

DOCUMENT RESUME

ED 197 196

CE 027 837

AUTHOR Wilcox, Suzanne Dale  
 TITLE Together We Can. A Consumer Education Module for People with Mental Retardation.  
 INSTITUTION City Univ. of New York, N.Y. Center for Advanced Study in Education.  
 SPONS AGENCY Office of Consumer's Education (ED), Washington, D.C.  
 EJB DATE [ 80 ]  
 CONTRACT 300-78-0552  
 NOTE 87p.: Prepared through Consumer Education Development Program.

EDRS PRICE MF01/PC04 Plus Postage.  
 DESCRIPTORS Adult Education: Behavioral Objectives: Consumer Economics: \*Consumer Education: Daily Living Skills: \*Decision Making Skills: \*Employment Services: Instructional Materials: Learning Activities: Learning Modules: \*Legal Aid: Material Development: \*Medical Services: \*Mental Retardation

ABSTRACT

This consumer education module is designed to help mentally retarded persons take charge of their lives as consumers. An introductory section contains information on the development of these learning materials. Following the introductory section, four units, each of which is designed to be presented in a five-hour session, are provided. The first unit contains six activities to help students become skilled consumers. These activities involve identifying areas of consumer concern, avoiding "rip-offs," supermarket role playing, decision-making skills, and saying no as a consumer. Activities in the second unit, which covers medical services, deal with the first visit, trusting the doctor, and steps that the individual can take to safeguard his or her own health. The third unit contains activities on a first visit to a lawyer, basic legal rights, steps to secure one's rights, and complaining to one's lawyer. Consuming employment services is the subject of the fourth unit, which consists of exercises requiring students to list their job goals, describe the job they desire most, express their job aspirations as they would to potential employers, and make field trips to a work site. Appendixes contain information on choosing a doctor and finding a lawyer.

(MN)

# Consumer Education Development Program

A National Study

TOGETHER WE CAN

Suzanne Dale Wilcox

A Consumer Education Module  
for People  
With Mental Retardation

New Careers Training Laboratory  
Center for Advanced Study in Education  
City University of New York

U S DEPARTMENT OF HEALTH,  
EDUCATION & WELFARE  
NATIONAL INSTITUTE OF  
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY.

Art Work by  
Madeleine Ward Moore

National Consumers League

Sandra L. Willett  
Mary F. Boyles

New Careers Training Laboratory  
Center for Advanced Study in  
Education  
Graduate School and University  
Center  
City University of New York

Alan Gartner  
Suzanne Dale Wilcox

Michigan Consumer Education  
Center

College of Education  
Eastern Michigan University

Rosella Bannister  
Charles Monsma

ED197196

CE 027 837

•General CEDP publications include the following:

Michigan Consumer Education Center

Classification of Concepts in Consumer Education

Rosella Bannister and Charles Monsma (1980)

Effective Consumer and Education Programs

Charles Monsma and Rosella Bannister (1979)

National Consumers League

Consumer Education: Alternative Modules for Curriculum

Mary F. Boyles (1980)

Current and Future Purposes and Objectives of Consumer Education

Sandra L. Willett (1980)

Research Issues: Consumers and an Uncertain Future

Dennis Pirages (1980)

The Educated Consumer: An Analysis of Curriculum Needs in Consumer

Education Suzanne Dale Wilcox (1980)

New Careers Training Laboratory

Disseminating Innovation in Consumer Education

Suzanne Dale Wilcox (1979)

•CEDP Curriculum Modules include the following:

Michigan Consumer Education Center

Citizen Participation: Increasing the Bargaining Power of Consumers

Charles Monsma (1980)

Inflation: Consumers Counter the Cost of Living

Rosella Bannister (1980)

Money Matters for Women: Telecourse Study Guide Ellen White (1980)

National Consumers League

Consumer Citizens: Helping Yourself and Others Mary F. Boyles (1980)

Food: Advertising, Issues and Action Mary F. Boyles (1980)

Medicare/Medigap Health Insurance Issues: Consumers Get Involved

Mary F. Boyles (1980)

New Careers Training Laboratory

It's My Life: Participation in Individual Service Planning by the Mentally Retarded Suzanne Dale Wilcox (1980)

Together We Can: Consumer Education for the Mentally Retarded

Suzanne Dale Wilcox (1980)

Urban Consumer: A Community Newspaper Suzanne Dale Wilcox (1980)

This material is based upon work supported by the Office of Consumers' Education, Department of Education, Contract Number 300780552. Any opinions, findings and conclusions or recommendations expressed in this publication are those of the authors and do not necessarily reflect the views of the Office or the Department.

TABLE OF CONTENTS

	Page
CREDITS AND ACKNOWLEDGEMENTS . . . . .	1
CONSUMER EDUCATION DEVELOPMENT PROGRAM . . . . .	2
CLASSIFICATION OF CONCEPTS IN CONSUMER EDUCATION . . . . .	4
TOGETHER WE CAN: PURPOSES, AUDIENCE AND SUGGESTED TIMEFRAME . . . . .	8
TOGETHER WE CAN MODULE . . . . .	10
OVERVIEW OF UNIT STRUCTURE	
<u>Unit One: Consumer</u>	
Learning Activity 1: Me, As A Consumer . . . . .	12
2: Poster Panel . . . . .	14
3: Avoiding the Rip-Off . . . . .	22
4: Supermarket Role Play . . . . .	23
5: Decision-Making . . . . .	24
6: Saying No . . . . .	32
<u>Unit Two: Medical Services</u>	
Learning Activity 1: The First Visit . . . . .	35
2: Trusting the Doctor . . . . .	37
3: Our Health is Our Business . . . . .	38
<u>Unit Three: Legal Services</u>	
Learning Activity 1: First Meeting With A Lawyer . . . . .	40
2: We Have Rights, Too! . . . . .	43
3: Getting Your Rights . . . . .	44
4: Complaining To Your Lawyer . . . . .	47
<u>Unit Four: Consuming Employment Services</u>	
Learning Activity 1: What Do I Like To Do? . . . . .	49
2: Dream A Little . . . . .	50
3: Learning My Script . . . . .	51
4: Field Trip to a Work Sight . . . . .	52
APPENDICES	
A: Doctor and Patient . . . . .	54
B: Consumers and Lawyers . . . . .	60
C: How to Start a Self-Help Group . . . . .	63
BACKGROUND RESOURCES	82

CREDITS AND ACKNOWLEDGEMENTS

The Consumer Education Development Program is a collaborative project, conducted by three organizations, benefiting from the advice and assistance of many people throughout the country. We appreciate the help given to us both from those within our own institutions, and by the many people in schools, colleges, community organizations, government agencies, consumer agencies, and the consumer education world. We are grateful and hope that this and other products of CEDP reflect that valuable help.

We especially express our appreciation to Dr. Dustin Wilson, Director, Office of Consumers' Education, U.S. Department of Education. It was he who initiated the idea for this project and who has been vital to its achievements. As Project Officer, he has been concerned but not intruding, available but not imposing, questioning but not badgering. We are grateful to him.

While the work of Consumer Education Development Program has been national, as we describe in the next section, in the development of curriculum models it has been local. This module represents work of the New Careers Training Laboratory and staff members of the Belchertown State School and the Westfield Area Mental Health and Retardation Board. At Belchertown, we are indebted to Dr. William F. Jones, Director, and Elizabeth Schafer, Director of Staff Development. At the Massachusetts Department of Mental Health, Westfield Area Office, we thank Richard Toscano, Director of Community Development and Joanne Bean. Also in the Westfield area, and immediately connected with trying out the learning activities herein are the members of the Western Massachusetts Self-Advocacy Group.

This training design would not be readable were it not for the tireless zeal of Charlotte Fisk who typed and re-typed it and the technical, supportive assistance of Ethel Mingo. Nor would it have ever gotten done without the helpful administration of Adda Manosalvas or the friendly advice of Audrey Gartner, Myrna Baron and Fran Dory.

## THE CONSUMER EDUCATION DEVELOPMENT PROGRAM

The fundamental premise of the Consumer Education Development Program has been that consumer education, if it is to be effective in the future, must be critically examined today. Researchers and practitioners have repeatedly called for a clearer definition of consumer education, an examination of its purposes and objectives and identification of its important concepts.

During the first year of the Consumer Education Development Program, the major work was devoted to addressing such questions as:

- What is being done in consumer education? And how effectively?
- What areas of concern are being addressed? And which were not?
- What are the needs of the future?
- How can new teaching materials best be developed and disseminated?

In addressing these and similar questions, we consulted with leaders and practitioners of consumer education from schools and colleges, and from community groups and government agencies. We convened meetings, read reports, visited programs, and talked with those doing programs, in an effort to describe accurately what was happening in consumer education and what was needed. The reports listed on the inside front cover of this module address these topics.

The CEDP publication which provided the linkage between the work of the first and second year is the Classification of Concepts in Consumer Education. This Classification expresses our view of the broad scope of consumer roles and influence, and the increasing complexity of consumer education. Using the classification of concepts as a base, we developed a set of curriculum modules, designed to illustrate various aspects of the classification system. These units were designed to present new material, to illustrate new approaches or to address new audiences, and were pilot-tested in various locations. The chart on the following page lists the concepts, test site location, site agency and the target audience.

CONCEPT TEST SITE PLAN

<u>CONCEPT CATEGORY</u>	<u>LOCATION AND AGENCY</u>	<u>TARGET AUDIENCES</u>
Resource Management (Financial Planning)	Detroit, Michigan WXYZ-Television	Adult Women, Separated, Widowed, Divorced
Economic System (Inflation)	Oregon Department of Education	Secondary School Teachers and Students
Economic System (Inflation)	Ypsilanti, Michigan Ypsilanti High School	Secondary School Teachers and Students
Citizen Participa- tion (Advocacy)	Atlanta, Georgia Jacqueline Lassiter Assoc.	Community Based Organization Personnel
Citizen Participa- tion (Advocacy)	St. Louis, Missouri City Schools	Urban, Elementary Teachers and Students
Citizen Participa- tion (Advocacy)	Iowa Consumers League	Rural Adults
Citizen Participa- tion (Advocacy)	Berkeley, California Vista College	Urban Adults
Resource Management (Purchasing)	New York City Public Schools	Urban Junior High School Students
Resource Management (Purchasing)	Western Massachusetts Belchertown State School	Deinstitutionalized Developmentally Disabled
Citizen Participa- tion (Advocacy)	Northampton Open Door Club	Developmentally Disabled

The planned outcome of the entire two-year CEDP study is to build a new design for consumer education that:

- is more far-reaching and integrated than ever before
- includes attention to topics of increasing interest to consumers -- such as human services, conservation, inflation and consumer
- incorporates expanded roles for consumers, such as the consumer-citizen role in influencing public policies which affect consumers
- assures increased attention to special groups served by consumer education, including women, the poor, senior citizens, the disabled, minority groups.

The CEDP study has produced an assessment of consumer education, a revitalized classification of concepts, and new approaches and materials which should lead to improved consumer education programs in a variety of educational settings.

In developing the training design in this module, a team of staff people from the New Careers Training Laboratory was engaged in various activities:

- Alan Gartner and Suzanne Wilcox met with staff people at the Belchertown State School, and at the Westfield Area Office of Mental Retardation.
- Suzanne Wilcox conducted a one-day needs assessment meeting with staff in the Westfield Area Office and members of the Western Massachusetts Self-Advocacy group.
- Meetings were held with a broad range of persons working in self-advocacy for mentally retarded persons across the country.
- The current literature, both on mental retardation and on training for people who are mentally retarded, was reviewed.
- Five training sessions were conducted by Frances Dory, Alan Gartner, Ethel Mingo and Sue Wilcox for persons with mental retardation.
- A conference was held in New York City on the topic of self-advocacy for consumers who are mentally retarded.

#### CLASSIFICATION OF CONCEPTS IN CONSUMER EDUCATION

The primary reason for developing the 1980 Classification of Concepts in Consumer Education was to provide a basis for program and materials development and to encourage exchange of ideas and information about consumer education. The identification and classification of concepts should diminish confusion, both within and outside the field, as to what consumer education is, and what consumers should know and be able to do.

The learning activities in Together We Can, are based on the conceptual framework which appears in Figure 1, the Consumer-Decision-Action System. The concept, consumer, is best described in the context of this system. Put simply, the system is a visual way of describing to act in one or more of a variety of ways: planning, purchasing, conserving, getting legislative or other protection for themselves and advocating for their cause. Consumers are thus seen as persons with a broad range of options relative to each of the specific consumption areas (e.g. housing, energy, food shopping, legal services).



