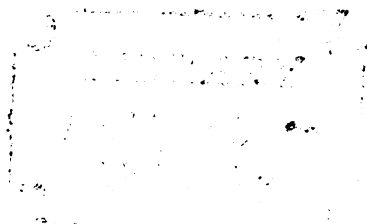This is to certify that the

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THE DEVELOPMENT, IMPLEMENTATION AND FIELD-
TESTING OF INSTRUCTIONAL METERIALS TO TRAIN
SERVICE PROVIDERS AS ADVISORS TO SELF-ADVOCACY
GROUPS OF DEVELOPMENTALLY DISABLED ADULTS

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Jhon Sidney Rowlson

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of the requirements for

<u>Doctoral</u> degree in <u>Ed. Adm.</u> and Curr.

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THE DEVELOPMENT, IMPLEMENTATION AND FIELD-TESTING OF
INSTRUCTIONAL MATERIALS TO TRAIN SERVICE PROVIDERS
AS ADVISORS TO SELF-ADVOCACY GROUPS OF
DEVELOPMENTALLY DISABLED ADULTS

By

John Sidney Rowlson

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ABSTRACT

THE DEVELOPMENT, IMPLEMENTATION AND FIELD-TESTING OF
INSTRUCTIONAL MATERIALS TO TRAIN SERVICE PROVIDERS
AS ADVISORS TO SELF-ADVOCACY GROUPS OF
DEVELOPMENTALLY DISABLED ADULTS

By

John Sidney Rowlson

The developmentally disabled presently lack resources to effectively advocate for themselves. Service providers are those who work directly with the disabled and are in a position to advise the mentally retarded as self-advocates. The self-advocacy group provides a forum for the learning and development of self-advocacy skills. Self-determination is a philosophical and psychological referent of the principle of normalization that provided an ideological framework for this project.

A review of the literature demonstrates the need for instructional materials designed to train service providers as advisors.

Three major tasks were identified: Product Development, Product Implementation and Product Evaluation. Product Development included the identification of content and organization of content into a Module Package. Product Implementation included the selection and training of service providers as advisors to self-advocates. Product

Evaluation included the development of an evaluation plan, development of instrumentation, data collection and data review.

Expert opinion was sought to identify the content. A National Survey of self-advocacy advisors was conducted. The results of the survey were used in a workshop of advocates and self-advocates to refine the content. A module format was chosen for organizing the instructional materials. Six modules were developed, with each module organized around a central theme. The six modules comprised the module package.

Fifteen service providers from two agencies that serve the needs of the mentally retarded in the Lansing, Michigan, area participated in the field-testing of the Module Package. The Module Package was implemented in six presentation sessions. Each presentation session corresponded to a module.

A number of data sources were designed to field-test the instructional materials. A Pre-test/Post-test was developed to measure content knowledge. Each module contained an Assessment Sheet, an Impact Questionnaire or Skill Development Checklist and a Module Evaluation Sheet. Other data sources included: anecdotal records, a participant observer, with each presentation session tape-recorded. A Follow-up Interview was conducted with each trainee.

A Process Review was conducted with data from the presentation sessions to determine the congruence between

the module intents and the presentation session occurrences. An Outcome Review was conducted to determine the contingencies between the antecedents and outcomes and to determine the congruence between the outcome intents and occurrences. The intent of the review processes was to determine recommendations for product revision.

The results of the Process Review indicated that the presentation sessions occurred as intended, suggesting congruence. Discrepancies of the transaction intents and occurrences when they appeared, were due to time constraints, excessive testing and the desire of trainees to include content that was beyond the intended scope of the presentation session.

The results of the Outcome Review indicated that four of the ten trainees contacted in Follow-up Interviews were involved with self-advocacy groups. All trainees reported that they had promoted self-advocacy with at least one developmentally disabled person and sought to encourage co-workers to embrace the concept of self-advocacy.

Recommendations for Product Development, Product Implementation and Product Evaluation were identified. A number of research needs were discussed.

DEDICATION

To "Millie"

ACKNOWLEDGMENTS

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CHAPTER ONE

INTRODUCTION AND REVIEW OF LITERATURE

Background

The civil rights movement sought to enfranchise those
minority groups previously limited in their participation
in the democratic process. The disabled have organized
ways similar to ethnic groups to increase acceptance and
participation in our democratic society. The developmental-
ly disabled, a silent minority (Kramer, 1980), continue to
struggle against social myths and prejudice, so they too
can live more normal lives (Wolfensberger, 1972). Self-
advocacy is the act of the developmentally disabled speak-
ing on their own behalf as they seek to gain and exercise
their rights.

The principle of normalization is an ideology that has
the role of guiding human management service systems to
create conditions for the developmentally disabled that are
as normal as possible (Wolfensberger, 1972). Self-deter-
mination is a philosophical and psychological referent
included in normalization. Under this principle, consumer
groups, self-advocacy groups and human service managers
work together to bring about normalizing self-determining
conditions. Self-advocacy groups are normalizing because

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it is socially normal for groups of people with similar living and working conditions to form groups and promote their own self-interest.

In general, the developmentally disabled lack resources to effectively advocate for themselves. Service providers are those who work directly with the disabled to be self-advocates. Service providers can open human service systems to increase opportunities for self-advocacy through consumer participation.

Sophisticated training materials and consultation capabilities are necessary in preparing self-advocates to protect their rights and represent themselves (Menolascino, 1978). People with mental limitations can learn to make judgments and decisions for themselves (Haskins with Stifle, 1980). They can be trained to vote, understand their rights, and develop self-advocacy skills (Herr, 1980). Self-advocacy groups provide a forum for the learning and development of self-advocacy skills, and offer an opportunity to participate in self-governance. The self-determination gained while asserting rights and assuming responsibility is good pedagogy and therapeutic (Nirge, 1972; Krugel and Shearer, 1976).

Professionals and other service providers will need to work with self-advocacy groups and service delivery systems in encouraging self-advocates to participate in the planning and delivery of services (Warren, 1979; Varela, 1978).

Helpers, counselors, consultants can advise self-advocacy groups in organizing themselves "... to participate in the governance of the social agencies created for their benefit" (Herr, 1980, p 10). Woodyard (1980) has highlighted the need of having advisors to assist in the development of self-advocacy groups. To meet this need, inservice training, staff development, consultation, materials and resources must be expanded (Stedman and Wiegerink, 1979).

Freire (1970) discussed entering into a dialogue with the oppressed as a precondition to developing an educational program for their liberation. An example of this occurred at a work activity center. Four workers entered into a dialogue about starting a union. As a result of these interactions, activity was initiated to answer these questions: Why are we treated differently? What are our rights?

An organization was founded and an election to select officers was held. The indigenous leaders became recognized. They had to learn new roles, tasks, and duties as officers of their organization.

The experience of working with "The Board" (as they refer to themselves) provided the background and orientation to gain an appreciation of the need for additional training and instructional materials for those who will work with the mentally retarded as they seek their voice in gaining power and control over their lives.

The general purpose of this project was to develop instructional materials to be used in the training of service providers as advisors to self-advocates. In order to accomplish this general purpose the following three major goals were identified. Namely:

To design and develop instructional materials;

To implement these materials in a field test;

To examine these instructional materials for product revision.

Review of Literature

Philosophical Issues

The Stigma of Being Labeled Mentally Retarded

Three per cent of the population, for a variety of reasons, fall significantly below the norm in intelligence and adaptive behavior (Farber, 1968; Blatt, 1977). These persons have been labeled by society as developmentally disabled, mentally retarded, mentally deficient, or mentally impaired. Labeling stigmatizes individuals leading to persons being devalued (Farber, 1968). When a group of people are devalued by society they are dehumanized resulting in a restriction of rights, freedoms or opportunities (Farber, 1968; Wolfensberger, 1972). Labeled mentally retarded adults become alienated, restricted, and their options limited (Blatt, 1977).

A "monolith" of education and mental health has been created and sustains itself because of a lack of alternatives. The "monolith" involves a network of seemingly open, but actually closed systems, reflecting a limited vision of human potential and possibilities (Blatt, 1977).

