
Space Center
444 Lafayette Road
St. Paul, MN 55101
(612) 296-5628

Ohio

Andy Amid, Acting Chief
Div. of Comm. Resources
Rehab. Services Commission
4656 Heaton Road
Columbus, OH 43229
(614) 438-1270

John A. Caprio, Acting Chief
Div. of Consumer Affairs
Ohio Rehab. Serv. Commission
4656 Heaton Road
Columbus, OH 43229
(614) 438-1205

Terry Etling
Rehab. Services Commission
4656 Heaton Road
Columbus, OH 43229
(614) 438-1220

Ed Minteer
Rehab. Services Commission
4656 Heaton Road
Columbus, OH 43229
(614) 438-1296

Robert L. Rabe
Acting Asst. Admin.
Rehab. Services Commission
4656 Heaton Road
Columbus, OH 43229
(614) 438-1300

Wisconsin

Harry Emerson
Policy Management Specialist
Wisc. Div. Voc. Rehab.
131 W. Wilson St.
7th Floor
Madison, WI 53702
(608) 266-8638

Ann Falconer
326 Swanton Road
#1
Madison, WI 53714
(608) 241-2571

Mike Falconer, Ex. Director
Governor's Committee for
People with Disabilities
One S. Park, #541
Madison, WI 53715
(608) 266-5378

Patricia G. Kallsen, Admin.
Wisc. Dir. Voc. Rehab.
131 7th Floor
W. Wilson
Madison, WI 53703
(608) 266-5466

Bonnie J. McGowan
Indep. Living Specialist
Wisc. Div. of Voc. Rehab.
131 West Wilson St.
7th Floor
Madison, WI 53702
(608) 266-5354

Patrick Mommaerts
Admin. Serv., Dir.
Wisc. Div. of Voc. Rehab.
131 W. Wilson
7th Floor
Madison, WI 53702
(608) 266-2957

Duane Zimdars, I.L. Pro. Coord.
Wisc. Div. of Voc. Rehab.
131 W. Wilson
7th Floor
Madison, WI 53702
(608) 266-1134

Special Guests

Valerie Ellien
UCIR
D-201 West Fee Hall
Michigan State University
East Lansing, MI 48824
(517) 355-1824

Bill Frey
Director of Research
UCIR
D-201 West Fee Hall
Michigan State University
East Lansing, MI 48824
(517) 355-1824

Andrew Vincent
UCIR
D-201 West Fee Hall
Michigan State University
East Lansing, MI 48824
(517) 355-1824

Ted Witham
Senior Program Specialist
Rehabilitation Services
Administration
300 South Wacker
Chicago, IL 60606
(312) 353-7345

Workshop Consultants/Trainers

Miriam M. Stubbs -- Director of Policy Development and Legislative Relations for RSA.

Jean Cole, Ph.D. -- Director of Training for The Institute for Rehabilitation Research, Houston, Texas. Co-sponsor of the Independent Living Utilization Project. Dr. Cole received her doctorate in anthropology from Rice.

Gerben DeJong, MPA, MSW -- Mr. DeJong is currently the Director of Research at the Research and Training Center, Medical Rehabilitation Institute, Tufts-New England Medical Center, where he supervises research projects including researching the areas of disability policy. As a research associate at the R&T Center, he served as the principal researcher in the areas of independent living, disability policy, and disability measurement. In addition, he has done considerable writing and speaking in the area of independent living.