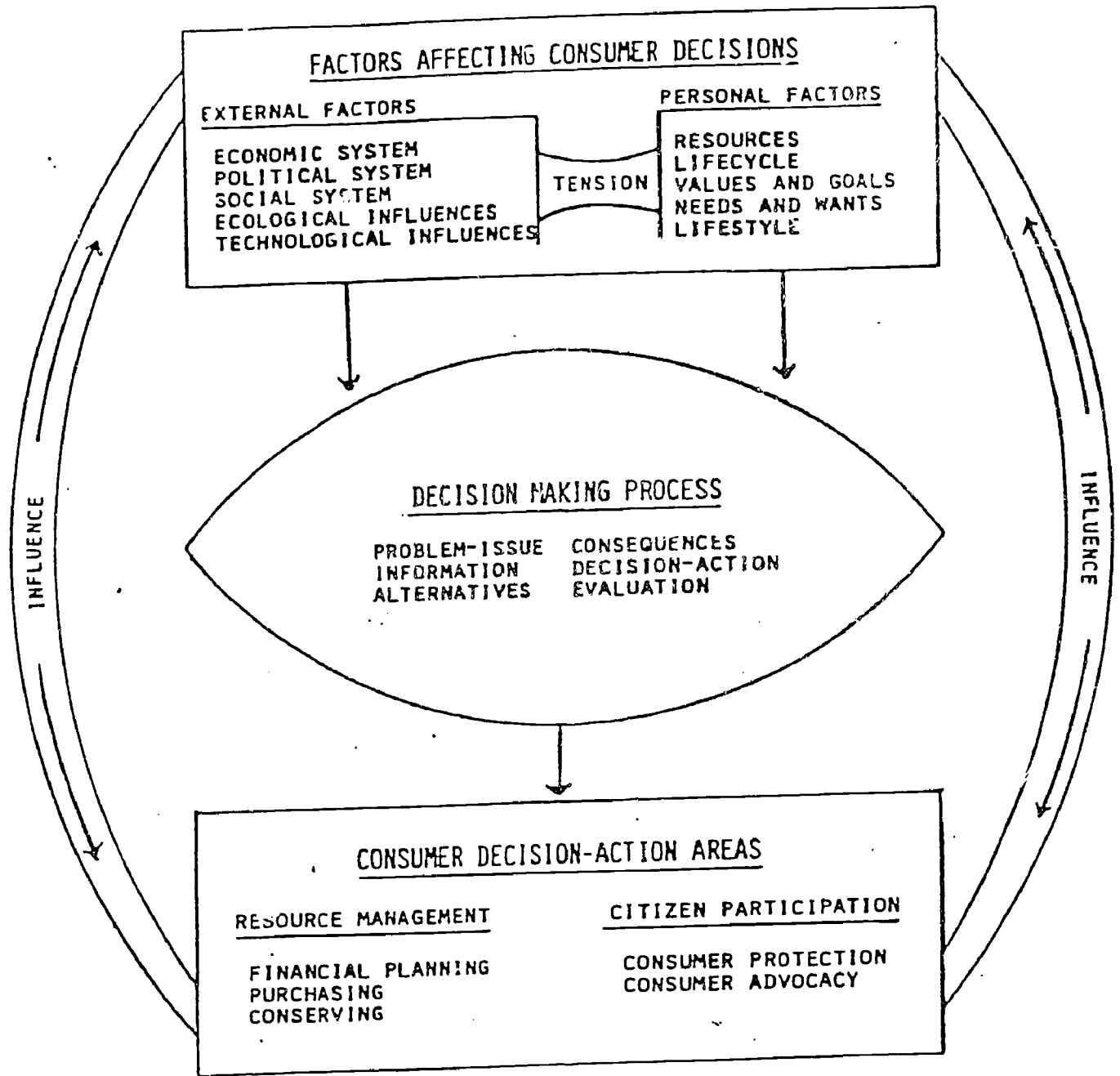


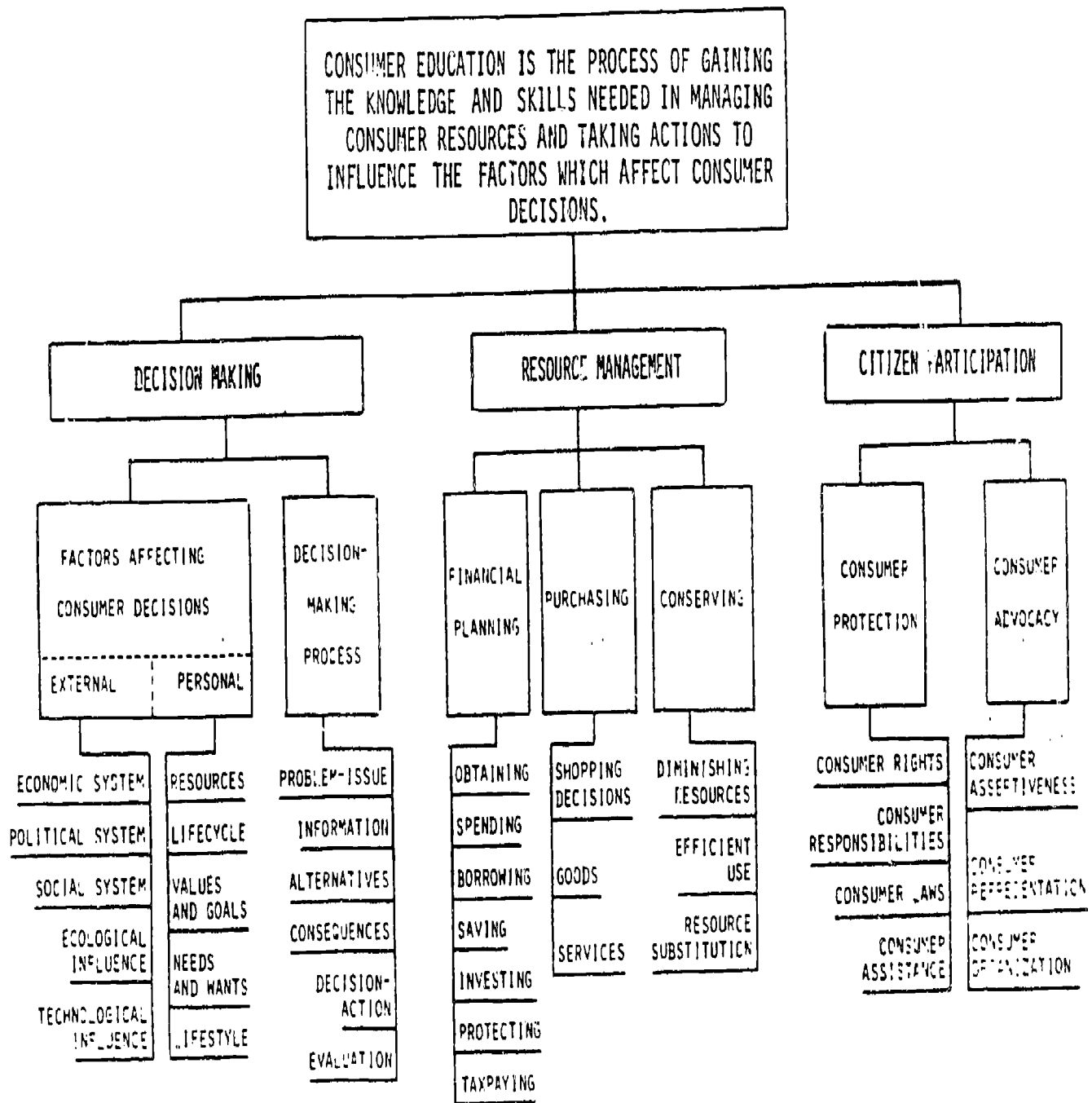
FIGURE 1. CONSUMER DECISION-ACTION SYSTEM\*

Suzanne Dale Wilcox, A Conceptual Framework for Consumer Education Curricula, City University of New York, January, 1980, p. 12.  
From Bannister, Rosella and Monsma, Charles, Classification of Concepts in Consumer Education, Consumer Education Development Program, Michigan Consumer Education Center, Eastern Michigan University, Ypsilanti, Michigan 1980, p. 10.

Building on a definition of consumer education, the concepts which make up the content of the field are identified and classified in Figure 2. The CEDP Classification of Concepts in Consumer Education provides a definition of each concept, discusses its application to consumer education on various models of consumer behavior, and identifies twelve contemporary factors affecting consumer decisions.

Consumer competence in the marketplace is not parceled out in clearly defined areas. Knowledge is interdependent; in reality concepts merge in endless combinations. In this curriculum module, Together We Can, we illustrate how the concept of inflation is related to many other concepts within the system.

The activities in this module form a portion of the classification of concepts which deals with the range of consumer behavior appropriate to all of us, but most especially to people in transition, to mentally retarded persons who are in the process of adjusting to life in the community after many years in an institution. Shopping, evaluating goods and services, advocating for themselves in the marketplace are all activities which are new to many people who are retarded.



-7-

FIGURE 2. A CLASSIFICATION OF CONCEPTS IN CONSUMER EDUCATION

\*From Bannister, Rosella and Monsma, Charles, Classification of Concepts in Consumer Education, Consumer Education Development Program, Michigan Consumer Education Center, Eastern Michigan University, 1980, p. 14.

## Together We Can Module

### Purposes, Audience and Schedule

This training module is based on a series of sessions conducted by four staff members of the New Careers Training Laboratory, City University of New York: Frances Dory, Alan Gartner, Ethel Mingo and Suzanne Dale Wilcox. Trainees included members of two self-advocacy groups of mentally retarded adults in Western Massachusetts, the Western Massachusetts Self-Advocacy Club in Westfield, Mass. and the Open Door Club in Northampton, Mass. Suzanne Wilcox met with staff and group members in the weeks which preceded the training sessions; she gathered information on the individual and collective needs of the group for education as consumers and designed the training sessions in collaboration with NCTL staff.

The materials grew out of the Western Massachusetts experience; they have been revised to reflect what was learned in the sessions and to add new resource materials, all with a national audience in mind. Thus, they form a potential educational package to facilitate independent living among the developmentally disabled. During the ten or so years in which such persons have been gradually moving toward life on their own, it has become apparent that consumer skills are among those they need. If most Americans are un-questioning and unassertive consumers, even more are those who have spent major portions of their lives in institutional settings.

The major purpose of this module is to give those developmentally disabled consumers living in communities some of the skills they need to take charge of their lives as consumers. We propose a model for decision-making to serve consumers as a framework for their choices and a range of exercises by means of which to learn and reinforce the model.

We expect that professionals, paraprofessionals and consumer advocates would deliver the training exercises which make up this module. And we hope that the setting for such delivery would be self-help mutual aid groups of persons with developmental disabilities. Such groups have come to be known as self-advocacy groups.

The pilot audience for this module, "Together We Can," was two groups of developmentally disabled individuals who have formed the Western Massachusetts Self-Advocacy Club and the Open Door Club. The Western Massachusetts group began in November, 1979, and was the local outcome of a statewide

conference sponsored by the Westfield Area Mental Health and Retardation Board. The Open Door Club was formed in Northampton in June, 1980 at the Hampshire County Association for Retarded Citizens. Open Door meets every Monday evening.

The Western Massachusetts Self-Advocacy Club meets twice a month and includes twenty-five people ranging in age from twenty to fifty-nine. All of the members live in the community, and most of them are former residents of the Belchertown State School, an institution which housed large numbers of mentally retarded persons in the state of Massachusetts.

The group members represent a broad range of "communitization" possibilities. Some live with their families; others live in group homes or apartments of one or two; still others live alone. Their work experiences vary equally. While many of the group work in sheltered workshops, some are employed in public institutions and private businesses. A few contemplate starting their own businesses. Others are being trained in transitional employment programs. There are a few people in the group whose handicaps presently prevent them from being gainfully employed.

From the client perspective, the Western Massachusetts Self-Advocacy Club represents a major effort on the part of formerly institutionalized people to help one another adjust to independent living. From the professional perspective, the group is meant to become the primary generic service access mechanism for persons who are mentally retarded. The already-defined means by which both the personal goals of clients and the strategic goals of professionals can be reached is training. Each of the group meetings includes some form of training, geared to facilitate the process by which consumers become "communitized" (Jones, 1979).

More intensive training in subjects related to being a consumer was offered by the New Careers Training Laboratory as part of the Consumer Education Development Program. Four topical areas were treated: Shopping, Consuming Medical Services, consuming legal services and employment services. Instead of being incorporated in the groups' regular bi-weekly meeting, these training sessions represented an alternative to the meeting. They began at 4 P.M. on the same day as the regular meeting and lasted until 9 P.M. They included dinner and cocktails, and were conducted in a local motel or conference center with extensive conference facilities.

Time Schedule: Each unit herein, with the exception of the more extensive ISP unit, formed an evening training session, lasting approximately five hours with a supper break. Six or seven such meetings with a group constitute the minimum time in which a group leader might deal with these five consumer topics. Ideally, the training designs might take longer, giving consumers an opportunity to try out and reflect on new behavior in the course of the training.

## TOGETHER WE CAN

### MODULE

This module, "Together We Can," has the primary goal of helping mentally retarded persons to assist one another in dealing with a range of consumer issues. Because they have so long been the passive recipients of a wide range of services, everything from housing assignments to clothing, persons with mental retardation benefit greatly from training which aims to activate them as consumers and to encourage them to help one another in dealing with consumer problems.

Learning to make decisions is, for those who are developmentally disabled and for each of us, a major part of assuming responsibility for our lives. It is a learning process made more necessary for persons who are mentally retarded than it is for most of us because the target population has been institutionalized for the greater portion of their adult lives.

The current trend toward normalization or communitization stems from the affirmation that persons who are retarded can grow and develop. Using this developmental model as a guide, judicial decisions now mandate a normal life in community for the mentally retarded. To facilitate such a life, groups of retarded people have formed in which people help one another adjust to new realities: work, independent living, the use of generic services, shopping, making decisions.

Taken together, the units which follow form a module for persons who are mentally retarded. Each of the units represents one life area in which all of us, but most especially the mentally retarded, need training in order to be better consumers: shopping, going to the doctor, making use of legal services.

Each of the units is designed in a common structure, a structure which is representative of our approach to learning. The structure is explained here so that professionals who work with groups of mentally retarded persons can more easily make use of the materials.

Each unit of the module is built around a goal. The overall goal of the module is to enable people to be more skilled consumers, able to make personal consumption decisions in a model of responsible awareness, assertiveness and creative problem solving. Each of these qualities forms the basis for a series of learning activities. Awareness, assertiveness, and problem solving are the objectives toward which the learning activities are geared. Since certain kinds of human performance give evidence that people have learned to be aware, assertive and skilled at problem-solving, these are simulated in our training sessions so participants can tell if they have learned them.

The learning activities in each unit are means to achieve certain objectives; they are also called operationally defined objectives or performance objectives because they are observable. They govern our choice of learning activities and are based on actual work with groups of retarded individuals, on observing their individual needs and connecting them to the expectations which society places on each of us, including mentally retarded persons. The objectives are derived from the needs we perceived in the group as played out against broader curriculum needs in consumer education.

The structure followed in this module includes, for each session: group size, time required, materials, physical setting, process and resources. Here, the descriptions are based on our experience; the use of the learning activities in another setting may yield considerable variation. Consider our statements, when they are very specific, to be estimates; your own training sessions may be longer or shorter, your groups may be larger or smaller.

Following the units, there are assessment instruments which can be used to study student performance. They give the organizer some indication of the extent of student achievement. Following the assessment, the group leader might choose to repeat those segments on learning activities which will reinforce objectives not achieved.

Throughout the unit, the professional who is doing the training is referred to as the facilitator. This term is used because it seems to reflect the role we envision for a group leader dealing with the mentally retarded or, indeed, any group of learners: one of providing the context and activities by means of which learning can take place, generating data from the group on a particular subject, and helping the group to learn by means of working through the data which has been generated on a particular consumer topic.

UNIT ONE:

CONSUMER

While there is a range of activities appropriate to being a skilled consumer, the activity which serves best to introduce the concept, consumer, is that of shopping. This activity is no small challenge for persons who are mentally retarded, especially for retarded persons who have spent years in an institution. Frequently, such individuals have done little shopping and have had little access to money.

The training provided within self-advocacy groups can assist mentally retarded persons to deal effectively with the most basic and the most sophisticated of consumer problems. In this unit, the training designs focus on basic consumer problems, those involved in shopping, with a sophisticated perspective, that of learning to understand the full impact of the concept consumer and how it affects the way a person acts in all facets of their life.

LEARNING ACTIVITY 1: ME, AS A CONSUMER

- Objectives:
- Given sentence fragments, speaks clearly about particular consumer problems.
  - Given oral expressions of a peer, listens to statements about consumer problems and responds with awareness and sympathy.

Group Size: Unlimited

Time Required: One hour

Materials: Cards with sentence fragments.  
Newsprint/magic markers

Physical Setting: Chairs spread out in pairs. Two rows.

Process:

- I. The facilitator explains to the group that there are many situations in which we are consumers, that is purchasers of goods and services. The facilitator also mentions that some of these situations are more difficult for some persons than they are for others, and that frequently it is possible for consumers to assist one another in solving their consumer problems. To do this, people must learn how to listen to the problems of others.



CONSUMER CARD

Consumer Questions

Something I really want to buy is ...

---

---

One thing that makes me angry as a consumer is . . .

---

---

If I could create a whole new product, it would be . . .

---

---

I would like to organize a group to change the following situation . . .

---

---

A bad experience which I have had as a consumer is . . .

---

---

A good experience which I have had as a consumer is . . .

---

---

- II. The facilitator describes the overall activity. To learn to do the above, participants will be asked to pair off; they will each be given a card containing certain sentence fragments which they will read to one another and complete in turn. At a given signal, they will move on to another partner.
- III: The facilitator gives the above directions, one at a time, hands out the cards and makes certain that the group is paired off, and that at least one person in the pair can read. If neither can read, or if there are a number of non-readers in the group, it will be necessary to have staff or volunteers work with pairs or small groups, making them triads. He/she gives the signal to begin.
- IV. After twenty minutes, the facilitator will give a signal to change places and the process will begin again.
- V. When the pairs have talked for another ten minutes, the facilitator will stop the communication and reassemble the entire group. He/she leads a discussion around the following issues:
1. What new consumer problems did you hear?
  2. Which of them was most difficult to listen to?
  3. Which problem did you most enjoy talking about?
  4. How would you describe a consumer?
- VI. The facilitator writes the word "consumer" on the newspaper, and then asks the question, "What does a consumer do?" He/she writes on the board the ideas generated in the group about being a consumer.

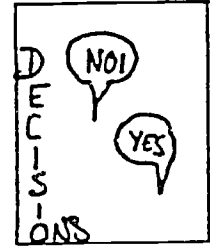
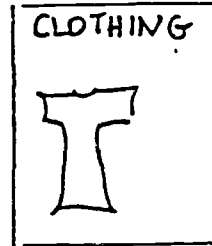
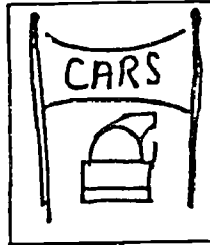
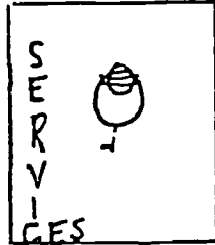
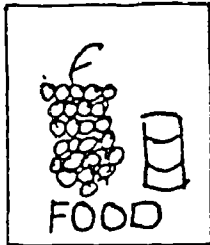
#### LEARNING ACTIVITY 2: POSTER PANEL

- Objectives:
- Given five symbolic representatives of areas of potential consumer concern, identifies area of greatest personal significance.
  - Given a situation in which the individual has chosen the area of greatest consumer concern, articulates verbally the reasons for personal choice.
  - Given a series of instances in which a person behaves as a consumer, identifies appropriate consumer behavior and classifies it.