The term "mental retardation" as an administrative term has "... little if any scientific integrity." (Blatt, 1977, p. 20). Blatt goes on to say that in 1973 the Grossman Committee revised the American Association on Mental Deficiency definition of psychometric retardation from one to two standard deviations from the mean. Psychometric retardation is essentially 75 I.Q. or less, or approximately three percent of our total population. Administrative retardation is that percentage of the population who at any point in time need or is known to need services, or approximately one percent (Blatt, 1977).

Neglect, lack of resources, segregation, and dehumanizing conditions represent the consequences of a closed system regarding the potential of people to learn. This closed system reinforces the social myth of the retarded as a deviant population that must be controlled and managed. This self-fulfilling prophecy has a long historical precedence (Blatt, 1977), but is not substantiated by empirical evidence which, based on current practices and technologies, have shown that people labeled mentally retarded can learn and grow as human beings (Wolfensberger, 1972; Blatt, Biklen, and Bogdan, 1977; Roos, no date).

There is literature identifying some of the problems of community placement. "Dumping", lack of coordination of services, neglect, abuse, or community resistance have been reported (Halpern, Sackett, Binner, and Mohr, 1980). The alternative is not to maintain institutions because of the problems of community placement, but to continue to develop alternative residential, vocational, recreational, social and democratic options (Steer and Jennings, 1976).

The insiders view of being labeled and experiencing institutional life is quite revealing. Their memories and stories of experiences while institutionalized describe a barren, demeaning and brutal world (Bogdan and Taylor, 1976; McIndless, 1978). The impact of labeling and institutionalizing creates a stigma and for some may be a life long issue that is difficult to overcome (Edgerton and Bercovici, 1976).

The Edgerton and Bercovici (1976) study suggested a difference when defining social adjustment; the researchers and program planners, or the persons who have been labeled. There appears to be a variety of criteria with the professionals seeking competence and independence while those labeled and studied found confidence and a sense of well-being to be more important. Edgerton and Bercovici (1976) go on to suggest that "... we should listen to retarded persons when they tell us about their lives." (p. 496).

Normalization

Normalization is an ideology used to guide human service system managers in planning and conducting their agency services and programs. Simply stated, the principle of normalization is the creation of conditions for the developmentally disabled that are as normal as possible (Wolfensberger, 1972).

Conditions need to be created for the mentally retarded that enable them to participate as citizens in a democratic society. Personal planning, decision making, and goal setting are socially normal adaptive behaviors. Voting, organizing and lobbying are normal democratic behaviors. Speaking on one's own behalf in one's own best interest is a fundamental democratic principle and has a strong historical precedence.

The principle of normalization suggest that human service systems develop an open view of learning, growth and human potential. A way for human service personnel to gain an open view is to accept Edgerton and Bercovici's (1976) suggestion and listen to the mentally retarded. This can lead to developing a perspective of their world as they see it.

Phenomenological Perspective

Service providers, administrators, families, home operators and others are gaining the perspective that

given access, a person with mental retardation can function
as an equal in the planning and delivery of services (Varela,
1977). Advocacy involves the interaction of individuals
and systems, or agencies. "From an individual perspective,
advocacy involves acting on behalf of or pleading the case
for another. An advocacy perspective starts with the
client and attempts to examine services through the eyes
of the client." (Neufeld, 1979, p. 45).

Phenomenology is a philosophical foundation of the
disciplines of anthropology, sociology, and various
approaches to psychology and education. It "... concentrates
on the field of constituted human meanings" and brings into
question the "... origin, development, structure, and
sedimentation of belief contexts as they impinge upon human
action." (Ihide, 1977, p. 143). Through this perspective
the issues, beliefs, actions and lives of this minority can
be understood. It is a perspective which attempts to
view behavior from the persons own frame of reference, and
examines how people experience their world. Reality is in
one's own mind. The concept of mental retardation is dif-
ferent for those who are doing the labeling, than for
those who have been labeled (Taylor and Bogdan, 1977).

Understanding mental retardation in phenomenological
terms requires a suspension or bracketing of one's own
assumptions and beliefs (Taylor and Bogdan, 1977). Mental
retardation is a social creation based on artificial
distinctions and commonsense understandings that perpetuates

a mythology. Socialization and enculturation tend to reinforce these myths. The service provider or anyone else involved in the field of mental retardation needs to examine and transcend their assumptions which are based upon their socialization. Failure to do so results in perpetuating the dependency of those with whom one is working (Goldenberg, 1978; Turnbull and Turnbull, 1979).

As part of an oppressed minority many of those labeled mentally retarded have adopted the myths of the society. Due to social expectancy, the vicious circle is completed in a self-fulfilling prophecy contributing to the myths described by Wolfensberger (1972).

In order to change this situation the consumer must be viewed with respect, dignity, and as a human being who is valuable. Consultation, collaboration and cooperation between the consumer and the service provider is the strongest position to work from, with an increased potential for positive results (Warren, 1979).

Although many professionals guard their territory from intrusion by the consumer, others seek consumer participation in planning and delivery of services. An unwillingness to listen may convey to the consumer that the service provider considers the consumer incompetent. Professional ignorance about the value of consumer participation could produce the same effect, the consumer as a self-advocate may need to educate the professional (Warren,

1979). The service provider must be flexible, open minded and capable of growth to appreciate the growth of others (Wolfensberger, 1972).

A phenomenological approach to education is involved in the practices of Freire (1970). He describes a process of developing a curriculum among illiterate people. The process is based on assumptions regarding oppression and the dehumanizing conditions of the people with whom he worked. He sought to liberate and not perpetuate oppression. The process of developing educational programs and bringing about liberation is similar to the process described by the founders of People First (Freire, 1970; Heath, 1977; Heath, Schaaf, and Talkington, 1978).

The process begins with the derived meanings of words. For the self-advocate, mental retardation is a concept that carries a heavily value laden meaning. The advisors, helpers, organizers or advocates take the position of being in communion with the people. This is a different position than teacher, therapist, social worker, "boss", parent, etc., which often maintains dependency, and can become a form of oppression, manipulation and dehumanization (Freire, 1970). The growth process relies on the psycho-logical referent of self-determination (Freire, 1970; Goldenberg, 1978; Nirge, 1969).

Self-Determination

Self-determination is the ability to control the basic conditions under which survival takes place (Goldenberg, 1978). Rank (1956) defined "... self-determination as a voluntary and conscious creating of one's own fate." (p. 20). Assertiveness, problem solving, decision making and self-disclosure are the skills needed by the self-advocate in determining and influencing the direction of life. The value of respecting a person's right to self-determination has pedagogic value. The therapeutic value of an improved identity and increased independence has been noted (Heath, 1977).

Self-determination is a social value for one who hopes to gain respect as a citizen, creating a more complete democratic society (Nirge, 1972).

Social Movements

Self-Help Groups

The self-help movement emerged in the 1930's when parents of the mentally retarded began to create alternatives to institutionalization (Stunman, Trunstein, 1976). The formation of groups of parents of handicapped children began "... as a spontaneous reaching out of parents to one another, eager to share their similar problems and concerns." (Segal, 1970, p. 4). There was a perceived

failure of society's institutions to provide care and
social support for the needy and stigmatized (Katz, Bender,
1976). Parents, friends and concerned professionals began
meeting to discuss problems and develop ways of coping
with their concerns (Segal, 1968).

Through the 1930's and early 1940's parent groups
focused on obtaining services for severely and mentally
retarded children. In 1946 these groups expanded their
concerns to encompass all retarded children. The American
Association on Mental Deficiency, the only professional
organization at the time interested exclusively in mental
retardation, invited members of parent groups to it's
annual meetings in 1947 and 1949 (Segal, 1970). The
National Association for Retarded Children was incorporated
in 1953 (Segal, 1970).

Meanwhile, special-interest groups representing many
disabilities increased the visability of the disabled,
heightened public awareness, and helped to destigmatize
disability making it less threatening to the public. The
formation of these groups paved the way for support of
public services and a movement toward full citizenship
for the disabled (Haskings with Stifle, 1980).