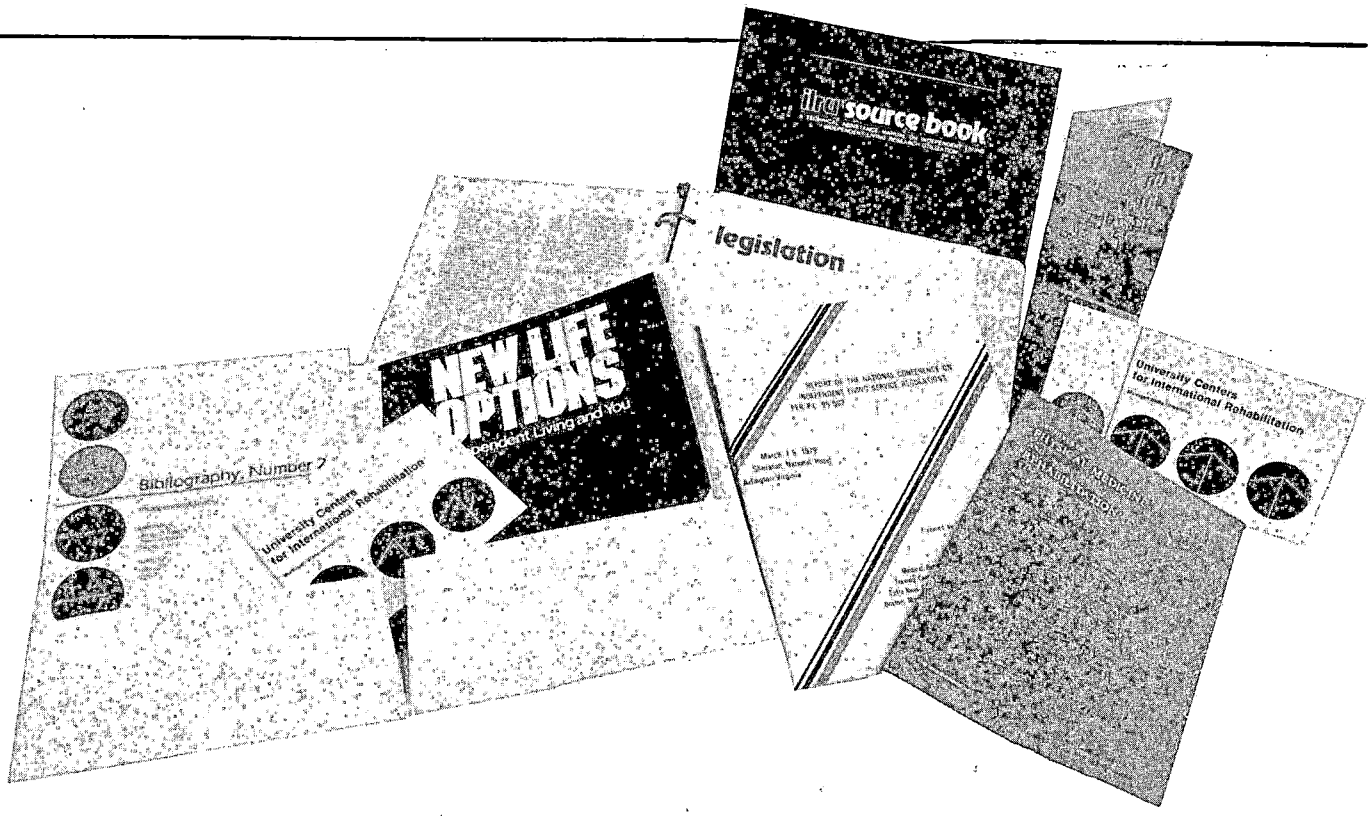
Kent Hull, LLB--Kent Hull is presently Assistant Professor and Director of the Developmental Disabilities Project at Michigan State University. He previously served as Director of Legal Services for the National Center for Law and the Handicapped in South Bend, Indiana where he worked in a wide range of issues concerning the legal rights of handicapped individuals. He is the author of a recently published book entitled The Rights of Physically Handicapped People.

Kathleen Miller -- Ms. Miller is the Administrative Assistant for the University Center for International Rehabilitation. Previously, she served as the Deputy Director of the Center for Handicapper Affairs in Lansing, Michigan. Ms. Miller serves on the boards of the American Coalition of Citizens with Disabilities, and the United States Council for the International Year of Disabled Persons. She has been involved in the development of handicapper coalitions, and recently, was awarded the Diana Award for outstanding work in human rights.

Michael L. Moore, Ph.D. -- Dr. Moore is Professor of Organizational Behavior, Personnel Management, and Industrial Relations at the School of Labor and Industrial Relations at Michigan State University. His fields of special interest are organization behavior, decision-making as it affects personnel administration, and the installation, operation, and evaluation of management-by-objective systems. He is an active consultant to organizations in business. government, and academic fields. In the consultant capacity, Dr. Moore has worked extensively with the Michigan Bureau of Rehabilitation.

Stanley E. Portny -- Mr. Portny is founder and president of Stanley E. Portny and Associates, Inc., a management consulting firm providing professional assistance in program planning, management and evaluation to federal, state, and private programs serving the handicapped. Previously, Mr. Portny was Vice President for Human Resources Programs at JWK International Corporation where he worked in a wide range of health and human service areas including the development and implementation, and quality assurance systems in state VR agencies. Most recently, Mr. Portny has been involved with conducting needs assessments in independent living for the states of Illinois and Virginia.