Group Size: Unlimited

Time Required: One half hour

Materials: I. Five posters, each representing a different consumer area with a word and an image. (Representations of these posters follow)

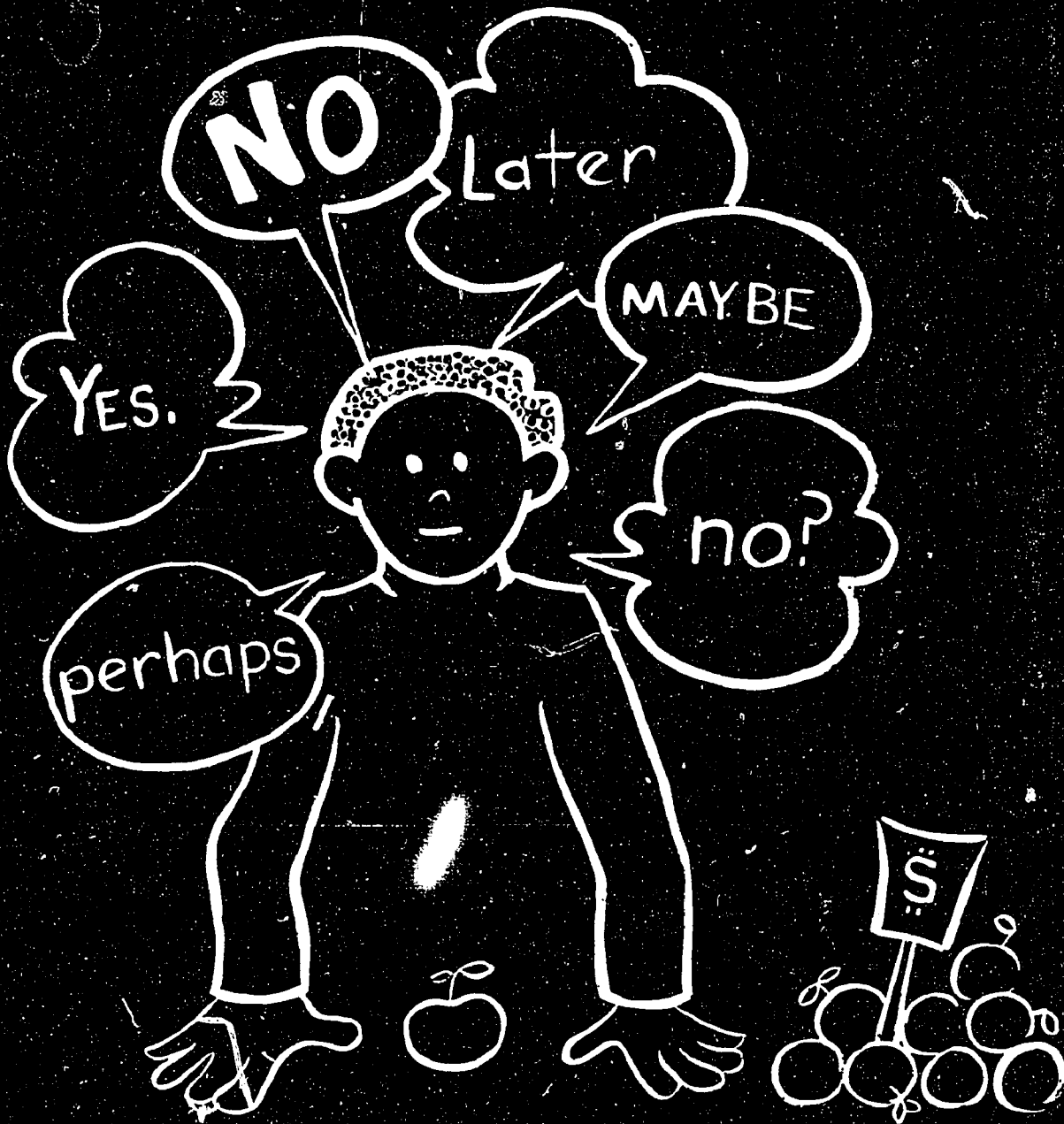


II: Five pads of newsprint, with magic markers for each.

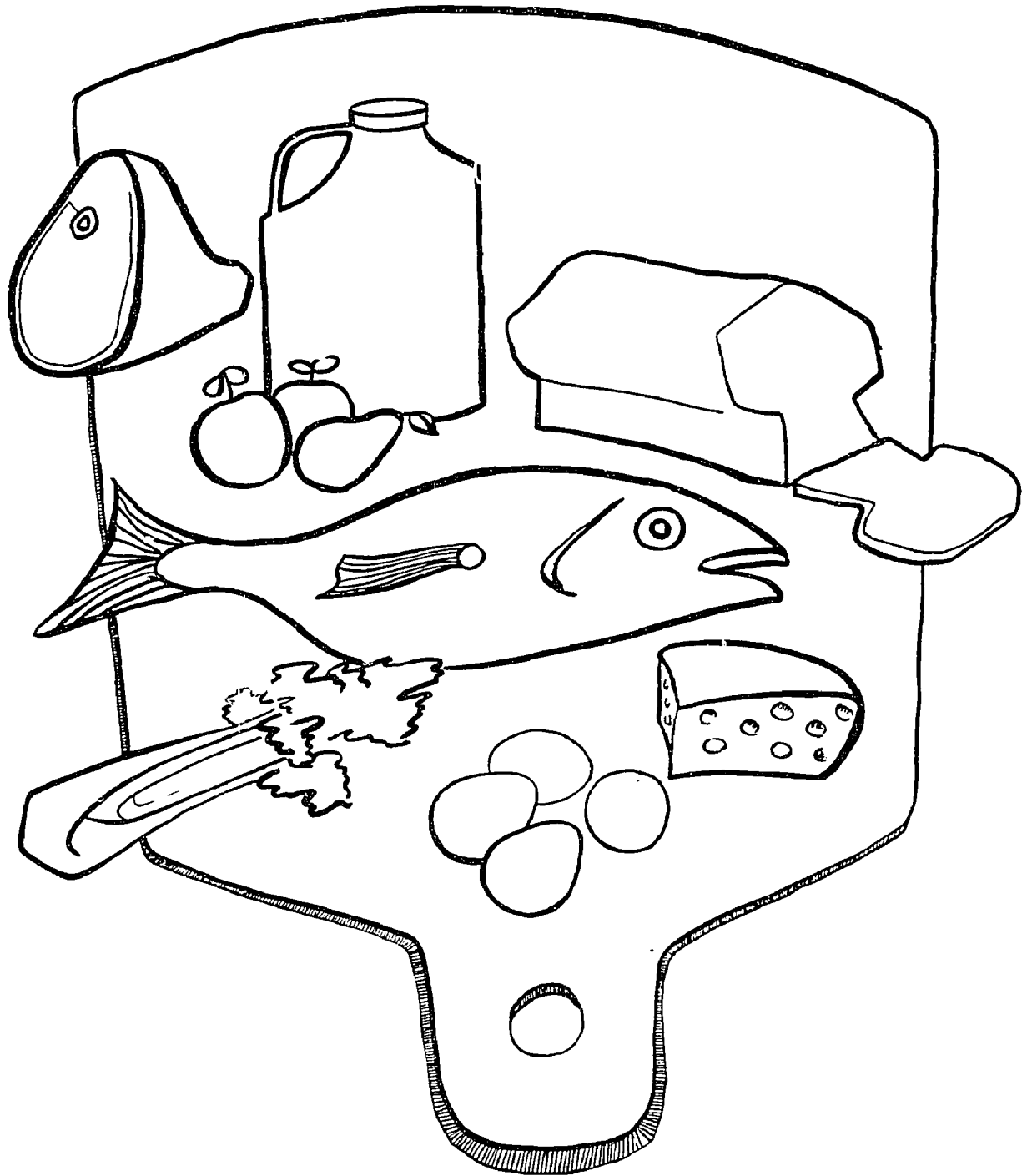
Physical Setting: Chairs should be arranged auditorium style for the beginning and end of each session. In addition, small groupings of chairs should be located near each of the five posters at various places around the room.

Process:

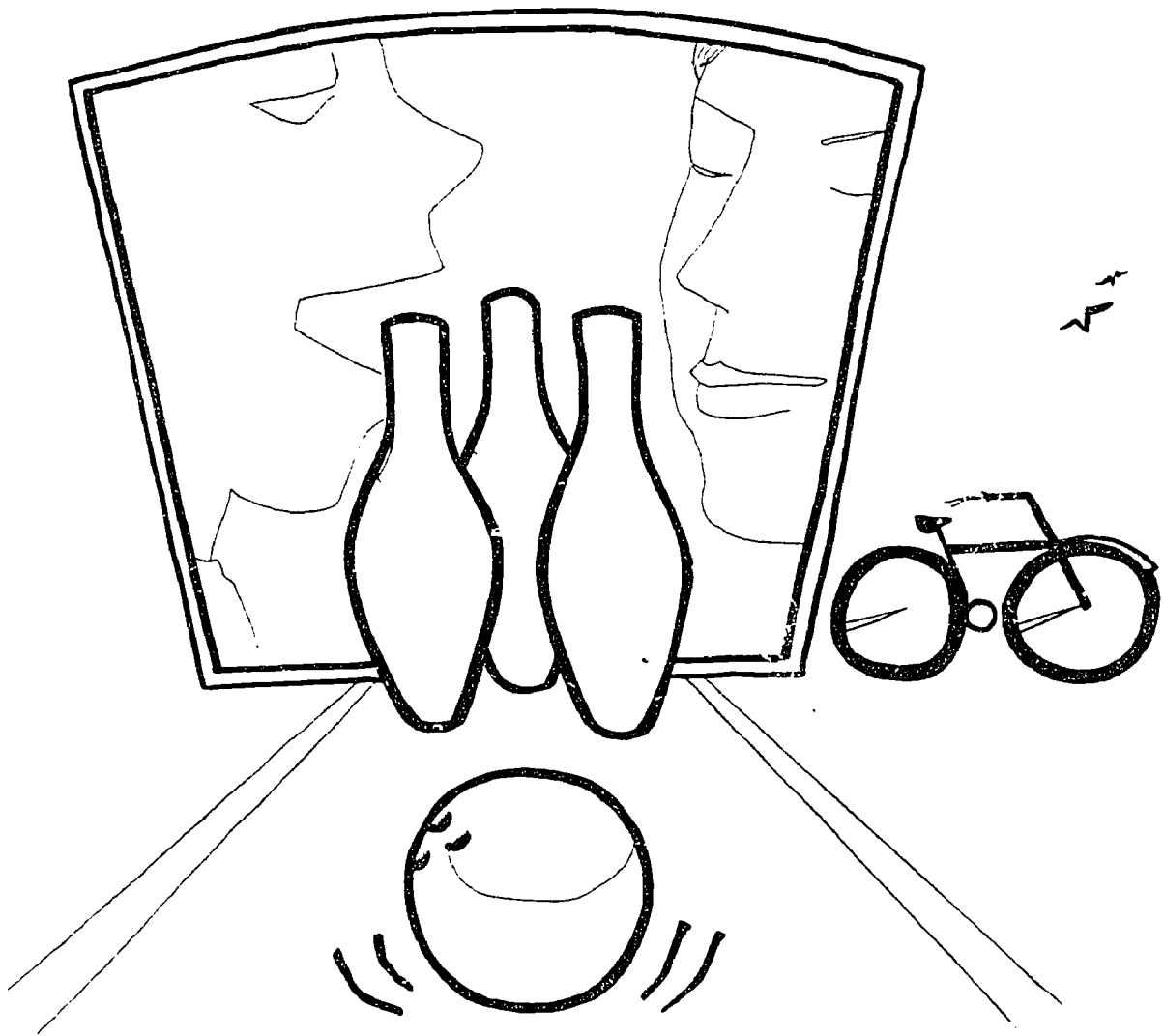
- I. The facilitator explains that, located in various areas of the room, there are five posters, each of them representing an area of consumer involvement: food, services, cars, clothing and decisions. After a brief explanation of each, the facilitator asks if there are any questions about the posters themselves.
- II. Participants are then told to think about which symbol/area reminds them of a recent consumer experience they have had or might be worried about. They should proceed to that location in the room where "their poster" is.
- III. At each location, there should be a staff person or volunteer, who can facilitate the mini-groups. This person should ask each person in the group to explain why they have chosen the consumer area represented by the poster. People should be allowed to tell their story fully.
- IV. The mini-group facilitator should appoint someone to record on newsprint the salient points in what is said, about "cars" for example.
- V. The facilitator should then gather together the total group, asking participants to draw from their discussion a series of action verbs which are "things a consumer does," reviewing while doing so the issues mentioned in each topical area as problems which these consumers have confronted.



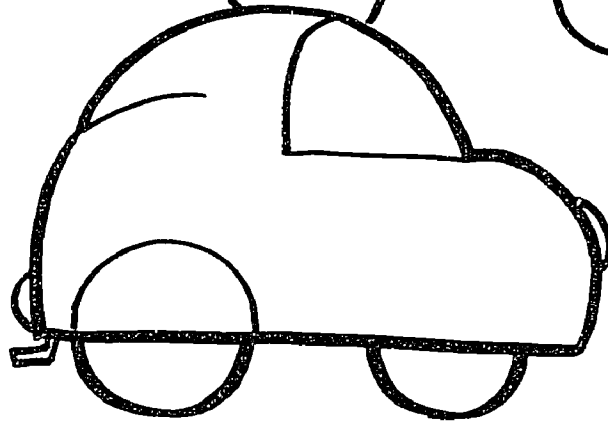
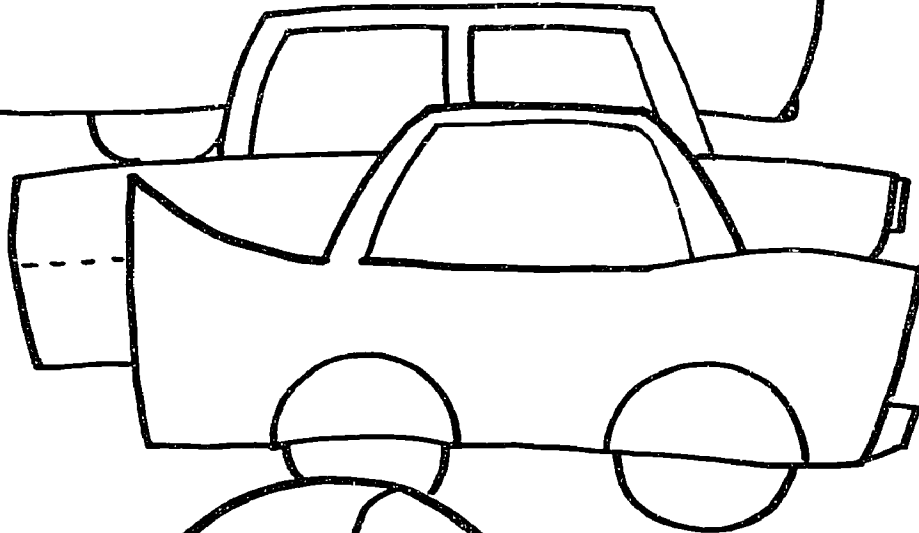
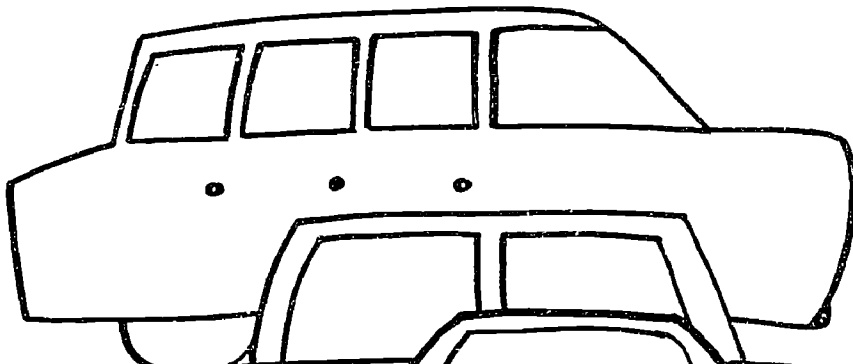
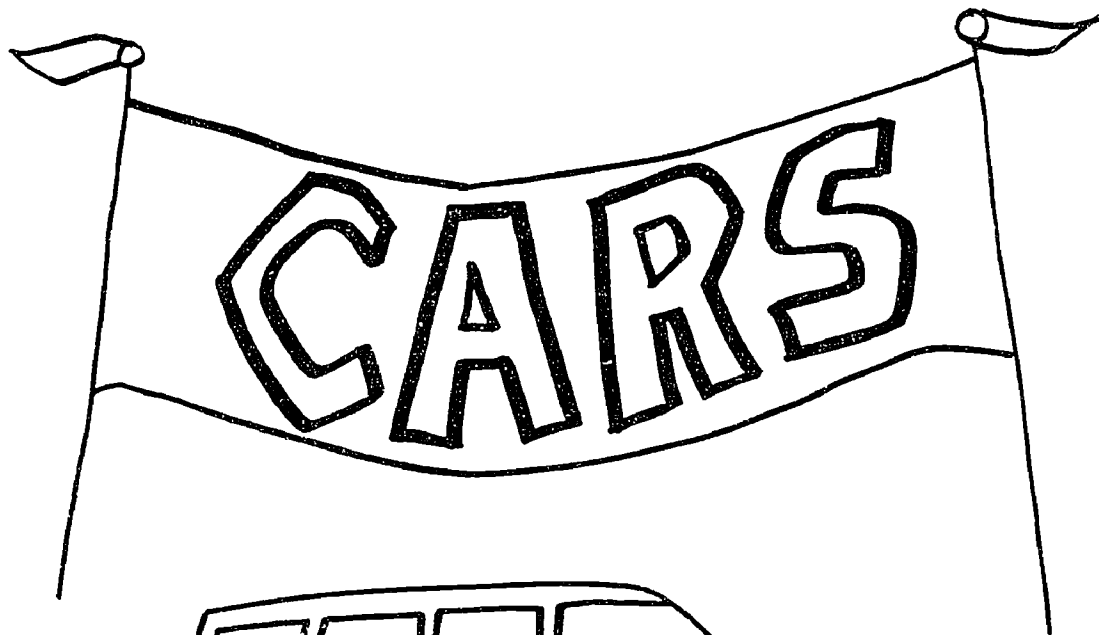
# DECIDING



# FOOD



# RECREATION





# SERVICES

doctors, lawyers,  
plumbers mechanics,





# CLOTHING

### LEARNING ACTIVITY 3: AVOIDING THE RIP-OFF

- Objectives:
- Given a situation in which there is a buyer and a seller and, presumably, a consumer transaction is going to take place, identify the roles and characteristics of each party to the transaction.
  - Given a situation in which the seller has a particular product, identify the parts (components) of decision-making process.
  - Given a business transaction situation, identify the "good" consumer practices which are revealed in the role play.