The civil-rights movement of the 1960's, the War on
Poverty, the Vietnam War, the youth counter culture and
the Woman's Movement further supported the effort of these
groups. National attention was on the effects of prejudice,

discrimination, segregation and economic deprivation.
People believed that these conditions contributed to a
denial of basic human and legal rights to minorities,
including the handicapped (Haskin with Stifle, 1980; Katz,
1976).

A new breed of activist emerged in the 1970's as more
and more of the disabled began speaking out. Vietnam
veterans did not accept the role of the handicapped person
staying at home behind closed doors. An increased mili-
tancy developed on the part of the handicapped with the
perception of being "the next minority." (Haskins with
Stifle, 1980, p. 8).

The activism of the disabled, and consumer groups
has resulted in victories in the courts and legislation.
The Developmentally Disabled Assistance and Bill of Rights
Act of 1978 (PL 95-602), the Rehabilitation Act of 1973
(PL 93-112), the Education for All Handicapped Children
Act of 1975 (PL 94-142) are some of the major federal
legislative achievements. Some of the litigation that
led to legislative action was Brown vs. Board of Education
(1954), Wyatt vs. Stickney (1970), PARC vs. Commonwealth
of Pennsylvania (1971), Lessard vs. Schmidt (1972), Mills
vs. Board of Education of District of Columbia (1972), and
Morales vs. Turman (1976) (Haskins with Stifles, 1980).

It is beyond the scope of this review to discuss the
legal and legislative actions that have involved the dis-
abled. The intent is to show how disabled persons, friends,

advocates and professionals have joined forces in a national disabled rights movement to gain full and equal citizenship for all the disabled.

The values inherent in these laws are consistent with those in the Normalization Principle which stresses the value of handicapped persons being able to live as much like the rest of society as possible (Kramer, 1974; Wolfensberger, 1972). Conditions are being created where disabled persons experience the respect entitled any human being (Wolfensberger, Nirge, 1972).

Advocacy and Self-Advocacy

Members of the advocacy movement believe in the need to provide resources to people with developmental disabilities in order to establish their first class citizenship. Advocates are those persons who intend to assist, represent and advise, regarding the rights, interests, and needs of people with disabilities (Addison, 1979). Advocates attempt to bring about social justice for those who have been or represent the potential to be treated unjustly. The advocate's goal is to provide the kind of involvement that results in persons becoming self-advocates. Their focus is on facilitating the learning of self-advocacy skills for an independent as possible life style for the developmentally disabled (Dybwad, 1980; Neufeld, 1979).

The Developmentally Disabled Assistance and Bill of
Rights Act of 1978 (PL 95-602) provides the framework for
an advocacy movement known as the developmental disabili-
ties movement, which seeks to assure developmentally dis-
abled citizens their human rights and needed services.
One of the goals of this movement is "... to provide
access for consumers to decision making that determines
what they receive and when." (Wiegerink, 1979, p.37).
The consumer has a role in planning and delivery of
services designed to benefit them (Warren, 1979). These
legal and legislative mandates represent a convergence
of theory and practice of the social science disciplines
of Law, Anthropology, Sociology, Education and Psychology
(Katz, 1976).

Varela (1977) discussed three themes of the self-
advocacy movement. The first theme states that the human
service system tends to view the problems of education,
housing, jobs and transportation as defects of the client.
The movement views the problems of access and unequal
distribution of benefits, as environmental and social
requiring legal and legislative action. The second
theme charges that human service personnel tend to see
only disabilities, not potential, and show a keen interest
in behavior modification rather than affirmative action.
The attitudes of service providers toward their clients
may become more negative as years pass, resulting in

lowered expectations and perpetuating low levels of
success and employment. A third theme emphasizes the
dignity and self-determination that arises out of self-
help. Peer counseling, assertiveness training, infor-
mation networks, interest in civic and legislative
matters are the tools of the self-advocate.

According to Hallgren and Norsman (1977):

> "Self-Advocacy is that component of the advocacy
> movement which is directed toward increasing the
> knowledge and understanding of basic human/civil
> rights and responsibilities and is a pre-condi-
> tion to meaningful citizenship." "Self-Advocacy
> is defined as advocacy by an individual whose
> rights, interests or needs are at risk of being
> diminished, in order to represent his/her own
> rights and interests and speak on his/her own
> behalf." (p. 1).

Asserting one's personal rights involves expressing
thoughts, feelings and beliefs in direct, honest and
appropriate ways which do not violate another person's
rights (Jakubowshi, 1976). Assertive behavior by persons
seeking their rights are the interpersonal skills of the
self-advocate. The skills needed at this level of com-
munication require ability to be interpersonally honest
and to have enough self respect to trust and express
thoughts, feelings and beliefs. Appropriate assertiveness
is learned; a social context for the learning to take
place is required. Individuals become socialized by
being able to communicate and relate with others in
society. The disabled learn in this process to speak

for themselves, be involved in making decisions about their lives, participate in determining their own direction and request needed services (Nirge, 1972).

There are programs and curricula designed to teach the law, legal systems (Riekes, Spiegel, Keilits, 1977), as well as legal rights and responsibilities for the mentally retarded (Hallgren and Norsman, 1977). Gardener's Self-Advocacy Workbook (1980) and Woodyard's Advisor's Guidebook for Self-Advocacy (1980), are valuable resources for self-advocacy groups. Individuals may need the support and encouragement of others to be self-advocates. Support groups provide additional energy, power and resources. Group experiences can lead to increased motivation, self respect, and self acceptance (Katz, 1976) with development of cognitive skills (problem solving, memory retention) (Freire, 1970) organizational abilities, and leadership (Heath, 1977).

The development of effective citizenship is brought about through the interaction of people facing concrete, real life problems. The identification self-advocates have with a site (workshop, home, center, etc.), provides a context for participation in real life problems (Curtis, 1974). The issues a support group deals with are relevant to their lives and stem from the dynamics of the site. The involvement by persons in their own programs and sites increases their skills as self-advocates through

participatory democracy. A sense of efficacy, competence, and personal power is developed and strengthened as self-advocates participate in meetings and committees, through defining group purposes and goals, choosing leaders, planning activities, and providing one and another emotional support.

Many minority groups have organized to communicate their cause to the public in the hope of gaining equality. The "Silent Minority" (Kramer, 1974) are those developmentally disabled and mentally retarded persons who have been denied many basic human or civil rights. The organization of the mentally retarded into support groups and coalitions is a way to achieve self-representation and gain more direct access to needed services (Menolascino, 1978).

In 1968 and 1970, the Malmö Congresses of the mentally retarded were held in Sweden. Issues of these conferences included: leisure programs, labor unions, social clubs, work opportunities and the frustration about not being allowed to make decisions.

In 1974 two staff and three residents from Fairview State Hospital and Training Center in Oregon attended a meeting in British Columbia billed as the "First Convention for Mentally Handicapped in America." These people returned and began organizing their own convention. The

result of this effort was the creation of People First,

an organization of people who (as the name implies) wish

to be known and seen as human beings.

> "Treat us as People First, then consider our
> handicaps; deal with our talents and positive
> features instead of just our disabilities."
> (Heath, Schaaf and Talkington, 1978, p. 6).

The Advisor To Self-Advocates

The Need for Advisors

A critical role is performed by those who assume the

responsibility to advise and facilitate the development

of self-advocates and self-advocacy groups. Self-advocacy

groups of physically disabled people usually have the

knowledge and skills needed to operate their own group

and do not need an advisor. However, most groups of

mentally retarded people do need advisors (Woodyard, 1980)

until the group has grown to become independent when the

advisor is no longer needed.

The skills and knowledge needed to be a participating

citizen in a democracy are learned. Voting on issues,

electing officers, planning and conducting meetings,

speaking in public, identifying and discussing issues,

and solving problems of a group, are examples of the

activity that take place when a group forms and develops.

"It is now generally recognized that the majority of the

mentally retarded when properly counseled and instructed
are able to make judgements and decisions for themselves."
(Haskins with Stifle, 1980, p. 126).