Len Sawisch, Ph.D. -- Dr. Sawisch is the coordinator of Consumer Development with the Michigan Bureau of Rehabilitation. Part of his responsibilities in this position are the management of grants for the three independent living centers in Michigan. Dr. Sawisch first became involved with handicapper issues when he was a member of STIGMA at Michigan State University. As a member of this organization, he worked for the equal integration of handicappers into the university. Dr. Sawisch was instrumental in starting the Center of Handicapper Affairs in Lansing, Michigan, where he served as the first director.



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5. APPENDICES

Appendices

- Index to figures
- Glossary of terms

Index to Figures

Glossary of Terms

Definitions Related to the Concept of Independent Living*

Independent Living - control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of physical or psychological dependence upon others.

Independent Living Center - a community-based, non-profit, non-residential program which is controlled by the disabled consumers it serves, provides directly or coordinates indirectly through referral those services which assist severely disabled individuals to increase personal self-determination and to minimize unnecessary dependence upon others. The minimum set of services that are provided by an independent living center are housing assistance; attendant care, readers, and/or interpreters; peer counseling, financial and legal advocacy; and community awareness and barrier removal programs.

Independent Living Movement - the process of translating into reality the theory that, given appropriate supportive services, accessible environments, and pertinent information and skills, severely disabled individuals may actively participate in all aspects of society.

Independent Living Program - a community-based program which has substantial consumer involvement, provides directly or coordinates indirectly through referral those services necessary to assist severely disabled individuals to increase self-determination and to minimize unnecessary dependence on others.

Services that an independent living program must provide or coordinate through referral are housing; attendant care; readers and/or interpreters; and information about goods and services relevant to independent living. Other services that are either provided or coordinated by independent living programs include transportation provision or registry, peer counseling, advocacy or political action, independent living skills training, equipment maintenance and repair, and social-recreational services.

Note: Custodial care facilities and primary medical care facilities are specifically excluded from the definition of an independent living program.

Independent Living Residential Program - a live-in independent living program that provides directly or coordinates through referral shared attendant services and transportation. Related services which increase personal self-determination and minimize unnecessary dependence on others may be provided.

Independent Living Services Provider - an organization which provides several discrete services which can be used to increase an individual's ability or opportunities to live independently. For example, a medical rehabilitation facility may provide out-patient services which are designed to maintain the physical health of a person who lives independently in the community. However, if the center does not provide or coordinate a full set of services including transportation, attendant care and so forth, it would be an independent living service provider rather than an independent living program. While an independent living service provider does not meet the criteria necessary to be classified as an independent living program, the services it provides may be used or coordinated by an independent living program.

Independent Living Transitional Program - an independent living program that facilitates the movement of severely disabled people from comparatively dependent living situations to comparatively independent living situations. The primary service provided by these programs is skill training in such areas as attendant management, financial management, consumer affairs, mobility, educational-vocational opportunities, medical needs, living arrangement, social skills, time management, functional skills, sexuality, and so forth. Additional services may be provided. Transitional programs are usually goal-oriented and/or time-linked.

Definitions Related to Policy Planning and Development

Cause Analysis and Specification - the step in policy planning which sifts through possible causes of the problem to separate causal factors from irrelevant ones.

Commitment and Implementation - the final step in policy development where mutual understanding, agreement and shared ownership plans are expressed between administration and staff and the plan is implemented.

Crisis Model - when persons lunge out in what tend to be stock reactions to what they perceive to be a problem.

Decision Analysis and Solution Choice - the step in policy planning which keeps managers "in focus" as they generate, evaluate and settle on a solution to accomplish.

Mission Statement - a prerequisite to the policy development process which sets the organization's direction by defining purpose, clients to be served, key organizational values, etc. Specific goals and objectives are derived from the mission statement.

Operational Concerns - the level two problem category in problem analysis. Includes delivery system problems, efficiency problems, structural problems and people problems.

Planning - the step in policy development where solutions to problems are turned into statements of objectives which include the desired results and method(s) by which these results will be measured.

Policy - a statement which structures courses of action intended to accomplish some basic purpose or intent.

Priority Analysis - the step in the problem identification phase of problem analysis which sifts out the important factors in a problem by evaluating each aspect of a problem (structure, mission, delivery, etc.) on the basis of its seriousness, urgency and growth to determine which aspects are crucial and must be dealt with.

Problem Analysis - a method of defining and categorizing problems so they can be dealt with systematically and creatively; the framework for making decisions and plans which ensures efficient use of resources.

Problem Specification - the step in the problem identification phase of policy planning which summarizes the problem in specific terms; identifying the goals, impact indicators and targets affects directly or indirectly; and showing how the problem is related to achievement of desired goals.