Group Size: Unlimited

Time Required: One hour

Materials: Two sets of dishes - or representative pieces from them; (One set, a very inexpensive variety, like Corelle; the other, bone china or something which resembles it.) table for counter, newsprint, easels, magic markers.

Physical Setting:

Process:

- I. The facilitator asks for volunteers or appoints two parties to the role play, buyer and seller. He/she briefs the "actors" individually on the roles they are to play. The seller is trying to make a sale of a very expensive set of dishes, bone china, and willing to use any and all persuasive arguments. The buyer, newly settled in his/her apartment in the community, needs dishes badly, both for personal everyday use and for having groups of friends over.
- II. The role play begins, each of the players overdoing their role: the seller persuasive and pushy, the buyer needy and undecided. The buyer, newly on a real salary, is motivated additionally by the desire to spend money as a status function.
- III. The role play ends before the buyer has made any decision, but immediately after the seller has offered the buyer a contract by means of which he/she could purchase the expensive dishes on the installment plan. The buyer decides to discuss the matter with a friend.

- IV. The facilitator divides the large group into smaller groups to discuss the role play. Staff persons or volunteers work with each small group to list on newsprint the "good" consumer practices in green, the "bad" consumer practices in red.
- V. Small group leaders engage the clients as fully as possible, asking for volunteers to write on the newsprint and for comments and discussion from the group.
- VI. Small group leaders review the decision-making process steps which are followed in the role play and which are represented symbolically in the enclosed diagrams for use by facilitators: (See Learning Activity 5)
  - 1) Problem
  - 2) Talk to friend
  - 3) Consider options
  - 4) Decide
  - 5) Evaluate decision

#### LEARNING ACTIVITY 4: SUPERMARKET ROLE PLAY

- Objectives:
- Given a supermarket shopping situation, demonstrate ability to make purchasing decisions.
  - In a situation where the individual is being helped with shopping by a friend, responds effectively to advice being given.

Group Size: Unlimited

Time Required: Forty-five minutes

Materials: Shopping cart or shopping basket; several sizes and brands of each of three or four products: loaf of bread, can of peaches, box of dish detergent, roll of paper towels.

#### Process:

- I. The facilitator assigns the roles: shopper and friend. The shopper is a somewhat "careless" consumer - attracted to packaging, choosing the "biggest" can of peaches, showing ignorance of "no frills" brands, very hungry, picking up spare items.
- II. The helping friend tries, in a somewhat humorous fashion, to give advice when the shopper makes mistakes.
- III. When the role play is over, the facilitator divides the larger group into three or four small discussion groups, assigning to them the task of listing what is "good" and "bad" consumer practice in the role play.

IV. In the small group, a list is made of "good" and "bad" consumer practices. When these are completed, the small group discussion leader guides the group in making a list of what to remember in doing supermarket shopping. If the group has trouble, a few are listed below:

SUPERMARKET SHOPPING TIPS

1. Never shop on an empty stomach.
2. Prepare a list in advance.
3. Make sure you have enough money.
4. Check the unit prices of items.

Learning Activity 5: DECISION-MAKING

Most consumers face the need to make decisions about consumption, non-consumption, and advocacy daily. Knowingly or unknowingly, we develop a model for making such decisions, a series of steps which we follow each time we make a consumer decision.

Many persons who are mentally retarded have not developed a format for making consumer decisions. By reason of having been institutionalized, they have had many decisions made for them by others. And even now, when they live independent lives in the community, retarded persons are learning to make sound consumer decisions. To "try out" a decision-making process in a group will benefit many such consumers. The following training activities are designed to assist retarded persons make consumer decisions by following a five step process:

- 1) Recognize that you have a problem regarding a consumption decision;
- 2) Talk to a friend about it;
- 3) Examine the options, seeking information about each of them;
- 4) Make a decision, choosing one of the options;
- 5) Evaluate the decision.

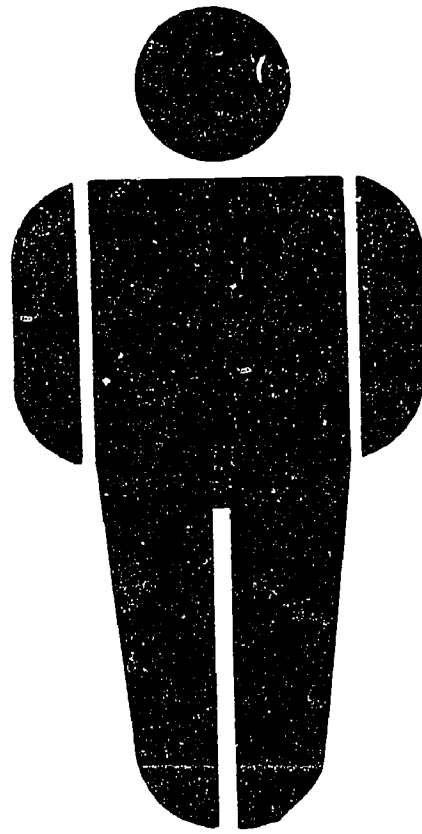
The visual representations of each of the steps is designed so that people who cannot read (and even people who can) will understand the message and be able to follow the steps in the decision-making process. Some of the features to be noted by trainers are: 1) the lined section, 2) the faces which represent feelings and 3) the symbol itself. The lined section represents the specific consumer problem. Note that it hovers over the head of the person making the decision until Step 5 in the process, when the consumer is "on top of" the problem. The small faces over the symbol represent visually the average person's feelings at this particular stage in the process. The symbols are really pictographs of the particular decision-making stage.

Accompanying the visual representations which the trainer can use with the group in a form enlarged from that in this book is a glove, to be used for review purposes with the group.

#### DECISION-MAKING Suggested Training Activities

1. Ask each group member to think about a recent, fairly large, consumer decision they have made, and then to pretend they have an opportunity to do it again. In turn, each person talks about the problem and goes through the steps again with the group.
2. Ask group members to think about a "consumer mistake" and to tell the story of making the decision. Then, have group members identify where the consumer "went wrong," which steps were omitted and which could have been done differently.
3. Place the five step posters at different places in the room and ask people to identify "DO'S" AND "DON'T'S" connected with each poster.
4. Role play a few buying situations - in which the consumer is at fault - a used car, a TV set, set of dishes. There are some ideas in other sections of this manual. Then ask participants in small groups to identify what the consumer did wrong.
5. Create some consumer decision-making situations where services are concerned. Have people think through the steps in this process-choosing a doctor, firing your lawyer, going to the SSI office.
6. Ask members of the group to role play situations in which advocacy is one of the options.

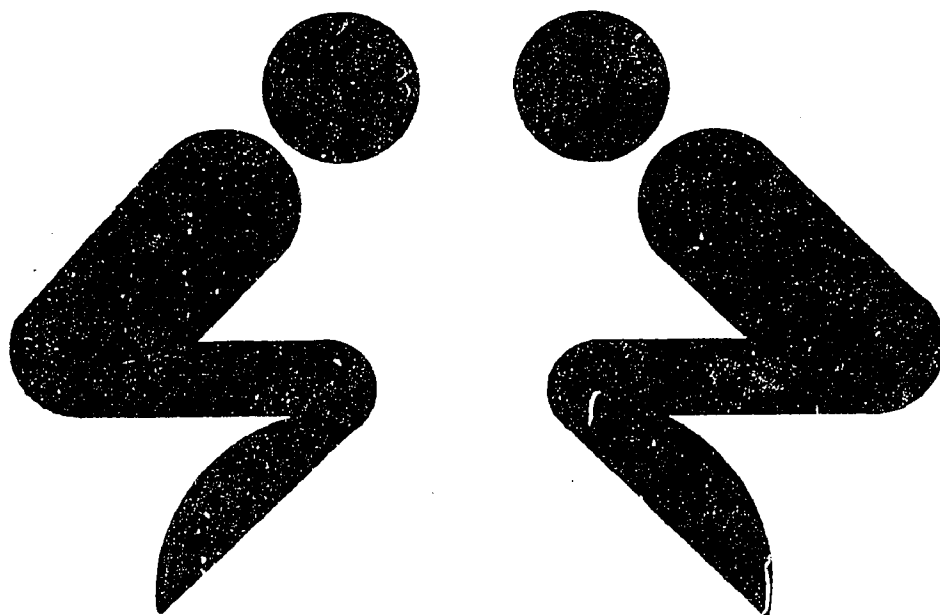
1.  problem



2.



talk

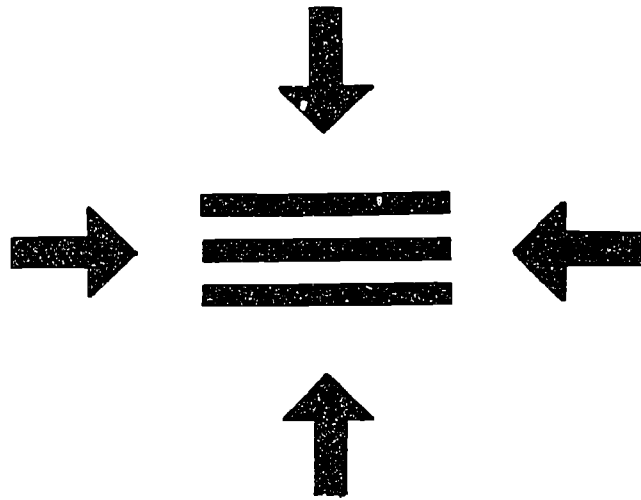


3.  options

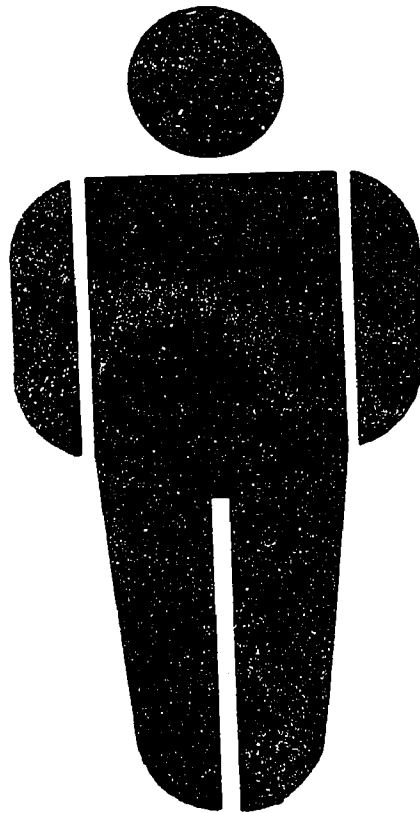




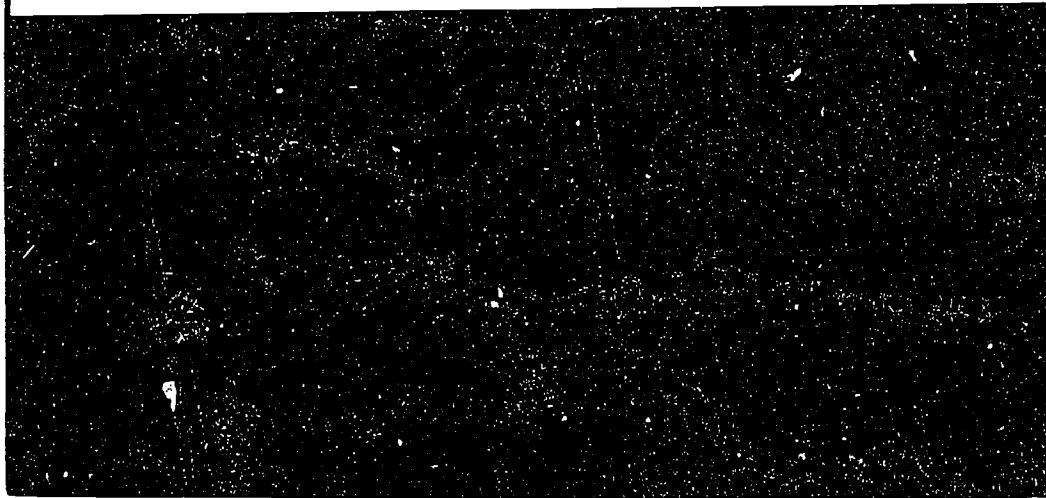
4.  choose

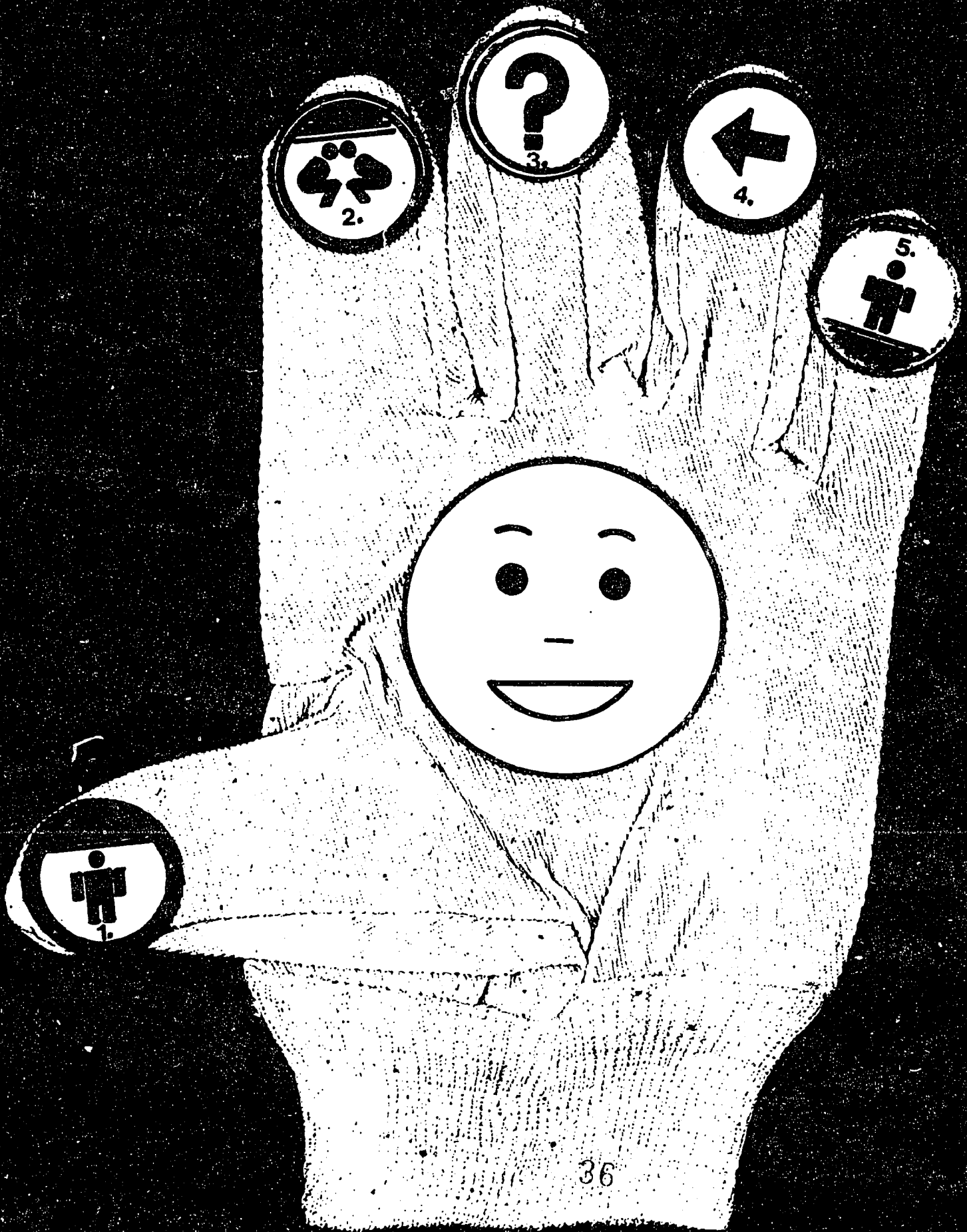


5.  evaluate



A series of horizontal lines, likely representing a table or a set of writing lines, located below the person icon. The lines are thin and closely spaced, forming a grid-like structure for data entry or notes.





36

LEARNING ACTIVITY 6: SAYING NO AS A CONSUMER

Objectives: • Given a situation in which assertiveness is called for, recognize that saying no is appropriate and learn to say no.

Group Size: Small groups, 6-10 persons

Time Required: One hour

Materials: Newsprint, magic markers

Physical Setting: Chairs in a circle.

Process:

- I. The facilitator explains to the group that there are many situations in which consumers must say no. Since this is somewhat difficult for some people, in this group people will have an opportunity to practice their skills. There will be four small plays in which people practice saying no.
- II. In turn, the facilitator introduces each of the following role plays, either assigning two group members to each of the parts or taking one part him/herself and asking a group member to play the other part.
- III. There are the Role Play Situations to be used with the small group:

1. Friends and the Theatre

John is trying to sell Mary a theatre ticket which he cannot use. The conversation, before the role play participants take it up, goes something like this:

John: Mary, I want you to buy this ticket to a play because I can't go. It cost \$5.50.

Mary: I don't have the money.