The advisor is a resource person who has knowledge
of normalization, group process, service resources, human
and legal rights for the disabled. Listening and group
facilitation skills are needed to insure effective com-
munication and empathy. Community placement, personal
choice, and self-determination are beliefs of advisors
(Woodyard, 1980).

Self-advocacy is a felt need, one that emanates from
the person and is expressed when people self-disclose the
conditions of their lives. Not all people have a need or
desire to be self-advocates, to vote, to join unions or
clubs, or to participate in meetings. Many citizens do
not participate in the democratic process, yet, all can
choose to do so because participation in the democratic
process is "normally" available. Unfortunately, "One of
the most fundamental democratic rights routinely denied
the mentally retarded is the right to vote..." (Haskins
with Stifle, 1980, p. 125).

The Advisor as a Facilitator of Learning

The function of an advisor is to be responsive to
the felt need of self-advocates. An advocate would speak
for the disabled person. An advisor would provide the

opportunities for the disabled persons to speak for themselves. An example of the distinction may be helpful.

> A woman assigned to a work activity center lost a
> tooth from her upper plate. She went to her home
> operator and case manager to see if she could have
> her plate fixed. The matter was unresolved for a
> year. A second tooth fell out of her plate.
> During a group counseling session, the woman ex-
> pressed a desire to have her teeth fixed. The
> therapist heard her request as something she could
> do for herself rather than advocating or speaking
> for her. The woman agreed to this approach and
> indicated that she wanted her teeth fixed within
> three months for her sister's wedding. The group
> being counseled became very supportive of her
> "getting her teeth fixed" and proceeded to offer
> suggestions. The woman involved her case manager
> and the home was called. The home operator ex-
> plained why her teeth had not been fixed, using
> the "defect in the client theme" (Varela, 1977),
> thus thwarting the case manager. A new plan was
> developed where the woman would "bug" the home
> operator and the case manager about her teeth.
> After two weeks a dental appointment was made,
> but the dentist pointed out that work could not
> be done until the woman cleaned her plate. Once
> again, the defect was in the client. A third
> tooth fell out. She continued to explore, with
> the group, other options. However, she did not
> mention her teeth for three weeks. Her silence
> on the topic was respected. One day she quietly
> smiled a toothy smile during the group meeting
> and congratulations were given. She got her
> teeth fixed three weeks before the wedding.

This example brings out the key issue for service providers who believe in advocacy and desire to see people become their own self-advocates. The service provider is in a position to intervene. A choice is made between doing something for a person or assisting a person to do something for themselves. Taking care of a person is different than caring for a person.

Rogers (1969) has discussed some principles and assumptions of learning. He points to the value of self-initiated, self-directed learning. This is the kind of learning that starts from within the person as that person struggles with life. There is a fundamental human need and continuous search for personal adequacy. The motivation is always there, as the person is always seeking the maintenance and enhancement of their perceived self. They are trying to do the best they can to be adequate. "From the point of view of the behaver himself, he is never unmotivated...even though it may seem so from an outsider's point of view." (Combs and Snygg, 1959, p. 56).

The advisor as a facilitator of learning must transcend the teacher-student relationship and develop a subject relationship. The interaction develops in a learning environment with advisor and self-advocate as teachers and learners, learners and teachers, learners and learners. The self-advocate is perceived as a subject who is active, not a passive object to be treated, taught, programmed and processed (Freire, 1970; Freire, 1978; Varela, 1977). As an active learner, the self-advocate is responsible for learning.

The advisor must be sensitive to the various forms of communication that indicate a need and interest in self-advocacy. The perception and expression of a need for self-advocacy skills may be masked because of personal

and environmental factors. A person may learn that
efforts will not be taken seriously resulting in learned
hopelessness and helplessness (Halpern, Sackett, Binner
and Mohr, 1980). The lack of alternatives, a restricted
life situation and people doing things for the person
rather than allowing for a dignity of risk (Perske, 1972)
all contribute to difficulties in seeking self-advocacy.

The Advisor as an Organizer Within an Agency

Woodyard (1980) discussed the advisor's relationship
to the sponsoring organizations management. The service
provider as advisor acts as a liaison between the self-
advocacy group and management. Managers historically have
made decisions for those they have served and focused
their attention on the disabled person's limitations.
This approach led to over-protection, few opportunities
for learning responsibility, decision making and practicing
dignity of risk. In order to overcome these obstacles and
advance the state of the art, Woodyard (1980) suggested
open communication and a willingness on the advisor's part
to educate the managers.

> "The principal vehicle for the acquisition of
> goods and power as well as for the development
> of self-determination...lies in the dynamic of
> community organization...Community organization
> is the mechanism by which previously isolated
> and vulnerable individuals band together to
> identify and pursue common goals." (Goldenberg,
> 1978, p. 108).

One role of the advisor is to be an organizer of the community of people with whom they are working (Herr, 1980). The advisor as organizer may need to understand agency goals and how they relate to self-advocacy. Three types of goals are considered for analysis. Integrative goals, the first type, seek improved juxtaposition of service giver and service users. The second type are socio-therapeutic goals where the agency seeks to improve function-ing or increase competence of citizens through community participation. The third type are environmental change goals which aim at the improvement of the environment within the community (Brager and Specht, 1973).

The goals of the self-advocacy movement can be viewed through the above classification system.

Integrative goals are likely to promote the preservation of the agency. Participation by a self-advocate in community life is encouraged to promote a greater ego investment with an internalization of com-munity values and traditions (Brager and Specht, 1973). This in part explains the effect state wide People First conferences have on participants (Heath, 1978). Agencies may seek to beguile participants into believing they have made an impact when, in fact, plans have been predetermined. This behavior serves to foster cooperative client sponsor relations without the transfer of power (Brager and Specht, 1973). The responsibility of the advisor is to
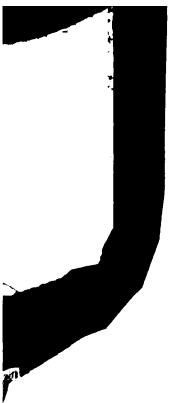
effect a transfer of power to the self-advocates. When
this does not happen, the indigenous leader only serves
a public relations function. The goal is a higher degree
of political integration with cohesion of service
recipients (Bragen and Specht, 1973).

Sociotherapeutic goals may be questioned because they
offer psychological solutions to political and systemic
problems (Brager and Specht, 1973). Heath (1977) dis-
cussed the psychological benefits of People First in
promoting group identity and independence. This growth
may be a prelude to action and social change. The question
of changing people or changing environments may be a moot
point for those who are hurting. For some, both need to
happen. The individual may change as a result of social
action or may change as a result of promoting social action.
An example may be helpful.

> A group of six workers in a work activity center
> confronted a staff person about a telephone policy.
> The policy in question stated that if a telephone
> call was business, the worker could make the call
> without cost. If the call was personal, the
> worker would have to pay the cost of the call ($.07).
> The workers felt this was an infringement of their
> right of privacy and inconsistent with staff policy
> regarding their telephone usage.
>
> A staff person listened to the complaint and
> suggested they continue to pursue the issue with
> the supervisor with the goal of negotiating a
> new policy. The leader of the group, a 71 year
> old man who had been previously institutionalized,
> but in the community the past seven years, became
> anxious. He cried and talked about his fear of
> making trouble; that it was better to drop the

issue and experience his hurt, loss of rights
and dignity than to assert himself and hurt
another. The others said they had a right to
assert themselves, offered him support, encourage-
ment and positive regard. He said he was scared
of being sent back to the institution and feared
this would be a consequence of noncompliance with
the policies of the program. The group provided
reality checks for him but he was threatened and
unable to accept their feedback. Then one member
said, "O.K., we will do it without you. We have
a right to our privacy." The group "chimed" in
their support of asserting their rights and were
ready to move without their leader. He realized
that they were serious and would not abandon him
if it got tough. He joined the group and they
worked out a plan and established a new telephone
policy with the supervisor.

In this example, it appears that the leader needed
the psychological benefits the group offered before he
would be willing to take the risk and move toward attempt-
ing to change an aspect of his situation.