Reality or "Maximizing" Model - the mechanism for identifying issues and generating good solutions to problems.

Situation Analysis/Problem Identification - the step in the problem analysis process which compares ongoing results with desired results to determine how improvements can be made.

Strategic Concerns - the level one problem category in problem analysis. Includes mission and goal problems, measurement problems, and effectiveness problems.

Systems Planning Cycle - a process for moving from an agency's ideals, to its present realities, to its plans for the future, and finally into new models for service.

Wicked Problems - problems with both an ethical wrongness and complexity (e.g., malnutrition or energy waste), generally human problems.

Definitions Related to Federal Legislation

Rehabilitation Comprehensive Services, and Developmental Disabilities Amendments of 1978 (P.L. 95-602) - federal legislation enacted in November, 1978 to amend and continue the Rehabilitation Act of 1973. The emphasis of the legislation is still on provision of services, but it also broadens the focus of rehabilitation research and training.

Title I (P.L. 95-602) - extends the basic vocational rehabilitation program.

Title VII (P.L. 95-602) - provides a three part program in independent living:

- Part A - authorizes a comprehensive independent living services program to be administered by the state vocational rehabilitation agency to meet the needs of disabled persons who may not qualify for traditional vocational rehabilitation services.
- Part B - authorizes a grant program for independent living centers.
- Part C - authorizes independent living services for older blind persons.

*Definitions related to the concept of independent living were developed by and reprinted through the courtesy of the Independent Living Research Utilization Project, The Institute for Rehabilitation and Research, Houston, Texas.

UCIR Publication List (Effective November 1980)

	Quantity	Price	Total Price
OCCASIONAL PAPERS			
DeJong, Gerben. *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research.* 1979.	_____	$3.00	_____
Evaluates independent living as a social movement, analyzes the movement's expression in disability services, and considers implications for disability research. 35 pp.			
de Mezerville, Gaston. *Disability and Rehabilitation in Rural Costa Rica.* 1979.	_____	$1.50	_____
Describes a status and needs study of disability and rehabilitation in two areas of rural Costa Rica. The four stated objectives of this study are to: identify functional limitations, assess the functional development of children, determine possible prevention factors, and state current practices and resources. 46 pp.			
BIBILOGRAPHIES			
Fritz, James E. and Dailey, Owen H. *Bibliography, Number 2: Independent Living.* 1980.	_____	$1.00	_____
Announces the availability of literature on major issues in independent living. Ordering information is provided. 16 pp.			
PROCEEDINGS			
Frey, William D. et al. *Priority Needs and Action Planning Conference, March 14-16, 1979.*	_____	$1.75	_____
Identifies and discusses the major United States rehabilitation needs and their priority which might be more effectively dealt with through international collaboration and exchange. 49 pp.			
Sigman, Susan J. *Policy Planning and Development in Independent Living: proceedings of a Region V workshop.* 1980.	_____	$3.25	_____
Presents a model for implementing policy planning and development in the design of programs which will be harmonious with the historical perspectives of the independent living movement. Materials are arranged in a sequential manner which simulates the actual training process. The document also includes an overview of a variety of independent living experiences, a resource bibliography, and a glossary of relevant terminology. 70 pp.			
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Advocates psychotherapy as an appropriate remedial alternative for mentally retarded persons who experience psychological disturbances. Presents a case history account of a young woman with Down's syndrome and her progress through therapy. 25 pp.			

ISSUE PAPERS (continued)

Galvin, Donald E. *"Policy Issues in Independent Living."* 1980. _____ .35 _____

Discusses five strategic policy issues which affect the development and implementation of independent living programs. Also briefly reviews related social movements to which independent living owes some heritage and support. 10 pp.

Jarvis, Robert et al. "Legislation and the Severely Disabled." 1979. _____ .35 _____

Reviews federal legislative provisions for services to the unserved handicapped population, especially to the severely disabled. The intent of the laws particularly for independent living is discussed. 15 pp.

Juhr, Gerald et al. "Barriers to the Development and Application of Technological Aids for Handicapped Persons." 1979. _____ .35 _____

Outlines barriers which impede efficient development and application of industrial technology to meet the needs of handicapped persons. The authors conclude that a comprehensive approach to policy change is needed in order to allow technological transfer to satisfy certain needs in rehabilitation engineering. 14 pp.

Juhr, Gerald et al. "Rehabilitation Programming for the Homebound." 1979. _____ .65 _____

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