John: It's O.K., you can give it to me later.

Mary: I really can't afford it.

John: It shouldn't be wasted and I know you'll like the play.

Mary: \_\_\_\_\_

2. Beauty Shop

Joan has had her hair cut and is trying to tell the beautician how she feels about it. (This might be changed to a barber shop situation for men in the group.) The conversation starts like this:

JOAN: My hair looks nice, but I think the sides look better if they are trimmed more closely.

BEAUTICIAN: I think the cut looks just great as is.

JOAN: \_\_\_\_\_

3. Waiting on Line

Joe is new at shopping for groceries and while he is waiting on line and looking about, some people have gotten ahead of him. His exchange with the checkout person when one more person gets ahead of him on line follows:

CHECKOUT PERSON: Excuse me, my cousin just came here and she's in a big hurry, do you mind if she goes ahead of you?

JOE: Well, I've been waiting on the line for twenty minutes . . . .

CHECKOUT: This will only take a second. My cousin has milk and bread, that's all.

JOE: \_\_\_\_\_

4. Short Changed at the Grocery

Hilary goes to the corner grocery store, where she knows the owner very well. He gives her too little change when she buys shampoo. Here's how the conversation starts:

HILARY: I think you have not given me enough change. I gave you \$2.00 and the shampoo cost \$1.29. You only gave me 40 cents.

CHECKOUT PERSON: Did you give me \$2.00. I'm not sure...

HILARY: \_\_\_\_\_

- IV. When each group member has finished trying out assertive behavior for saying no in a role play situation, the facilitator will try to get feedback from the group on how well the person did. If the person did not do very well, the facilitator might ask if they would like to try again, acting on the feedback.
- V. When the role plays have been done, the facilitator asks the group to list other situations in which people have difficulty saying no, making a list of these on newsprint and discussing in a general way the problems with saying no.

UNIT TWO:

MEDICAL SERVICES

Persons who are mentally retarded confront those difficulties which we all face in consuming medical services: finding a good doctor, learning to communicate with her/him effectively, understanding the technical vocabulary, knowing how to provide health services for one's self (keeping healthy), knowing when to move on to another doctor, in effect, when to "fire" the first one. And for each of these challenges, they require a set of skills. In addition, they need some skills which are related to their transitional status (moving from institution to normal community life, if that is where they are) and to their particular disability, that of mental retardation.

The activities which follow focus on both kinds of skills, but it is the role of the facilitator to raise at appropriate points those issues which all consumers face and those special issues for persons with mental retardation. Some examples of the latter are:

- Is the doctor treating me kindly or does he/she seem uncomfortable with my disability?
- Does the doctor have the specialized knowledge to deal with my special health problems (if there are any)?
- At what point should I (the consumer) or my relative or advocate question the doctor about these issues?

LEARNING ACTIVITY 1: THE FIRST VISIT

- Objectives:
- Given the situation of a first meeting with the doctor, identifies key elements of an effective consumer/producer situation.
  - Given the opportunity to reflect on a role played first meeting, communicates his/her feelings about the meeting and about the doctor-patient relationship on a personal level.
  - Given the above, lists the necessary elements of staying healthy.

Group Size: Unlimited

Time Required: One hour

Materials: Newsprint, easels, magic markers

Process:

- I. The facilitator chooses three staff members or group members to do the role play; the "actors" are doctor, patient, patient's spouse.
- II. The facilitator briefs the actors. The doctor is brusque, prescribes pills without examining the patient, seems hurried, uncaring, unconcerned about the person in front of him/her. The patient goes for this first visit at the "wrong" time; patient is very ill, looks up doctor in phone book after consulting spouse, tries in vain to get doctor to examine him, to get information about fee. The spouse exhibits strong concern that the patient see a doctor, vague concern after the meeting that it has not been too effective.
- III. The role play over, the facilitator divides the large group into smaller ones, each with a facilitator.
- IV. Each of the small groups has a leader, either a staff person, a paraprofessional, a group member who has been trained. The leader invites individuals to the role of the patient. Leader repeats the doctor's behavior above, gives individuals a chance to "try out" new ways of dealing with the doctor. After each group member who volunteers does the role play, the leader facilitates a group discussion of what he worked.
- V. After five or six trials, the leader obtains from the group a list of "what to do" on the first meeting with a doctor. This list should include questions to ask: what is your fee, what kind of doctor are you, will you be available whenever I am sick, and things the doctor should do (and the patient should make sure that he/she does) such as: a complete medical history, a complete examination, conveying an attitude of interest in and concern for the patient.

Tips for the Facilitator:

Read the article in Appendix A, Doctor and Patient, as background material before you do this session.



LEARNING ACTIVITY 2: TRUSTING THE DOCTOR

- Objectives:
- Given a simulated blind walk, communicates reflections on the trust relationship between patient and doctor.
  - Given a group situation in which one is reflecting about personal health, identifies the most appropriate attitude: I am responsible for my own health.

Group Size: Unlimited

Time Required: One half hour

Materials: One easel, newsprint, magic marker.

- I. The facilitator "blind folds" three group members and instructs three staff persons to take them for a "blind walk" while the rest observe.
- II. After two or three minutes, the three group members are released from blind folds and seated at the front of the room. The facilitator asks each to describe to the group how it felt to walk blindfolded around the room.
- III. The facilitator then asks the three persons to return to the larger group and he/she asks the larger group: how is the blind walk like going to the doctor? The facilitator records on newsprint the similarities.
- IV. After about ten minutes, the facilitator raises the question, "What questions should we ask the doctor to make certain that we are in control of our own health, that we are not trusting the doctor too much?"
- V. The facilitator records, or gets a group member to record these questions. If the group seems unable to deal with this abstract level, the facilitator either raises the questions and invites group members to come to the front of the room and role play asking the questions OR draws the questions out from the group and gets them to role play.
- VI. The facilitator then asks group members to say what they have learned in doing the exercise.

LEARNING ACTIVITY 3: "OUR HEALTH IS OUR BUSINESS"

- Objectives:
- Given consideration of the doctor-patient relationship and keeping healthy, lists activities for each day that will keep a person healthy.
  - Given the knowledge that a person is responsible for his/her own health, develops personal health plan.

Group Size: Unlimited

Time Required: Forty-five minutes

Materials: Newsprint, magic marker, small pads, pencil

Process:

- I. The facilitator divides the large group into smaller groups, each consisting of three persons. The small groups are given the assignment of putting together a list of activities which will keep a person healthy. One person in the group should record these on the pad which the facilitator gives each person.
- II. After fifteen minutes, the facilitator stops the small group discussion and asks one group to report. The group member reads each item, and as he/she does, the other groups stand if they have the same activity on their list. The facilitator makes a general list.
- III. When the first list has been read, the facilitator asks groups to report items which have not been mentioned. The list is enlarged to include these.
- IV. Following these group activities, the facilitator asks each person to write down (if they can write) or think out their own PERSONAL HEALTH PLAN. (In other words, individuals write down in order those items which they consider most important to maintaining their own health.)

HINTS FOR THE FACILITATOR

Here are some of the activities listed at our training session for "staying healthy."

- = Stay out of the rain
- = Keep trim, lose weight
- = Eat right
- = Exercise, be careful
- = Brush your teeth
- = Rest well
- = Keep clean
- = Don't get overexposed in heat or cold
- = Keep your house at a healthy temperature.

Here are some of the "good questions" raised at the training sessions which we ran, questions to ask the doctor:

- What is in this prescription?
- What effects will it have?
- How much of it should I take?
- When should I take it?
- What kind of doctor are you?
- What is your fee?
- How much does an examination cost?
- What tests are done in the examinations?
- What are your hours?
- What hospital do you send patients to?
- Are you available in emergencies?

UNIT THREE:  
LEGAL SERVICES

Overview:

The person with developmental disabilities shares some of the same difficulties all of us encounter when we go about consuming legal services, among them: how to find a skilled and trustworthy lawyer, asserting one's self with the lawyer, talking about fees, complaining forcefully when services are inadequate. And then there are legal concerns which are more pressing for persons with developmental disabilities. These include finding a lawyer who is knowledgeable about the specific rights of the developmentally disabled/and who is comfortable with such persons; making use of the established advocacy system as an alternative to paying for legal services in some cases. They include knowing the special and general rights of people with mental retardation. The issues around guardianship are significant: whether a person is mentally incompetent and therefore needs a guardian, how to divest one's self of a guardian, what the advantages and disadvantages are to each individual.

Some training within the area of legal services seems to be needed concerning the concept of limited guardianship, a court-approved legal relationship which gives the guardian the duty and right to act on behalf of the ward in certain, defined aspects of his life. So, too, persons with problems of mental retardation need more specific training on their legal rights, those which need to be defined and fought for. Among such rights is one which professionals ought to keep in mind as they work with self-advocacy groups, the "right to fail." If retarded persons are offered as much autonomy as they are capable of, this will include the possibility of failing just as everyone else enjoys this possibility. The training sessions which follow represent an effort to assist people with mental handicaps to deal effectively with the law.

LEARNING ACTIVITY 1: FIRST MEETING WITH A LAWYER

- Objectives:
- Given a situation in which legal services are being provided, identifies consumer and producer roles.
  - Given the same situation, identifies appropriate questions for the consumer to ask.
  - Given the same situation, lists qualities to be sought in a lawyer.

Group Size: One large group unlimited.  
Small discussion groups of six to eight persons with discussion leaders.

Time Required: One and a half hours

Materials: Desk or table to simulate lawyer's office  
Newsprint  
Magic Markers  
Tape  
Role descriptions

Physical Setting: One large room  
Several smaller places, one for each group (one or if a large room, divided into several areas)

Process:

- I. The facilitator assigns the roles of lawyer, client, and client spouse, acquaints each with roles, explains to total group that this is to be a short play in which participants act out the first meeting with a lawyer. See role descriptions, next page.
- II. When the short play is over, the facilitator tells the group that they will be divided into small groups to evaluate what was good and bad about the performances of the consumer (the client) and the producer (the lawyer).
- III. In the small groups, the group leader will record good behavior - both consumer and producer - in green; bad behavior in red.
- IV. When these lists are completed, the group will generate a list of good questions to ask a lawyer at the first meeting.

HINTS FOR THE FACILITATOR

A few of the qualities which the Westfield group mentioned when asked to enumerate qualities of a good lawyer are:

Has a lot of cases  
Wins cases  
Experience  
Knows the laws for people like me  
Ethical, honest  
Sensitive, supportive  
Competent, does things right

The Westfield group mentioned the following list of times to see a lawyer:

To make a will  
Accident  
Suing someone  
Your rights are violated  
Guardianship  
Bankruptcy  
Arrested - criminal lawyer  
Housing

At the same training session, the following possible questions to ask a lawyer at the first meeting were raised:

- What are your fees?
- What experience have you had working with people like me?
- Do you often handle cases like mine?
- What are your office procedures and the way you normally deal with people?
- Do you have office hours at night and on the weekend?
- Do you deal with your cases alone, or with whom do you consult?

#### Role Descriptions

You can type or write these on 3" x 5" cards, to be handled to those playing each of the three roles.

- LAWYER            You are a very busy, somewhat gruff criminal lawyer. You specialize in defending people who have committed murder, but you do not tell everyone that right away. You have been in practice for a number of years, care about people but charge very high fees.
- CLIENT            You are a person with some retardation handicaps who is living in your own apartment. Your landlord has just drawn up a new lease, with a great deal of "small print," which you do not fully understand. You want some advice from a lawyer, before you sign it, and, in general, want to have a lawyer.
- CLIENT'S SPOUSE    You want to make certain that your spouse goes to an honest lawyer, who knows how to deal with cases for persons with developmental disabilities.

LEARNING ACTIVITY 2: WE HAVE RIGHTS, TOO!

- Objectives:
- Given a filmed presentation, lists common rights which all people have.
  - Considering those rights, identifies which rights are being denied.
  - Upon consideration of rights which are being denied, plans appropriate steps to begin obtaining such rights.

Group Size: Unlimited

Time Required: Find movie length. Add one half hour for discussion

Materials: Projector, screen, Film, "People First" Newsprint, magic markers, tape

Physical Setting: One large room

Process:

- I. The movie, "People First," which can be easily obtained from the People First organization in Oregon or your local library, is shown to the group, preceded by a brief introduction during which people are requested to view with the question, "What are my rights?" in mind.
- II. When the movie is over, the facilitator direct participants to form a triad (group of three) with two people near them. They are to list the rights which were mentioned in the film.
- III. The facilitator then asks volunteers to "write a right" on pieces of newsprint taped around the large room. A discussion with the large group is conducted to determine which rights are missing. These are then added to the newsprint.
- IV. Facilitator reads the rights around the room, asks the group to give examples. Participants are then asked to go and stand near the newsprint if they have experienced or are experiencing the denial of one of the rights.
- V. Participants bring their chairs near each piect of newsprint. A group leader helps them discuss the situation in which they were denied the right and together, each small group lists strategies for obtaining one's rights.
- VI. The facilitator reassembles the large group. They list strategies for getting their rights.

## HINTS FOR THE FACILITATOR

Some of the rights which clients might list and which cannot be taken away include:

- the right to choose where you live,
- the right to choose what to buy,
- the right to decide whether or not to get medical care,
- the right to choose whether or not to receive services for mental handicap,
- the right to marry,
- the right to complete freedom in the choice of friends,
- the right to make mistakes.

### LEARNING ACTIVITY 3: GETTING YOUR RIGHTS

This activity includes two short role plays, each intended as a catalyst for discussion on the subject of getting your rights.

- Objectives:
- Given a situation in which a person's rights are being denied, lists appropriate steps to be taken.
  - Given a list of appropriate steps to be taken, demonstrates necessary skills to obtain rights: assertiveness, representing one's case to a group, persistence.

Group Size: Unlimited

Time Required: One hour, forty-five minutes

Materials: Role description sheets.

#### Process:

- I. The facilitator assigns the roles for two short role plays and trains people to their roles by giving each person or group the Role Descriptions.
- II. The facilitator introduces, in turn, the two short role plays, "Whose Room Is It, Anyway?" and "The Case of the Hotel Lounge."



- III. "Whose Room Is It, Anyway?" involves a client who lives in a group residence and a resident manager. The client is reading a letter at his/her desk when the resident manager comes in, friendly at first, but then criticizes paintings on wall, reads client's mail. The resident manager explains why he/she has come in. The client is to have no more guests in his/her room.
- IV. "The Case of the Hotel Lounge" is a play concerning an evening during a conference of self-advocacy groups at a hotel. Ten persons who are mentally retarded come to the hotel cocktail lounge. The maitre d' refuses to let them in. He claims that there is no more room, but they can see five tables through a window.
- V. After the role plays, the group is divided in half, each to make lists answering three questions:
- = What rights do we have in this area?
  - = What rights are being violated?
  - = What should we do next?
- VI. In the two groups, participants, after the answers are placed on newsprint, practice role playing a good response. People take turns so that everyone has an opportunity to try out responses and to criticize individual try-outs.

HINTS FOR THE FACILITATOR:

1) "Whose Room Is It, Anyway?" Some of the following rights may be mentioned in connection with living. We have the right to:

- understand why we are living where we live,
- live as independently as possible,
- be made aware of our possible choices,
- choose where we want to live,
- have a chance to learn all we need to know, in order to live where we have chosen.

We have the right to choose:

- how we want to live,
- how to spend our time,
- with whom we want to live,
- our friends,
- the clothes we wear, the way we wear our hair, and other things related to the way we look,
- how to spend our own money,
- when, where and if we want to go to church.

We have the right to privacy:

- a place to keep our personal belongings
- a place to be alone
- a place to go to the bathroom
- a place to take a bath or shower alone

2) "The Case of the Hotel Lounge"

Some discussion points might include"

Why We Want To Get In:

1. We are consumers of the hotel's services.
2. We are paying customers.
3. We are people.
4. We have rights.
5. There is a law which protects us.

What We Want

To get into the Plaza Lounge

How To Get It

1. Confront the maitre d'
2. Then see others in the hotel management structure.
3. Get your arguments together.
4. Remember there is a law to protect you.
5. Get some other people to come along and help (ADVOCATES)
6. Do not back down.

ROLE DESCRIPTIONS

"Whose Room Is It, Anyway?"

- I. CLIENT - Nice, pleasant, forceful person who is friendly to resident manager, but progressively more speechless as he/she becomes more obtrusive.
- II. RESIDENT MANAGER - Nosy, very solicitous person who seems to derive a good deal of pleasure from bossing the clients around. Very snoopy in the client's room, passing judgement on each item.

"The Case of the Hotel Lounge"

- I. MAITRE D' - Snobby and sophisticated, very business-like, looking "down the nose" at the groups of persons with mental retardation. Determined to remain calm, and not to let them in the lounge.
- II. GROUP OF CLIENTS - Eager to have some fun in the hotel cocktail lounge during their weekend stay at the hotel for a conference for self-advocacy groups. Various group members speak up to express viewpoints: want to relax, watch stage show.

LEARNING ACTIVITY 4: COMPLAINING TO YOUR LAWYER

Objectives: ● Given a situation in which an individual has engaged a lawyer, identify when it is appropriate to complain.