Environmental change goals are criticized because
they may be naive and utopian. They represent the most
radical and far reaching of the goals. In order for these
goals to be realistic they must be set in regard to the
cultural and economic system (Brager and Specht, 1973;
Alinsky, 1971; Freire, 1970).

The principle of normalization seeks to change
society's view of the mentally retarded. The principle
attempts to change society's myths about those labeled
mentally retarded creating more acceptance and integration
into society. The attempt is made to remove the stigma
of the label and the deviant status that the label places
on people (Wolfensberger, 1972).

Agencies that utilize the normalization principle
seek to change attitudes and conditions in the community
that will allow for greater acceptance and integration
resulting in the generic use of community services free of
discrimination. The self-advocate plays a key role in
defining and shaping the objectives sought. This consti-
tutes self-determination in action, a concept of normal-
ization and deeply embedded in democratization of service
agencies (Nirge, 1970; Brager and Specht, 1973). Agencies
that assume an advocacy role realize that rehabilitation
services are not enough. The purpose of advocacy is to:
1) assist the disabled person in every way possible to
actualize his potential; and 2) utilize agencies as
advocates to actively participate in improving how society
feels about the disabled (Diamond, 1979).

The Service Provider as the Advisor

There are two forms of advocacy; internal and external.
Internal advocacy operates within the system or agency that
employs those acting as advocates, while external advocates
receive their financial support independent from the
systems where they perform their advocacy services. The
advisor to self-advocates provides an advocacy function.
Service providers as advisors perform internal advocacy
activities. A major objection to internal advocacy, and
to service providers acting as advisors, is that there

may be a conflict of interest between agency goals and those of the self-advocates. The advisor may not be objective or view the situation from the self-advocate's perspective and "cool out" the self-advocates in order to protect their position within the agency. The adage, "Whose bread I eat, his song I sing", points to the disadvantage a service provider may experience when developing advocacy services within an agency (Woodyard, 1980; Neufeld, 1979).

Another problem of the service provider being an advisor is that of the consumer differentiating between the various roles the service provider may perform. For example, the service provider may be a rehabilitation worker in a workshop, responsible to train and monitor worker progress and productivity. In this role, the disabled worker may perceive the service provider as a "boss". When the self-advocacy groups conduct planning and decision making sessions, the service provider will need to be perceived as a friend, helper, advisor, but not as a "boss". Some consumers and service providers may have difficulty adjusting to this kind of role flexibility.

The advantage of the service provider being an advisor and advocate is that they have greater access to information and services. Consumers often live restricted lives where contact with people outside of the service delivery system is minimal. The service provider can

assist by: bringing disabled persons into the community;
opening doors to other self-advocacy groups; encouraging
participation in workshops, conferences and conventions;
and ultimately, moving the agency to include more consumer
representatives on its advisory boards (Woodyard, 1980;
Neufeld, 1979).

The Need For Instructional Materials

The process of being labeled mentally retarded in
this highly technological society where intelligence is
valued has resulted in discriminatory and segregationist
policies. Some of these policies have resulted in people
being devalued by society, perpetuating a myth of deviance,
while others are paternalistic in their treatment of the
retarded. Recent developments have led to the creation
of an ideology that stresses the value of the potential
for growth and development of the individual.

The advocacy movement seeks to gain respect and
dignity for all disabled people through the Principle of
Normalization (Wolfensberger, 1972; Nirge, 1976). Self-
advocacy represents the struggle for people to speak for
themselves in making decisions that effect their lives,
and deepens society's commitment toward democratic ideals.

An advisor to self-advocates is needed to pose
questions, make suggestions, develop options and alterna-
tives so that self-advocates can make their own decisions.

Self-advocates may need an advisor until they can operate
independently. The goal of an advocate and advisor is the
independence of self-advocates. An advisor needs knowl-
edge and skills in order to facilitate learning as they
function as a resource person for a group.

The service provider may act as an advisor.
Functioning in an agency they run the risk of a conflict
of interest between the service agency and the activities
of self-advocates. Service providers are in a position
of contact and involvement to encourage and assist in the
promotion of self-advocacy at the service delivery site.
The service provider can work within the system to open
doors and develop self-advocates. Self-advocacy may range
from a person deciding what clothes they will wear each day,
to being on an advisory board and becoming involved in
legislative issues. The responsibility for consumers to
make their own decisions can be encouraged by the service
provider.

Alternative perspectives are needed by service
providers so they can impact and change the service delivery
system. Service providers can assist in changing attitudes
to allow for greater integration of consumers into society
(Steer and Jennings, 1978; Mamula and Newman, 1973; Varela,
1977).

In many programs around the country there are people
who have chosen to facilitate the development of

self-advocacy; sometimes feeling alone, without a clear direction. Daily responsibilities and pressures as well as personal interest and abilities make it difficult for many service providers to take the time and expend the energy to search out and discover an advisor advocacy perspective that would enable them to foster the development of self-advocates. Staff development and sophisticated training materials and resources are needed (Menolascino, 1978). In order for such materials to become available and useful, research, design, development, implementation and evaluation must take place prior to dissemination (Stedman and Wiegerink, 1979).

There are some instructional materials and resources designed to assist people to become self-advocates (Heath, 1976; Hallgren and Norsman, 1977; Gardner, 1980; Woodyard, 1980). These materials provide guidelines, direction, information, and training exercises. However, only portions of these materials are designed to address the training needs of advisors. Materials have not been developed that specifically address the training needs of service providers who desire to become advisors to self-advocates.

CHAPTER TWO

PROCEDURES

Project Design

The general purpose of this project was to develop
instructional materials to be used in the training of
service providers as advisors to self-advocates. The
goals were:

To design and develop instructional materials;

To implement these materials in a field-test;

To evaluate the instructional materials for

product revision.

Three tasks were planned to accomplish the general
purpose and goals of this project.

1)   Product Development included those sub-tasks
      and events that led to the instructional
      materials package. The sub-task of Assess-
      ment of Need was completed through the events
      incorporated in the review of literature and
      personal experience. The second sub-task,
      Identification of Content was accomplished
      through the events of a national survey of
      advisors, an advisor workshop and a synthesis
      of data. The incorporation of an instructional

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format with the content was the third sub-task.
A module format was selected for the organi-
zation of content into a module package.

2)   Product Implementation included those sub-tasks
and events that led to the field-testing of the
module package. The selection of trainees was
the first sub-task. The schedule of training
sessions was the second sub-task.

3)   Product Evaluation included those sub-tasks and
events that led to recommendations for product
revision. The development of an evaluation plan
was the first sub-task. Instrumentation was
developed for the second sub-task. The third
sub-task was the data collection conducted
during and after the field-test. The final sub-
task was a review of data to determine recom-
mendations for product revision.

Figure 1 identifies the project tasks, sub-tasks and
events.

Methodology

The procedures used to complete the three major tasks,
namely: Product Development, Product Implementation and
Product Evaluation, will be described.

Product Development

```
                    Assessment of Need

    Review of                            Personal
    Literature                           Experience


              Identification of Content
                        |
              National Survey of Advisors
                        |
                 Advisor Workshop
                        |
                    Synthesis
                        |
              Instructional Format
                        |
                  Module Design
                        |
                 Module Package
```

Product Implementation

```
              Selection of Trainees
                        |
          Schedule of Training Sessions
```

Product Evaluation

```
                 Evaluation Plan
                        |
            Develop Instrumentation
                        |
                 Data Collection
                        |
               Analysis of Data
                        |
          Recommendations for Revisions
```
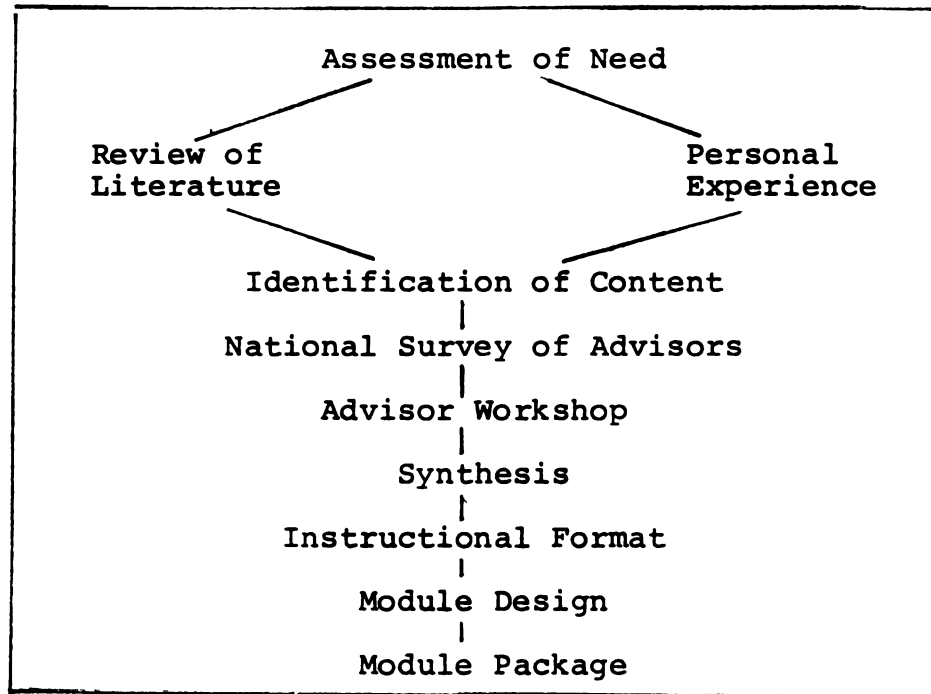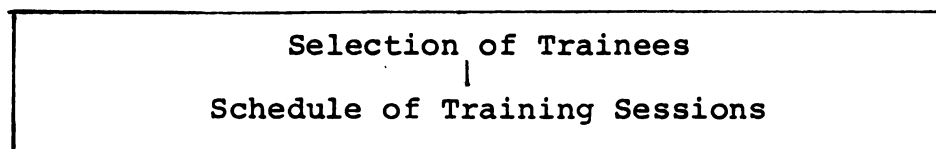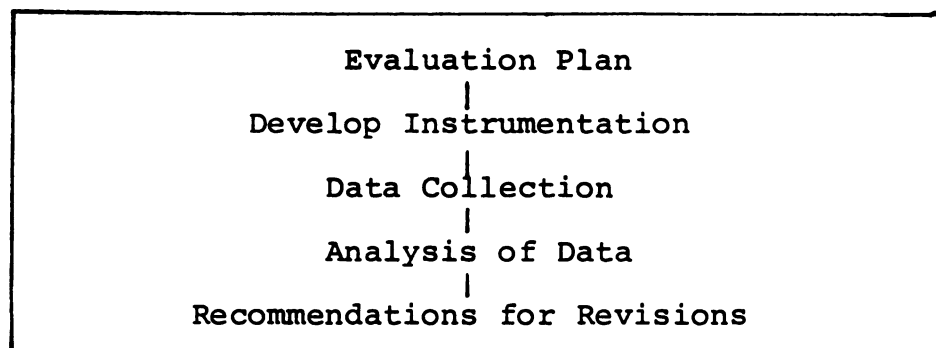
FIGURE 1

PROJECT DESIGN

Product Development

The purpose of the product development task was to develop instructional materials that could be field-tested. This task involved two sub-tasks, namely: identification of content, and the organization of the content into a format for the curriculum package.

Identification of Content

This section describes the process used to identify the content for the instructional materials. The question raised was: "What content would be useful to train advisors to self-advocates?" Three events were planned to answer this question. The first event to identify the content was a National Advisor Survey. Data from the national survey were used in structuring the second event, an Advisor Workshop. The third event was a synthesis of the data from the survey and workshop into logical categories including the organization of content by knowledge, skills and attitudes.

An explanation of the procedures used in each event follows.

National Survey of Advisors

A survey of self-advocacy group advisors was conducted to determine the content for the development of instructional materials. The feedback of advisors from around the nation was sought to gain their ideas about the skills, resources, knowledge, principles and perspectives useful in a training program for self-advocacy advisors.

The Association for Retarded Citizens through the Office of Protection and Advocacy provided a list of self-advocacy groups. This list included the names and addresses of 85 groups from 18 states. A survey package was sent to all listings.

The survey package consisted of a letter of explanation, a statement of endorsement for the study, a Position Paper, a bibliography, a Survey Response Sheet and a self-addressed stamped envelope (Appendix A).

The letter of explanation identified the nature and purpose of the study. Directions were provided on the use of the Position Paper and Survey Response Sheet. The advisors were asked to read the Position Paper and note their salient ideas on the Survey Response Sheet.

The Position Paper was a brief review of the literature including a statement about the need for additional instructional materials to train advisors. A bibliography was included with the Position Paper.

The Survey Response Sheet had one open ended question, namely: "What would be useful in a training program for advisors of self-advocacy support groups?" Respondents were instructed to write on the Survey Response Sheet. The idea of a structured response sheet was discarded because of potential bias in formulating questions and the possibility of inhibiting responses.

There were twenty-three respondents to the National Survey with a return rate of 27%. The total used in identifying content was twenty-one, giving a 24% utilization rate. Two surveys were received after the content was identified.

The characteristics of the respondents included: seventeen advisors to self-advocates, two self-advocates and three others.

The National Survey was sent out once. No attempt was made to follow-up on non-respondents.

As surveys were returned they were read and the ideas recorded according to the content of the idea. Similar ideas were grouped. As more National Surveys were received, categories of content became apparent as the groupings became longer. Different perspectives within a category were noted for future use.

The ideas, suggestions, perspectives and resources contained in the body of the National Survey responses were reviewed two times. Following a compilation

of all the survey data, the National Surveys were reviewed. Categories were modified, grouped, changed or dropped as the original data were re-examined. After reading some of the suggested readings, the National Surveys were again reviewed; thus, providing greater insight into the meaning of some of the responses.

The results of the survey were used to help identify the content for the instructional materials. Themes, consistent ideas, advisor issues, additional resources and materials were sought. This information was categorized and used in developing a Workshop for Michigan Advocates and Advisors.

Advisor Workshop

An Advisor Workshop of advocates and advisors from the State of Michigan was conducted to further identify, develop, define and refine the content. The survey provided a rich source of ideas to which Advisor Workshop participants reacted.

A potential Advisor Workshop participant was a person who: 1) had been an advisor to self-advocates for more than one year; or 2) was an identified advocate for the disabled, or 3) was a self-advocate.

Advisors who attended the Second Annual Michigan People First Conference and advisors who were assisting in transporting self-advocates to the planning sessions

for the Third Annual Michigan People First Conference were contacted personally and invited to attend the Advisor Workshop. Follow-up telephone calls were made over a period of several weeks.

Twelve people identified as potential Advisor Workshop participants were sent a letter of workshop intent, an agenda for the workshop and a map (Appendix B). The six who participated in the workshop were from the Lansing, Michigan, area. They represented different roles along an advocacy/self-advocacy continuum. The workshop participants included: a lawyer from the Civil Rights Commission, the Citizen Advocacy Coordinator for the Michigan Association for Retarded Citizens, the Director of Training for the Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc., the Coordinator for Training for the Greater Lansing Association for Retarded Citizens, a residential casemanager and a self-advocate.

As indicated above, the results of the National Survey were used to identify the content of the instructional materials. The results were also used to determine the goals for the Advisor Workshop and the content of one sample instructional module.

The goals of the Advisor Workshop were:

1. To identify the content for the instructional materials for advisors to self-advocates.

2. To identify additional materials and resources.

3. To discuss issues related to advocacy and self-advocacy.

The Advisor Workshop was designed as an intense eight hour work session. The session was to start at 9:00 a.m. and continue until 5:00 p.m. with lunch provided. Telephone calls and other external or work related business was discouraged so participants could concentrate on the tasks without interruption. Each participant was given a workshop packet which contained a copy of the National Survey, nine National Survey responses and a sample of an instructional module. (Appendix C).