- Given a situation in which an individual has engaged a lawyer, demonstrate necessary skills to complain effectively in order to obtain needed services.

Group Size: Unlimited

Time Required: One hour

Materials: Newsprint, magic markers

Process:

- I. The facilitator asks the large group to think about occasions when it would be appropriate to complain to a lawyer.
- II. The facilitator asks the group, helping them where necessary, to divide into triads, groups of three in which one member is the lawyer, the second, the client and the third the helper.
- III. The facilitator asks each group to establish a situation in which one ought to complain to the lawyer, then to act out that situation. The client complains to the lawyer, the helper comments on whether or not it was effective.

- IV. The facilitator circulates about, observing which clients are particularly effective, then chooses two or three to demonstrate the procedure for the whole group.

HINTS FOR THE FACILITATOR:

There are many situations in which it would be appropriate for a consumer to complain to a lawyer. Some of those which might arise in the group are: inappropriate fee charges,\* inability to be reached on the phone or in person, appearing to be prejudiced against the client for reasons linked to mental retardation, appearing to take the side of the client's adversary, not listening to the client or taking him/her seriously. Other situations, those specific to certain people, will undoubtedly arise in the course of group discussion.

---

\*In Appendix C, Consumer and Lawyers, appropriate legal fees and practices are discussed at length.

UNIT FOUR:  
CONSUMING EMPLOYMENT SERVICES

Overview:

When a mentally retarded person seeks a job, he or she must use services and contracts provided by agencies like the Department of Mental Health and/or its associated Job Development Program. Consumers of job-seeking services need a set of very precise skills to be able to assess their needs and strengths, to make them known to job counselors and to future employers as well. They need to know how to match their own skills with jobs in a realistic way and yet a way which does not abandon their highest career aspirations. And it is important for them to press for training which will equip them to perform the particular jobs they seek.

The training activities which follow touch on some of the above skills: assessing needs and strengths, matching these with job preferences, leaving what training is needed and communicating all of the above to one's job counselor. Together, these skills enable individuals to consume employment services adequately.

LEARNING ACTIVITY 1: WHAT DO I LIKE TO DO?  
WHAT AM I GOOD AT?

Objectives: • Given time for reflection, list job goals as well as needs and strengths.

Group Size: Unlimited

Time Size: Three-quarters of an hour

Materials: Blackboard chalk

Physical Setting: One large room

Process:

- I. The facilitator writes two questions on the black board or newsprint, "What do I like to do?" and "What am I good at?"

- II. The facilitator divides the large group into small groups of three. The actual groups might be drawn up ahead of time by the facilitator, taking care to make certain that each group contains at least one person who will understand the process enough to assist the other two group members.
- III. In the small groups, the facilitator asks the members to talk in turn about their answers to the first questions, talking about what they have done in different jobs during their lives and, then, sharing what they have liked and disliked about their various jobs.
- IV. After ten or fifteen minutes, the facilitator directs the groups to begin discussing the second question, "What am I good at?" Again, it may be useful to direct group members to talk about each of their past jobs in turn, saying which they were good at and which they were not. Then, the facilitator might direct group members to discuss what jobs they have never done which they think they would do well and why.

#### LEARNING ACTIVITY 2: DREAM A LITTLE

Objectives: ● Given an opportunity to reflect, describes most desired employment situation.

Group Size: Unlimited

Time Required: One-half hour

Materials: None

Physical Setting: Large Room

#### Process:

- I. The facilitator introduces this activity by explaining that the activity has two parts: one in which individuals will go off and think about career aspirations and dream about what they want to do, another in which they will share what they have learned about themselves.

- II. The facilitator directs participants to engage in some dreaming activities around the subject of jobs. Participants are to close their eyes and think about the following: If you were free and could do any kind of work you wanted, what would it be? Think about and decide what you would like to do. Now, imagine that you are in the situation or occupation you have named. Where are you? Describe the setting. What are you doing? What other people are there? What are they doing?
- III. The facilitator asks participants to share their dream with those sitting near them and then asks individuals to volunteer to share findings with the whole group.

### LEARNING ACTIVITY 3: LEARNING MY SCRIPT

Objective: • Given individual awareness of career job strengths, needs and wants, expresses such aspirations in a clear, well-organized "script" to be used with potential employers.

Group Size: Unlimited

Time Required: Depends on the quantity of videotape equipment available. Enough time for each participant to be videotaped saying her/his 3-5 minute script, and then to play back tapes with time to discuss each one.

Materials: Video camera, recording equipment, and monitor for playback. Ideally, one equipment set-up for each group of six-eight persons.

Physical Setting: One room for taping and discussion for each group of six to eight persons.

#### Process:

- I. The facilitator describes the overall design of the learning activity. In this activity, you are going to rehearse your part in a short, real life play. This is what the play is about. You have heard that there is a job at the Drew Corporation in an area in which you are very much interested. (Each person should think of their own). As part of the application process for the job, you must present yourself to Mrs. Joan Winooski. You have been told to cover three points:
- 1) What You Like To Do and Want To Do
  - 2) What You Are Best At
  - 3) Why You Want This Job.

- II. The facilitator then breaks the group into smaller groups, the size of which is based on the availability of video equipment. The task of each group is given it before breaking. Each person must prepare and then present their script on video tape. The preparation might include practicing the script before the whole group or it might mean that the group would divide into groups of two to rehearse scripts.
- III. Once the scripts have been videotaped, the group would view each person's script and make suggestions to them on improving it.

#### LEARNING ACTIVITY 4: FIELD TRIP TO A WORK SITE

Objective: • Given a particular focus, observes what is going on at a work site and talks about it.

Group Size: Unlimited

Time Required: Two hours

Materials: Attached questions and 3" x 5" cards

Physical Setting: One work site or several work sites, over time.

#### Process:

- I. The facilitator chooses one work site to visit, (or possibly two) and makes the necessary arrangements.
- II. Immediately before the visit, the facilitator asks the group to give examples of questions which may be raised as they tour the work site. Questions on the attached sheet may be used to fill out the number of questions asked by participants.
- III. The facilitator gives each person in the group one question. (Two persons may have the same question.) On a 3" x 5" card, the facilitator or group member writes the question or a key word from it as a reminder.



- IV. The group then tours the work site, each person looking for answers to his/her question. When the tour is over, each person shares with the group the answers which have been found.

Possible Work Site Questions

1. How many different jobs do you see at this site?
2. What are the people actually doing on their jobs?
3. What materials or tools are they using?
4. What are their working conditions? (standing, sitting, lighting, space, noise, safety, hazards, lounges, etc.)
5. Do the people seem to like what they are doing?
6. How do the employees seem to get along?
7. Which employees work alone and which work in teams?
8. Is there a difference in the jobs men and women hold?

APPENDIX A  
DOCTOR AND PATIENT\*

+Marvin S. Blesky, M.D. and Leonard Gross, How to Choose and Use Your Doctor (New York: Arbor House, 1975).

## CHOOSING A DOCTOR

### WHAT TO LOOK FOR

If you don't have a family doctor, or are dissatisfied with the one you have, there are ways of maximizing the chances of finding a competent doctor to meet your needs. Doctors are unevenly distributed in the United States, and many people have not choice of physicians. If you do have a choice, here's how to make a wise selection.

1. Choose a doctor when you are healthy, before you need one. This gives you both the time and the psychological ease to evaluate what you want and whether a particular doctor meets those criteria.
2. Choose a general practitioner or general internist (or pediatrician for small children) as a family doctor. Let that doctor recommend specialists as they are needed. Don't refer yourself to a surgeon or other specialists before selecting a family doctor. Specialists usually are not familiar with your total health picture and are often shortsighted about causes and effects outside their area of expertise.

But you should see a specialist, preferably one who is board-certified, whenever one is needed. They are more likely to have advanced, ongoing training than a general practitioner. In parts of the country where specialists are rare, family doctors often take on the functions of surgeons, gynecologists, and dermatologists. This saves patient travel and other expenses, but often results in second-rate medical care.

3. Compile a list of candidates. Ask for a recommendation from another health care professional whom you trust (such as a dentist or a family doctor from a previous neighborhood). Ask friends and relatives for recommendations, if you think that they have good judgment and would look for the same qualities in a doctor that you want. If neither of these sources exist, call the chief resident of a local hospital (a "teaching" one, if possible) or go to the outpatient department and ask for referrals. Only if you are armed with several choices will you be able to select the best doctor.
4. Check the doctor's credentials. Look into the doctor's educational background and, especially, hospital affiliation(s) before going further (the place where the doctor is affiliated is important, because that's where you'll go if you need hospitalization).

If there is more than one hospital in the area, you can compare them by using three criteria. First, the hospital should be accredited (by the Joint Commission on Accreditation of Hospitals). Second, it should be a "teaching" hospital - one with a formal program for training medical students or

resident doctors or other medical personnel. Third, a voluntary (non-profit) community or municipal hospital is usually preferable to a proprietary (profit-making) one.

There are directories available, in medical libraries and in many public libraries, which contain information on physicians. They include the reference book which doctors use, the American Medical Directory, put out every few years by the American Medical Association. Also, there are various state directories -- your local medical society should be able to tell you if one exists for your area. Sometimes there is also a consumer group's directory, offering more extensive information, particularly about fees.

It is a good idea to select a family physician who has received special training in family medicine or internal medicine and is either "board-certified" (i.e., has passed the qualifying requirements and the examination given by the specialty board) or "board-eligible" (has taken the training but not the examination).

5. Check on particular factors which are important to you, by telephone, before making an appointment. Here are some to consider:

Is the office in a convenient location?  
Are the office hours ones you can make?  
Does the doctor or staff speak another language (if someone in your family is more comfortable with one)?  
Does the doctor practice alone or in a group? (Group practice means that if your doctor is away, you can usually be seen by one of his or her colleagues)  
What is the Charge for a routine visit?

6. Recognize your personal feelings about what you want in a doctor. Communication is at the heart of a successful patient-doctor relationship, so it is essential that you feel comfortable with your doctor. Therefore, honor your own prejudices in this area. You may prefer a female or a male doctor or one whose race, religion, or background is similar to yours. The doctor's attitude toward such matters as drinking, birth control, and abortion may be important to you.

7. Visit the doctor. Only after a personal visit will you be able to evaluate whether a physician is the right one for you. A routine checkup is probably the best situation in which to evaluate a new doctor, although it doesn't show you how he or she reacts to more stressful situations. You need not view it as a waste of time and money if you go through an appointment and then decide not to go back to that doctor -- it's an investment which could save you untold grief later on. Look and listen carefully on your initial visit. Ask yourself these questions:

- a. Is the office reasonably neat, clean and well-running? Are appointments scheduled so that delays are minimal? Emergencies occur, of course, but be wary of a doctor who chronically keeps patients waiting hours or rushes them through.
- b. Did the doctor ask for a complete medical history (including information about family) and do a thorough exam? The history should include questions about your eating and drinking habits, exercising, sex life, and employment. These data enable the doctor to treat you as a whole person, rather than dealing in isolation with any symptoms that arise. Did he or she seem relaxed?
- c. Did the doctor take notes on what you related and what the physical examination revealed? If not, the information can't be used in later treatment by this doctor or by any subsequent ones.
- d. Was the doctor prevention-oriented? Did he or she discuss health care matters in general?

#### MEDICAL CHECK-UP - WHAT TO LOOK FOR

Many times doctors tend to do less than a complete physical exam and it is a good idea for a patient to know the things he or she should expect in a full check-up.

#### I. THE HISTORY

The first part of the examination is the history, which consists of any problems or complaints a patient has, previous illness or hospitalization, immunizations, medications, history of illness in the family, review of systems (a list of common symptoms which the patient may have, such as "smokers cough" or diarrhea), and a "social history" (occupation, travel, habits such as smoking and drinking). There are certain questions the doctor should ask. If he/she doesn't you should tell him or her about them. These include:

1. Does anyone in your family have diabetes, high blood pressure, tuberculosis or heart disease? If so, your risk of developing these diseases is increased, but early detection and treatment may prevent serious complication and allow you to lead a normal life.
2. What immunizations have you had? About half of the people in this country are not properly immunized to polio, diphtheria, or tetanus. Recently, an epidemic of diphtheria broke out in a Texas community.

3. What medications do you take, including non-prescription drugs? All drugs have more than one effect on the body and many drugs interact with each other.

4. What is your diet like? What foods do you eat at each meal? Dietary factors can be implicated in causing some of the most common diseases in the U.S. (like heart disease, diabetes, and many intestinal problems). Physicians often do not adequately stress the relationship between nutrition and disease. Your questions may encourage such discussion.

5. Do you ever get any chest pain, do you have any shortness of breath, do you smoke, do you urinate frequently, have you had any change in your bowel movements? When was your last period, do you have discharge from your vagina/penis? Is it hard to urinate? All of these questions may aid in the early diagnosis and treatment of a treatable condition.

## II. THE PHYSICAL EXAMINATION

The physical exam follows the history. This consists of what is called "vital signs" -- temperature, pulse and blood pressure. Blood pressure should be checked lying down and sitting up. The doctor should check your skin from stern to stern and feel for swollen lymph glands in your neck, armpits and groin. He/she should look in your eyes with an ophthalmoscope (like a miniature flashlight), and your ears with an otoscope (a similar instrument) as well as in your mouth, feel around your adam's apple for an enlarged thyroid gland. He/she should check the pulses in your neck, both arms and both legs. If you are an older person he/she should listen with a stethoscope to the pulses in your neck. He/she will examine your heart and lungs; in examining your heart the doctor should do it while you sit up and lie down. If you are a woman, he/she should palpate your breasts and inspect them from side to side while you with your shoulders back. The doctor will palpate your abdomen, feeling for tender spots and masses. Women should keep an ongoing record of their menstrual cycles (ask your obstetrician/gynecologist for a menstrual calendar, or make up your own), and women should have a pelvic exam with a pap smear done periodically; talk to your physician to decide how often. Men should be checked for hernias and lumps in the testicles, and it is generally advised that all men and women over the age of forty have a rectal exam once a year.

## III. LABORATORY TESTS

There are certain laboratory tests which should be done periodically. Again, talk with your physician to decide how often. At a private doctor's office these will cost extra money, but at clinics they may not. The ones that should be done are: complete blood count, urine-analysis, chest x-ray, TB skin test (PPD), and stool test for blood. People over the age of forty should have electrocardiograms. And every

few years, additional screening tests should be done: blood sugar, cholesterol and other fats in the blood (to reduce the risk of heart disease), uric acid (it goes up in gout and other conditions), tests of kidney function, tests for venereal disease.

If the doctor who examines you forgets to do part of the physical exam (like the rectal exam), don't feel relieved -- ask why not. Ask about the lab tests you should have done and if there's a way they can be done without the extra cost to you.

#### IV. MEDICATIONS

If the doctor prescribes medication for you, ask for the name of the medication in writing. The druggist should label the bottle with the name of the drug. Since many drugs cost more when prescribed by brand name rather than their generic name or non-brand name, ask the doctor to prescribe by the generic name of the drug. Ask him/her what the side effects of the drugs are, if they interact with other drugs or alcohol and how long they stay good on the shelf. If the doctor doesn't know the answers to some of these questions, you might request that he/she or another member of the office staff look them up before your leave. Questions like these are not rude or insulting -- they reflect your rights as a consumer of health care.

APPENDIX B

CONSUMERS AND LAWYERS\*

\*Excerpted and condensed from "How to Choose a Lawyer (and what to do then)." Consumer Reports, May 1977, p. 284



## HOW TO FIND A GOOD LAWYER

A little background about the legal profession may help you in selecting a lawyer. Most lawyers have completed four years of college, followed by three years of law school. They must then pass a state bar exam. Lawyers are trained as generalists, but most specialize as soon as they begin practicing law. (There are too many field of law for any one person to become proficient in more than a few.) Many lawyers consider themselves generalists, by which they mean they regularly handle the limited range of legal issues which typically confront individual or small businesses. Those lawyers, however, would be the wrong people to go to with major corporate legal problems or complex tax questions.

The legal profession is organized into large law firms, which usually handle the legal affairs of major corporations, and small firms or individual practitioners, who serve individuals and small businesses. Large firms have a greater breadth of experience and knowledge to tap, although their lawyers (partners, who own the firm, and associates, who work for it) specialize. Offices are often plusher and more impressive (with higher overhead meaning higher rates, of course), but the service is less personalized for all except the largest clients. Individual lawyers or small firms, on the other hand, do give more attention to individual cases and are better equipped to handle personal matters.

How can you best choose a lawyer? Here are some steps to take:

1. Analyze what you want -- a one time legal service (e.g., the drawing of a will); the establishment of a relationship with a lawyer whom you can turn to over the years; or the hiring of someone to handle your business' legal affairs. Try to determine (perhaps by talking with others) whether you have a particularly complicated problem or a relatively routine one.
2. Ask for referrals, but only from people who are able to judge well and who are likely to give you good advice. If you work for a business which has lawyers on staff they may be able to suggest someone. So may a bank officer you deal with or a stockbroker or a CPA. A friend or relative is a less reliable source, unless that person has had enough dealings with lawyers to have some sense of quality. If these sources fail, a university law school may work. Ask to speak to a professor who specializes in what you are interested in (family law, trusts and estates, real estate transactions, etc. -- look at the law school catalogue if you are unsure), and ask for referrals. Many professors are helpful in this respect, as are law school librarians (often also lawyers).