Part I (a.m. session) of the Advisor Workshop was designed to identify content for the instructional materials and discuss issues related to advocacy and self-advocacy. The Advisor Workshop began with a reading and discussion of the Position Paper. Next, the participants were instructed to read the returned National Surveys. The product for the morning sessions was to be a list of major topics around which instructional materials would be developed.

Part II (p.m. session) included reviewing existing materials and making recommendations for additional materials, reacting to the sample Module design, discussion of the role of the service provider as an advisor, and training ideas and activities. The product for the afternoon session was to be a list of training activities congruent with the content with consideration given to the discussions.

A trained anthropologist who was also an advisor for self-advocates functioned as a participant observer during the Advisor Workshop. Her responsibilities as a participant observer were to record observations about the discussions as a perception check with the workshop director, as well as assist in determining the consistency between the intents of the workshop and occurrences.

Process notes were kept by the Advisor Workshop director. These notes were intended to be an additional data source and to be used when conducting perception checks with the participant observer.

As indicated, suggestions and recommendations for the major topics were established in cooperation with the Advisor Workshop participants, utilizing the National Survey responses. The respective viewpoints from these two information sources were compiled and compared for consistency. A list was established that contained major headings with content items under each. Themes were determined by synthesizing the categories, headings and items from the list established at the Advisor Workshop and the third list from the National Survey.

The suggestions from the National Survey and Advisor Workshop were organized within themes according to: knowledge, cognitive information obtainable through readings, lecture and discussion, skills, abilities that a person can demonstrate (such as facilitating a group in

making decisions), attitudes and beliefs (those dispositions that may limit or open one to the ideas of self-advocacy) (Figure 2).

Philosophy and Orientation to Self-Advocacy

Role of Self-Advocacy Group Advisor

Working With Self-Advocates

Facilitating A Self-Advocacy Group

Human Rights and Responsibilities

Starting and Maintaining Self-Advocacy Groups

FIGURE 2. CONTENT THEMES

Instructional Format

A module is an instructional unit organized around a central theme. A module should include: goal statements for intended learning; a rationale stating the purpose for the module; objectives to be accomplished by the learner; and activities designed to facilitate learning.

The module format was selected because of its potential for individualization. Service provider positions include aides, counselors, instructors, rehabilitation workers, casemanagers and residential workers. In some agencies, staff development and in-service training may take the form of individualized study while in others it may be in the form of in-service workshops.

Six themes and related goals were identified reflecting the literature, the views of the National Survey respondents and the Advisor Workshop participants. These themes and goals formed the basis for the modules. A rationale for each module was developed. The rationale provides the learner with a statement of why they are learning what they are asked to learn. Specific objectives were identified for each module. The objectives focus attention on what is to be learned. Activities for each module were also developed. These activities were designed to reduce the abstract nature of the content.

Each module included procedures for gathering data from each trainee. These trainee measures focus on identified knowledge, skills and attitudes of the trainee relative to the content of the instructional package. Proficiency and attitude measures were used to reflect changes observed in the trainees (Cronbach, 1973). The trainee measures were:

a. Pre-test/Post-test

b. Assessment Sheets

c. Impact Questionnaires

d. Skill Development Sheets

e. Follow-up Interviews

In addition, each module incorporated a feedback loop for product revision. These process measures were concerned with events taking place in the presentation session (Cronbach, 1973). The module evaluation measures included:

a. Participant Observer Notes

b. Module Evaluation Forms

c. Presentation Session Notes

d. Attendance Records

e. Anecdotal Notes

The modules provided structure for six two hour training sessions. The content of each module was limited to allow for a brief lecture and considerable discussion and inter-action. The interaction provided opportunities to gain additional perspectives and increase the likelihood that trainees would become supportive of each other in their attempts to use newly acquired knowledge and skills.

Product Implementation

The purpose of the Product Implementation task was to field-test the package of six modules (Appendix D). This task involved two sub-tasks: selection of trainees and schedule of training sessions.

Selection of Trainees

The idea of self-advocacy within a comprehensive service agency had been promoted for one year prior to Product Implementation. Discussions about self-advocacy with staff and administrators from three components of the agency (Life Consultation, Residential and Training and Habilitation) had been conducted. A summary report of the

Second Annual Michigan People First Conference was presented to the administrative staff of the agency. A fifteen minute video-tape on People First was presented at a Training and Habilitation staff in-service. Staff reactions to the idea of self-advocacy ranged from disinterest and skepticism to support and curiosity.

Clients from a work activity program and a living center in the Lansing, Michigan area, participated with their advisors in planning to participate in the Third Annual Michigan People First Conference. These advisors and other service providers from the living center shared a belief in self-advocacy and participatory democracy.

Service providers from a comprehensive community agency for the mentally retarded and a non-profit residential program were sought to participate in the advisor training. It was felt that administrators would experience a conflict of interest if trained to be advisors. In addition, it was believed that they could function better to promote self-advocacy within the agency at all levels. Announcements were made at administrative and staff meetings about the training and the training schedule. A site interest survey (Appendix E) was sent to each administrator and supervisor. Supervisors were called and reminded about the training.

The trainees were to volunteer to participate in the training. No attempt was made to randomly select training

participants. The training was made available to all service providers in the two agencies.

The site interest survey generated one response from Life Consultation indicating three case managers wanted to attend the training. The other contacts were by telephone or personal request.

Fifteen service providers from two agencies started the training sequence. One person was employed the week training began and was assigned by her supervisor to attend. The other trainees chose to participate.

The trainees had at least one representative from each major service provision job classifications. There were seven professional staff, seven para-professional staff and one administrative staff person. Casemanagers, mental retardation therapists and a physical therapist were considered professional staff. Training and habilitation instructors, resident managers, resident counselors and resident aides were on a para-professional level.

Eleven of the trainees were from Programs for the Mentally Retarded (PMR) with four from Moore Living Center. Programs for the Mentally Retarded (PMR) has three components: Life Consultation, Training and Habilitation and Residential. Life Consultation provides case management services. Training and Habilitation provides day programs for persons past the age of twenty-five. Residential Services involve the living alternatives offered by PMR.

Moore Living Center is a residential program with case

managers, counselors and aides (Table 1).

Ten women and one man attended from PMR. Moore

Living Center had three women and one man.

TABLE 1. SELECTION OF TRAINEES

Programs for the Mentally Retarded

    Life Consultation

        Case Manager   3

    Training and Habilitation

        Mental Retardation Therapist   2
        Training and Habilitation Instructor 1
        Physical Therapist   1

    Residential

        Administrative Assistant   1
        Resident Manager   1
        Residential Aide   2

Moore Living Center

        Case Manager   1
        Resident Counselor   2
        Resident Aide   1

            TOTAL   15

Twelve of the fifteen trainees completed the training.

A case manager withdrew due to illness. The administrative

assistant indicated that she was over extended and withdrew.

The resident manager withdrew. All of the people from

Moore Living Center completed the training.

Schedule of Training Sessions

The decisions when and how long each training session would last was based in part upon an understanding of the job requirements each agency placed upon it's service providers. Staff who work in day programs were needed at their sites each day until at least 3:00 p.m. They usually work until 5:00 p.m. Tradition in one agency had in-service sessions from 3:00 p.m. to 5:00 p.m. Consideration was given to weekend or all day sessions but this was ruled out because time was needed for the trainees to read, observe and complete the various on site consumer involvement activities. Besides completing assigned tasks, trainees would need time to assimilate what they were learning. The trainees were perceived as active rather than passive learners and were expected to spend time and energy applying the knowledge and skills gained while performing their regular job functions.

Staff from residential programs were considered to have more time flexibility than those in day programs. The decision was made to accomodate day program personnel, recognizing time constraints and staffing needs of the sponsoring agency. Travel time between sites was considered resulting in the decision to offer the training sessions from 3:30 p.m. to 5:30 p.m. on Wednesdays for six consecutive weeks. Approximately 20 hours of service provider time, including 12 hours of classroom time, six hours to

complete activities, one hour for consultations and one hour for a follow-up interview, was required.

It was anticipated that absences would occur. Therefore, each training session was tape-recorded and individual make-up sessions were scheduled as necessary. During make-up sessions, themes, goals, rationale and objectives were reviewed prior to listening to the tape. Additional directions given to the trainee included:

1. "The taped-session will be played so you will be able to listen to the discussion."