DON'T turn to strangers (such as ambulance drivers or court clerks) who may be receiving fees, payoffs, or additional business for making referrals, or to bar association "referral services." Local bar associations usually maintain lists of members who want more clients, but the associations rarely exercise any control over the quality or cost of those legal services, and make no attempt to refer the caller to a truly appropriate lawyer for his or her need.

DON'T choose a lawyer on the basis of an advertisement -- it is much safer to go on the personal recommendation of a trusted person. But do read the ads available in your community to get an idea of prevailing rates, and don't hesitate to mention your findings to the lawyer you select.

Consumer directories to lawyers are available in a few places -- they give such information as background, description of lawyer's practice, and fees charged. They can be helpful and give a good idea of comparative fees.

Until a couple of years ago lawyers (like doctors and other highly educated professionals) simply did not advertise. It wasn't "professional"; it was frowned upon if not totally forbidden by state bar associations; and, in many places, it was illegal. A landmark Supreme Court decision in 1977 changed that -- states may no longer forbid advertising by lawyers, although they can restrict the kinds of advertising allowed.

Despite much furor on the part of many of the older, more established (and richer) bar associations and lawyers, advertising has now become commonplace in newspapers in some parts of the country. The advertising is usually for the small firms, individual practitioners, or clinics, and focuses on routine legal services, often at relatively low fees. Sometimes the ads state a speciality or an ability to handle foreign-language-speaking clients. As might be expected, the rates of young, inexperienced lawyers are lower than those of older or large-firm lawyers.

3. Interview any seemingly good candidates -- on the phone for an initial screening and in person if the lawyer seems right. (Many lawyers will give an initial consultation at no charge.) Use the interview to learn:

- how much of the lawyer's time is spent handling the kind of work you need done (the more, the better, as a general rule);
- how the lawyer bills;
- how comfortable he or she is discussing these matters and explaining things in comprehensible language;
- whether you are comfortable with the office and the way you are treated there.

APPENDIX C

ORGANIZING A SELF-HELP GROUP

This appendix contains excerpts from the publication, How to Organize A Self-Help Group by Andy Humm. It is a publication of the New York City Self-Help Clearinghouse, Graduate School and University Center, City University of New York.

## Getting Started: Finding Each Other

Self-Help doesn't start until you find at least one other person with whom to share. This may be the most difficult step. You may want to be in a self-help group for those with your problem or condition, but you're timid about being the one who gets the ball rolling.

Look at it this way: As soon as you can find one other person you can start sharing the organizational burden. And just because you are the one to get the ball rolling doesn't mean you have to be the one solely responsible for keeping it rolling.

Sometimes the idea for a self-help group doesn't occur to a persons until he or she speaks with someone else who shares his or her concern. But if you do start out alone, you've got to do some thinking about where people like yourself can be found. The section in this manual on Publicity gives you some idea of how to reach out to others. For your exploratory meetings you need just a few people. They can be contacted by doing a little leg work.

People with health or addiction problems can contact hospitals or counseling centers for possible referrals. If possible, put up flyers in the waiting rooms of these places. Those interested in forming a neighborhood group have only to go door to door in their building or area. If you problem is in dealing with a particular institution (such as a welfare center) there's nothing wrong with asking around right there among the clients to see if there's interest in forming a group.

Your core group of interested persons has a few things to decide before the first meeting of the group. First, decide just what the group is (see section on Statement of Purpose). Most of your other early decisions will concern planning for the first general meeting. The rest of this manual offers information on meeting space, membership, how to learn about self-help, the question of involving a professional and much more. If you get an overview of the organizing process now, you can anticipate what you will have to take care of and when you will have to take care of it.

### How To Learn About Self-Help

One way is to read through this manual. We cover the organizing process as thoroughly as we can and give illustrations from groups meeting in the City. There are also other books which you can read, some of which are listed at the end of this manual.

But the best way to learn is by doing. Before you try your hand at forming your own self-help group, you can learn about how they work by visiting or joining an existing group, even if you think that it has little to do with your specific interests or concerns.

Go to an open meeting of Alcoholics Anonymous and listen to how people find a way to share their stories. If a group announces a program to which the public is invited (check neighborhood publications for these announcements), go and see how such an evening is conducted. Go with a checklist of things that you want to find out, such as:

- How are new people greeted when they come in?
- How is the meeting organized?
- What kinds of roles do group leaders play at meetings?
- How many people does the group rely upon to run their coffee hour or social?
- How does the set-up of the room enhance or hinder what they are trying to accomplish at a meeting?
- How did they find their space and how do they pay for it (if they do)?

Without being too nosy you can find out the answers to these and many other questions as they relate to a specific self-help group. Most important is the overview that you can get from observing a group in action. Contact with an effective group can be a confidence builder for you as you set about forming your own.



## The Statement of Purpose: What You're About

The first decision a group makes is determining its purpose. The purpose of AA is to help "drunks" stop drinking. The purpose of the National Association to Aid Fat Americans is "to increase the happiness and well-being of overweight people." The Colostomy Society exists to educate and rehabilitate people with colostomies and to sensitize those who deal with them. The purpose of the Coalition for Lesbian and Gay Rights is to work for gay rights and to build a coalition of gay and non-gay groups who believe in equal rights for gay people. The purpose of a group is the way it defines itself.

All your goals, short and long range, will be set in light of this purpose. Sometimes a group forms around an immediate need (such as tenants who want better elevator service) and then realize that by uniting to help each other they can meet a variety of needs under a general purpose (such as neighborhood improvement).

When you first seek out a group of people with your condition or problem you need not have predetermined the purpose of the group which you have in mind. In fact, deciding the purpose makes a good topic for discussion at the exploratory meetings of the people whom you gather together.

Ask yourselves, "Why are we here? What do we hope to accomplish? For whom?" When you then advertise the first general meeting of the group you can say that it is more than just a group for people who are addicted to coffee, for example, but for those who want to fight an addiction to coffee through self-help.

Not all disagreements that arise in your group will be solved by simply invoking the statement of purpose, but it can serve as a starting point for your discussions about what is and what is not appropriate for your group to do.

## Membership

Who can join the group and who cannot? Your policy in this area does not have to be written in concrete, but it's good to give it some serious thought before you start soliciting members.

-- In a health group, for instance, will it be for people with the health problem or their families and friends as well?

-- Will those at terminal stages of a disease be excluded from a group for people who are recovering from it?

-- What geographic limitations will be put on membership?

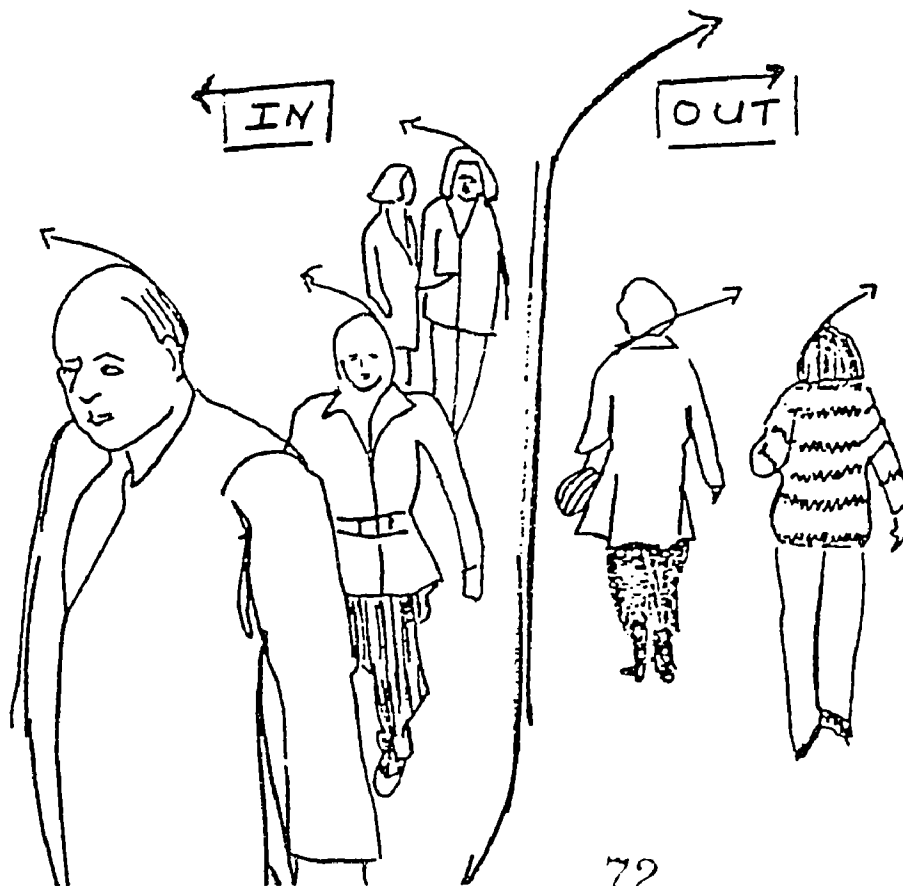
-- Is there a membership fee and can it easily be waived for those unable to pay?

-- What must someone do to become a member, for example, must they attend a certain number of meetings?

Many of these questions can be answered in light of your group's statement of purpose. The main requirement for membership in most self-help groups is an endorsement of the organization's purpose. In AA, for example, they only require that you want to stop drinking. If a group excludes certain people, it should have a clearly stated policy about membership to avoid charges of arbitrariness or unfairness.

Remember that self-help groups are somewhat informal. Don't make it difficult for people to join. What's more, involvement for many people is temporary. They get what they want out of the group and then they leave. Unless the group sees lifetime membership as a necessity, there should be easy ways for members to leave a group without guilt. In some groups, such as the Compassionate Friends (for bereaved parents), members recove sufficiently from their bereavement after a time with the group and then drop out. However, they might return for occasional reinforcement at a time of stress such as on the dead child's birthday when the parent is most reminded of his or her loss.

To restate all this as an organizing principle: Self-help groups should provide easy access and exit for members.



## Organizational Structure: Keep It Simple

Don't take on more structure than you need. A small discussion group does not need a board of directors, but it may need a member to act as facilitator of the discussion. If you take on formal officers and elected representatives let it be because you need them to run an effective group. Base your decisions about structure on what will best serve your group's purpose.

If you are mainly involved in a discussion-type group then you can set aside a little time before or after the discussion to take care of business matters. Some structure is needed to hold people in the group and to give them a sense of belonging. This means that you should at least define what it is to be a member of the group (see section on Membership).

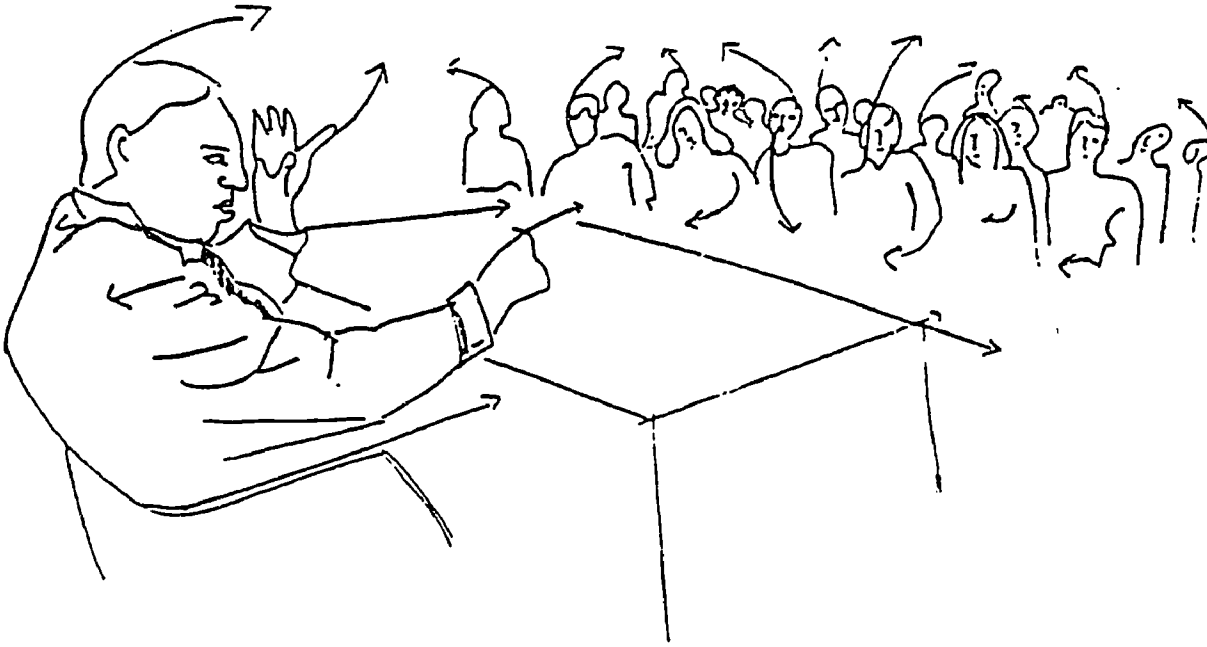
Leaders, people who take and share responsibility well, will emerge even if there are no formal leadership positions in the group. If all goes well in a small group, such people help the group mature and expand without assuming titles. But if a person starts to dominate the group in a negative way, it may be time to institute more formal leadership roles so that the group can identify its leaders instead of being coerced by an aggressive one.

### Identifying Leaders

If you're reading this manual you're probably one of them -- one of the "energy people" who get the group started or keep it running. These people don't have to be charismatic or have great speaking ability; they have to have the will and the determination to make the group work. If these people don't see ways for themselves to give to the group, they may drop out. If your group is just starting or growing, they may drop out. If your group is just starting or growing, there are always tasks that need to be accomplished. Put your energy people in charge of specific tasks. Besides getting important work done, it increases the meaningfulness of their involvement.



## First Meeting



"If you plan to have a speaker, then the discussion could center on what he or she presents to the group."

When you're ready for the first general meeting of your group, be ready with more than just a time and a place. (In setting a time, however, be conscious of other community meetings taking place at the same time.)

First impressions mean a great deal, so have someone be responsible for greeting people as they come in. The biggest task at this meeting is to get the group going right away. Self-help has to start happening from day one or you may lose people. Plan some kind of activity -- perhaps a discussion -- in which everyone can participate actively. If you plan to have a speaker address the group, then the discussion could center on what is presented. Try and get people to speak in terms of their own experiences rather than in abstract ideas (see section on Group Discussion).

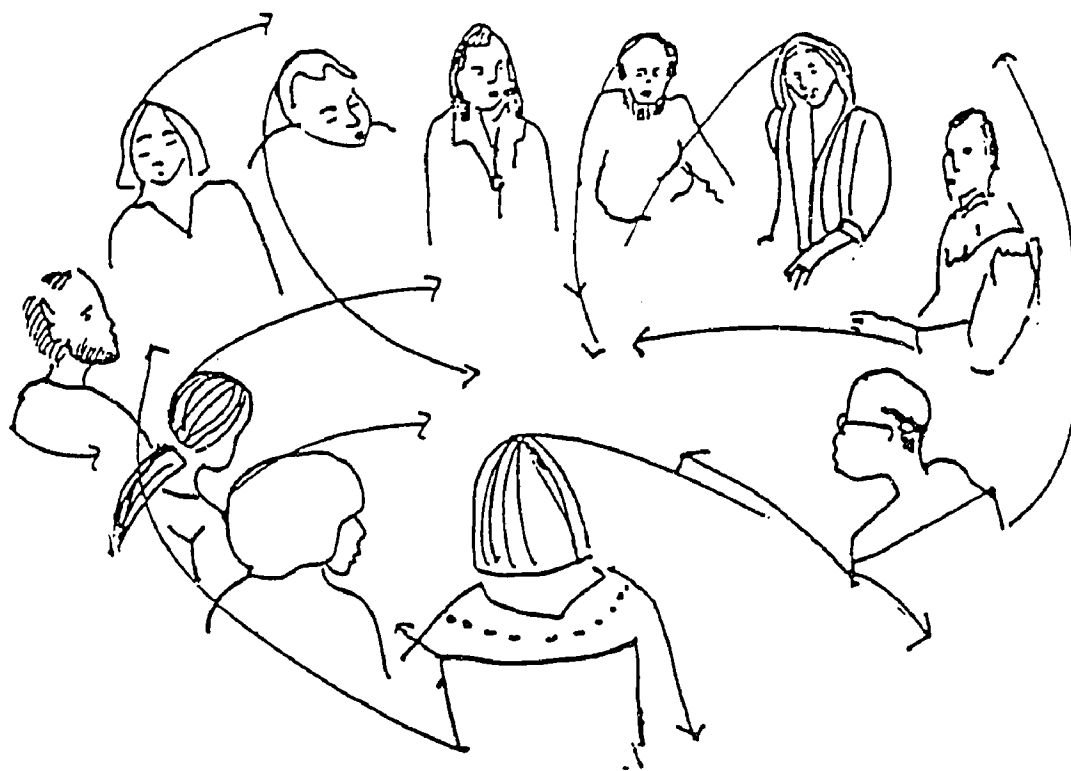
Have several short-term projects planned in which people can involve themselves. There are many tasks for a group which is just starting and these tasks need the involvement of a lot of people to get them done. Some examples are:

1. planning and leading discussions
2. planning programs for meetings (lining up speakers)
3. taking care of social hours (making coffee, cleaning up)
4. preparing publicity (writing press releases, ads, flyers)
5. disseminating publicity (i.e., putting up flyers, placing ads, etc.)

6. working on the newsletter (writers, typists, artists, etc.)
7. handling money for the group
8. writing correspondence for the group
9. acting as one of several phone contacts for the group

Have a list of appropriate projects ready so that new people can plug in to them. Give them an opportunity to choose a specific project or an area of interest themselves. Don't shame people into accepting responsibility.

#### Group Discussion: The Guts of Self-Help



"By sharing your story with others...your problem becomes less fearsome. When you listen to others you start to feel less alone."

Those in self-help groups benefit from membership in a variety of ways: by socializing with others, by volunteering time to the group, by serving on the board or on committees, by attending its programs, etc. But the core of self-help remains in group discussions, i.e., telling your story and listening to the stories of others.

By sharing your story with others, even if they're strangers, your problems become less fearsome. When you listen to others, you start to feel less alone. You find out that others have gone through the same problems, felt the same pain and, most heartening of all, some have worked out solutions and are at peace with themselves once more.

Sharing in a self-help group can take a variety of forms such as consciousness raising groups, guided discussion groups, rap groups and professionally led groups. The first three are pure self-help, participated in only by members. The last, a more traditional form of group, may have self-help elements.

Decisions have to be made about the size of the group(s), the topics which will be discussed (and which won't be), whether or not someone will act as facilitator, and the nature of the sharing. In most self-help groups, members feel free to share their stories without fear of being criticized or psychoanalyzed. The discussion time is one for formulating feelings and experiences and sharing them and for giving others a chance to do the same.

What follows are some factors to consider in planning your discussion groups. Pick and choose which will serve your needs best:

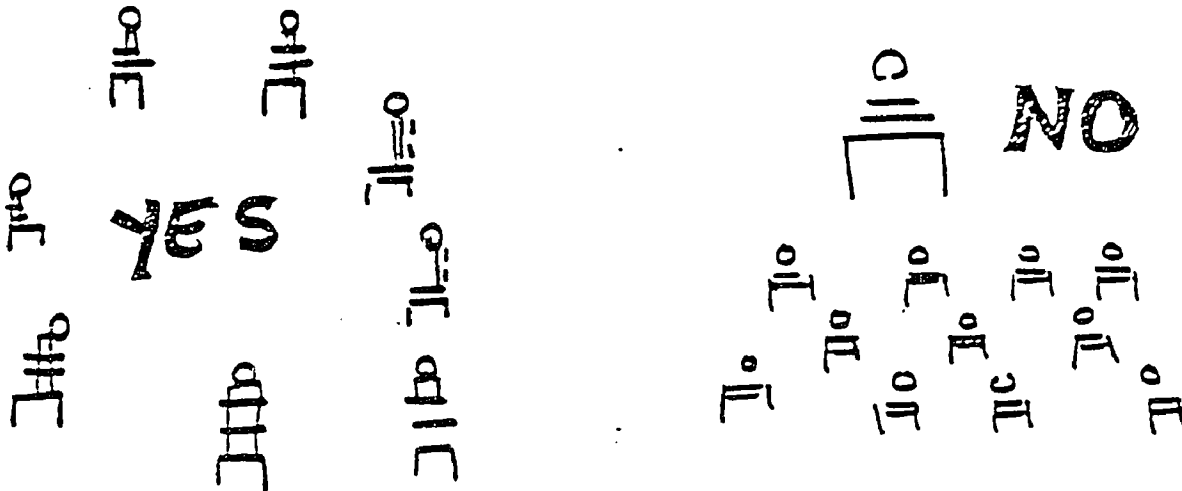
1. Size of group: Group discussions can be any size from two people upwards, but if everyone is to participate equally and to get the full benefit from the discussion, then an ideal size is 6 to 10 people. If your group has more people than this (and most do) don't overlook the chance to break down into small groups for discussion purposes. If the larger group has just listened to a speaker, they can then break down into small discussion groups afterwards. This gives everyone a chance to express themselves on a topic rather than letting a few aggressive members dominate a question and answer session.
2. Role of the facilitator: The person who runs the discussion can be and usually is a participant in the talk as well. His or her function is to keep things moving and on the topic. As facilitator, be aware of people who try to dominate discussions. Learn how to handle them effectively. Encourage, but do not pressure, quiet members to contribute.
3. Confidentiality: Assure members that whatever is said in the group stays there. This is more important in some groups than in others. It may depend largely on the sensitivity of the issue with which your group deals.
4. Disturbances Take care of anything immediate that's bothering you. If immediate disturbances (someone smoking, a dog barking) aren't taken care of they can hurt everyone's full participation in the discussion.

5. Speak in the first person: Avoid generalities about "one does this or that." Stick to your own experience.

6. Seating: Sit in a circle so that every member can see every other member. Avoid traditional "classroom" style set ups if possible.

7. What to share: Share as much or as little as you want.

8. Questions: Other members may ask questions for clarification of what is being said, but should not ask "leading questions" which require analytical responses or which imply an analysis in themselves.



"Sit in a circle so that every member can see every other member.

Avoid traditional 'classroom' style set ups if possible."

## Newsletters

A newsletter can be the tie that binds a self-help group together. Even if it's just a one page xeroxed bulletin, it can create a sense of belonging in members. It's also a very practical way of keeping everyone abreast of group activities.

A calendar of events, then, is the least a newsletter should feature. As time goes on, articles can be added such as a report on upcoming programs. Personal stories of members can be shared in the newsletter -- a consideration of members who can't make the regular meetings of the group. Opinion articles might come next on issues concerning the group. If the organization has board meetings, the proceedings of the meetings might be briefly noted as well.

Having printed material on your group such as a newsletter or a brochure is very important. It gives you something to hand newcomers at meetings and helps them to take your group more seriously.

As regards the physical production of the newsletter, most groups don't bother with typesetting it. It can be simply typed up and then run off at the local copy shop. Take the time to shop around for a place that will do your newsletter quickly, conveniently and least expensively.

Make more copies of the newsletter than you have members. The extras can be used for outreach. Be sure to keep in touch with groups that have interests similar to yours by adding them to your mailing list and supplying them with your newsletter. It should also go to those members of the press who can do the most with it, such as community newspapers that publish a listing of local events that are coming up.

## Social Action



"When all regular channels of appeal fail, a demonstration...  
is a possibility."

A Social Action Committee of a self-help group can work on the external problems affecting the group. A group of cancer patients, working through self-help on the problems of living with their illness, could, through a Social Action Committee, strike out against such external threats as insurance and job discrimination, health care costs and the lack of responsiveness in the medical profession to their emotional needs when being treated. The Committee, in the cancer group example, might also want to take on such larger issues as fighting carcinogenic foods, the nuclear problem, and unsafe cancer-causing work conditions. These larger problems are best tackled through a coalition of groups. A small self-help group can, however, take on the immediate problems which face its members.

## Social Action (cont.)

Some groups actually get started when people get together to fight a common foe and then discover the value in sharing their own experiences with each other. It strengthens those involved with a cause to take the time to learn about the people that they're fighting alongside.

Coalition building is advisable, especially in working for social change in a place as big as New York. While the way one cancer group runs its meetings may be quite different from the one across town, the two groups may be able to agree on some common goals, which they could work together to achieve.

In New York there are coalitions of women's groups, lesbian and gay organizations, black groups and others. There's no reason why it can't happen with other types of self-help groups. Consult the directory of the New York City Self-Help Clearinghouse to learn of other groups dealing with your concerns.

Social Action Committees of self-help groups might consider a variety of projects:

1. Media Watch How are people with your problem or condition depicted on TV, radio, and in newspaper stories? Assign members to keep an eye on a certain station, paper or magazine. Write letters to your local station demanding more sensitivity toward your group. Ask for meetings with station representatives. Write letters to the editors in print media when they publish articles that are of concern to you. Be sure to praise as well as to criticize when appropriate.
2. Speakers Bureau: People from your group who can speak intelligently about your issue can be enlisted for such a project. The problem, if your cause is not well-known, is getting bookings for your speakers. Requests may come in after a successful publicity effort. Mention your speakers bureau in your literature. Promote it to those who need to hear your message most. Those who do the actual speaking for the group stand to gain also. Advocating a position is a good way to become convinced of it.
2. Demonstrations: When all regular channels of appeal fail, a demonstration vs. those whom you have a grievance against is a possibility. Usually, only those members who have solved some of their own problems in the group will consider such an option. However, it can be a constructive way to work off anger against the institutions which have oppressed you as well as a chance to grab some publicity.

of course, meetings with those with whom you have a problem should be sought first. You don't need a permit if you're marching in the streets or using sound equipment. For your own protection, contact the local police precinct before the action, but don't let them talk you out of having it.

4. Legislative Watch: Most self-help groups don't have lobbyists, paid or unpaid. But you can keep on top of local, state and federal legislation affecting your group by maintaining a close relationship with your representatives. They are there to serve you and your interests. Let them know your views often.



# Eleven Points To Effective Lobbying

- 1.** Make an appointment to visit your legislator.
- 2.** Identify yourself and/or the organization you represent.
- 3.** Make sure you inform the legislator that you are a registered voter in his/her district.
- 4.** Be prepared. Deal in facts. Leave supporting documents.
- 5.** Get your point across in the fewest possible words.
- 6.** Don't argue, name call, or threaten.
- 7.** Give the legislator a chance to express his/her point of view and be a good listener.
- 8.** Don't be afraid to admit ignorance on special points. Say you will find the answer and report back.
- 9.** Even if turned down, leave on a friendly note since you may want to join forces on another issue or get back later on the original issue in question.
- 10.** Give special recognition to the legislators who are known to be on your side, and ask them for advice and help in reaching other legislators.
- 11.** If lobbying with a group, one person should speak on behalf of the group.

## Fund Raising

Expenses for a self-help group can vary from needing money for the coffee after meetings to elaborate budgets for office space, staff and advertising. Thus, fundraising can vary from passing the hat to staging star-studded benefits.

Many groups can survive on an annual dues basis. If your group does institute membership fees, be sure to allow for the fact that some people won't be able to afford to pay. Offer these people reduced rate or complimentary memberships.

If you rent your meeting space, you might take up a collection at meetings to cover those expenses.

Fundraising among members can be accomplished through direct appeals, through selling things at meetings or through social activities such as dances and dinners. One group has the motto, "Parties are for fun, not funds," but use your own judgement based on your needs.

To raise money from the community at large, there are a number of events you can consider. Whatever type you choose, the key to its success will be reaching people sympathetic to your cause.

Have you thought of these fund raising ideas?

Block Party

Bazaar

Street Fair

Boat Ride

Food Festival

Raffle

Bingo

Theater Benefit

Ski Trip

Dance

Walking Tour

Solicitation letters to local merchants, banks and groups

## Professionals and Self-Help

Professionals, such as doctors and social workers, are likely people to start self-help groups because they come into contact with many needy people who could be helped by being with each other. About one-third of all self-help groups involve a professional. In some cases, the professional initiates the group and/or acts as a facilitator. In others, the members use a professional as a consultant. Groups such as Alcoholics Anonymous do not involve professionals directly, but rely upon them for many of the referrals that they get. Most groups exclude professional helpers from playing that role in the group, but they're open to them as occasional speakers. Your group will decide its relationship to a professional based on its need.

There can be some problems. Some professionals resist the self-help movement, perhaps seeing it as a threat to their business or simply as amateur (and, to their minds, second rate) therapy. Furthermore, when a group does engage a professional, there is the danger that he or she will co-opt the group. If this happens, the basic sharing nature of the group can be lost and with it the group's effectiveness.

Being aware of these possible pitfalls before you get started is a step towards avoiding them.

Even when a professional is the group's initiator, the decision about his or her role belongs to the group of self-helpers. Parents Anonymous, the group for child abusers, requires that its chapters have a mental health professional as a sponsor and that this person have "a profound respect for the self-help concept". In PA, however, the professional is more of a consultant than a leader.

Recovery, Inc., the group for ex-mental patients, was founded by a professional. To prevent domination by professionals, the group has a rule that no professional may be a group leader or hold office.

Thus, the professional is advised to take a very self-effacing role, doing what he or she can to advance the organization without harming the nature of the help being offered, i.e., self-help. The professional must ultimately be willing and ready to withdraw from the group he or she has established once the group can make it on its own.



"Professionals, such as doctors and social workers, are likely people to start self-help groups."

## Some Parting Thoughts on the Self-Help Movement

In working in self-help, as in anything, it's always valuable to look at the larger picture from time to time. These groups don't exist in a vacuum, but in a society which affects them very much.

Some critics of the self-help movement, such as Ruth and Victor Sidel, say that all groups must have as a part of their agenda the redistribution of wealth and power in society. "Don't settle for adjustment to an unjust society," they say, "you must struggle to modify that society." These critics also say that small groups rise and fall because they are without an ideological base and that without some common purpose to keep them going the group cannot be sustained by isolated special interest and special purpose.

Indeed, most people join self-help groups to deal with an immediate problem or concern which they are trying to live with from day to day. It may be that these people can only deal with larger societal problems when they've gotten their local concerns together through self-help.

A leader of a gay group was asked if he didn't feel that there were more important problems in the world to focus on than adjustment to homosexuality. He said that he thought there were, but that until gay people become comfortable with their orientation, they're not going to be able to deal with these larger problems in society. The problems of single parenthood, asthma, or the fear of flying, to name a few, may not seem so great when compared to extreme conditions of poverty, hunger and disease, but these more personal concerns can consume an individual to distraction from all others unless they are dealt with first.

The founder of Epilepsy Self-Help stresses that he sees self-help as a "transitional mechanism," something a person ideally moves through, not like AA where one maintains membership indefinitely. He believes groups should strike a balance between a rational component, an emotional component and an action component, saying that "successful projects give good feelings." Members should get from a position where they say, "I can communicate with those in the group," to one where they can say, "I can communicate with those outside". Groups should not be a place where people can find a "rest."

SOME CONDITIONS FOR EFFECTIVE SELF-HELP GROUPS

The following are some factors which seem to be related to ongoing effective mutual aid groups:

- (1) Groups that are constantly expanding, thus allowing for the older members to model and play the helper role;
- (2) Groups that develop many leaders and helpers with considerable shared leadership;
- (3) Groups that provide many pay-offs or extra gains -- such as media attention, etc.;
- (4) Groups that have developed strong ideologies, missions, whether a social ideology or the AA type;
- (5) Groups that have resources -- meeting place, newsletter, funds;
- (6) Groups that have developed strong group traditions;
- (7) Groups that have developed varied activities;
- (8) Groups that have developed a strong experiential knowledge base.

## BACKGROUND RESOURCES

- Beyer, Barry K. and Anthony A. Penna. Concepts in the Social Studies. Washington, D.C.: National Council for the Social Studies, 1972.
- Bliss, Tamara, et al. The Doing Book: An Experiential Approach to Consumer Education.
- Bruner, Jerome S. Toward A Theory of Instruction. Cambridge, Mass.: The Belknap Press of Howard University Press, 1978.
- Consumer Education in the Human Services. Ed. by Alan Gartner, Colin Greer, and Frank Riessman. New York: Pergamon Press, 1979.
- Creland, Charles Carr. Mental Retardation: A Developmental Approach. Englewood Cliffs: Prentice-Hall, 1978.
- Educational Service, Inc. Choice: Suggested Activities to Motivate the Teaching of Economics. 1975.
- Feldhusen, John F. and Donald J. Freffinger. Creative Thinking and Problem Solving in Gifted Education. Dubuque: Kendall/Hunt Publishing Company, 1980.
- Freire, Paulo. Pedagogy of the Oppressed. New York: Herder and Herder, 1970.
- Friedman, Paul R. The Rights of Mentally Retarded Persons. New York: Avon/American Civil Liberties Union, 1976.
- Gartner, Alan and Riessman, Frank. Self-Help in the Human Services. San Francisco: Jossey Bass Publishers, 1977.
- Joyce, Bruce. Models of Teaching. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1972.
- Mager, Robert F. Goal Analysis. Belmont, CA: Fearon Publishers, 1972.
- Newman, Stephen and Nancy Kramer. Getting What You Deserve: A Handbook for the Assertive Consumer. New York: Doubleday and Company, 1979.
- Popham, W. James. Establishing Instructional Goals. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1970.
- Simon, Sidney; Leland W. Howe; Howard Kirschenbaum. Values Classification. New York: A & W Visual Library, 1978.
- Sanders, Norris M. Classroom Questions: What Kinds? New York: Harper and Row, 1966.
- Scharlatt, Elisabeth Lohman. How To Get Things Done in New York: E.P. Dutton & Co., Inc., 1973.