2. "If at any time you want to comment or discuss any of the points or issues raised, I will stop the tape."

3. "The tape recording is a catalyst for thought and discussion."

4. "Listening to the tape will assist you to understand the direction the group is going."

Following the make-up session, the Impact Questionnaire, Module Evaluation and following week Assessment Sheets were filled out by the trainee.

Product Evaluation

The purpose of the Product Evaluation task was to review the results of the field-test data. This task involved four sub-tasks: determine evaluation plan, develop instrumentation, data collection and data review.

Evaluation Plan

The task Product Evaluation involved field-testing the module package. The field-test is a form of evaluation used to determine the need for revisions (Cronbach, 1973). Revisions should focus on improving the relevance and design of instructional materials (Meyer, Frank and Rodee, 1970).

> "Formative Evaluation is process of systematically trying out instructional materials with learners in order to gather information and data which will be used to revise materials. The implication of the term 'formative' is that the evaluation process occurs while the materials are still being developed." (Dick, 1977, p. 311).

Scriven (1973) suggests that any curriculum builder is involved in formative evaluation. Formative evaluation relates to the stage of development of curricular material (Stake, 1967). The module package was in a formative stage of development, requiring the testing and revision of the materials.

Stake's (1967) model (Figure   ), was useful in developing an evaluation plan. Stake's (1967) data matrix provides a structure to illustrate the inter-relationship of data sources used in descriptive evaluation. The matrix identifies three bodies of information: Antecedents, Transactions and Outcomes. Antecedents are those conditions which exist prior to training. Transactions are those en-counters of trainee with facilitator, trainees with each

other, author with reader, etc. Transactions comprise
the process of education and are dynamic. Outcomes and
Antecedents are static. Outcomes are the result of an
educational experience. The impact of instruction could
be measured on facilitators, administrators and others.
Within the descriptive matrix, Stake (1967) includes
intents and observations. Intents are defined as all
intended learning outcomes, and are synonymous with goals
and objectives. Observations include those tools and
methods used by evaluators to gather information and data.

	INTENTS	OBSERVATIONS	
ANTECEDENTS			
TRANSACTIONS			
OUTCOMES			

FIGURE 3. STAKE'S MODEL FOR DESCRIPTIVE EVALUATION

Stake's model guided the development of the evaluation
plan for the present project (Figure 4). Using Stake's (1967)
data matrix, the Module package represented the intended ante-
cedent. Process review focused on individual modules
determining congruence between the intended transactions
and the observed transactions. The observed antecedents
were reviews in relation to the transactions and outcomes.

	INTENTS	OBSERVATIONS
ANTECEDENTS Instructional Materials Trainee Assessment	Module Package Module Content	Assessment Sheets Pre-test

PROCESS REVIEW
Congruence

	INTENTS	OBSERVATIONS

TRANSACTIONS
 	
Presentation
Session
Interaction
	Activities
	Listed in
	Each Module
		Module
		  Evaluation Sheets
		Participant
		  Observer
		Anecdotal Record
		Tape Recordings

OUTCOME REVIEW
Contingencies

OUTCOME REVIEW
Congruence

	INTENTS	OBSERVATIONS

OUTCOMES
 	
Trainee Gains
	Module Goals/
	Objectives
		Impact
		  Questionnaires
		Skill Development
		  Checklists
		
		Post-test
		Follow-up
		  Interview

FIGURE 4. DESCRIPTIVE DATA SOURCES

Outcome review was incorporated to determine the congruence between intended outcomes and observed outcomes, and observed antecedents were reviewed in relation to the observed outcomes (Stake, 1967). Stake (1973) cautions against attempting to determine causality due to the difficulty in measuring casual relationships. Figure 4 is an application of Stake's Model (1967) for descriptive evaluations with the relationship between data sources and review procedures.

Data Collection Instruments

The instruments used to gather data were designed and developed for the purposes of this project. The instruments were designed to either gather data relevant to specific modules or relevant to the module sequence.

Evaluation of the individual modules was sought to determine the impact each module had on the trainee and to provide data for revisions of the module. Instruments were developed for assessment, module impact, skill acquisition and module evaluation by each trainee. An observational methodology was designed to determine the congruence between module intents and occurrences. (Figure 5).

Modules II through Module VI included Assessment Sheets (Appendix D). These assessments were intended to identify what the trainee knew about the content to be

	Intents	Observations
Antecedents		Assessment Sheets
Transactions	Module Activities	Participant Observer Module Evaluation Sheets Anecdotal Records Tape Recordings
Outcomes		Impact Questionnaires Skill Development Checklists

FIGURE 5.   PROCESS REVIEW OF MODULE EVALUATION INSTRUMENTS AS APPLIED TO STAKE'S DATA MATRIX

covered in each module. Assessment Sheets provided data for the observed antecedents.

Modules I, IV, V and VI had Impact Questionnaires (Appendix D). These questionnaires were intended to determine the trainees comprehension of the content presented. In addition, an attempt was made to determine how the content affected the trainee's relevant attitude and beliefs. This was a measure of observed outcomes for each module.

Skill Development Checklists (Appendix D) were used in Modules II and III instead of Impact Questionnaires. These modules focused on the acquisition of advisor skills. This was an outcome measure.

Module Evaluation Sheets (Appendix D) were intended to provide feedback concerning the trainee's perception of the session and module. Data were gathered about trainee satisfaction including recommendations for product revision. This was a measure of module transactions.

A procedure was developed to monitor the congruence between module intents and occurrences. This procedure involved the use of a trained Anthropologist as a participant observer in each session. Her role was to record the content of interactions during the presentation sessions. This record provided data about information presented, values expressed by the trainer and trainees, along with information about attitudes and feelings of trainees. Feedback was also given about the presentation transactions.

Anecdotal records were kept by the trainer. These records were used to note perceptions about the use of the materials, interactions of the group and critical incidents.

Data were sought to determine the overall impact the module package had upon the trainees. The instruments used to gather these data included a pre-test/post-test and a follow-up interview. (Figure 6).

	Intents	Observations
Antecedents		Pre-test
Outcomes	Module Goals	Post-test Follow-up Interview

FIGURE 6. OUTCOME REVIEW OF MODULE PACKAGE INSTRUMENTS AS APPLIED TO DATA MATRIX.

A test (Appendix F) was developed to assess each trainee's knowledge upon entering the training sequence and to review possible change after training. The dimensions of the test included: 1) normalization, 2) advocacy and self-advocacy, 3) mental retardation, 4) decision making

and problem solving, 5) group dynamics, 6) assertiveness, and 7) legal issues. Pre-test data were used to determine each trainee's current knowledge on the measured dimensions. It also served as an advanced organizer for the training. Following the six weeks of training, the test was re-administered as a post-test.

A structured Follow-up Interview (Appendix G) was planned to determine each trainee's perceptions about the impact of the training. The intent was to determine to what extent each trainee had been influenced by the train-ing and to get additional feedback abou the design, format and presentation of the instructional materials.

Data Collection

Module Evaluation Data Collection

Assessment Sheets were administered at the end of each session for the next module session. For example: The assessment for Module II was given at the end of session I. One week lapsed between sessions, giving the trainer an opportunity to refine the planned presentation in relation to trainee assessments. This information had the potential effect of altering the intended activities for the next presentation session and was useful in making product and process adjustments.

The Impact Questionnaire and Module Evaluation Sheets were also administered at the end of each presentation session and had the same potential effect as the Assessment Sheets.

Skill Development Checklists were administered during activities as part to the learning experience.

The participant observer and trainer met immediately after each session and reviewed the field notes. These review sessions were intended to last one hour each. In addition, the Anecdotal records kept by the trainer were reviewed with the participant observer.

Module Package Data Collection

The pre-test was administered during the first forty minutes of the first training session.

The post-test was administered one week after the completion of the training sequence. Appointments were made with each trainee for the forty minute re-test period. A brief discussion followed each post-test to plan and schedule the Follow-up Interview.

The Follow-up Interview was conducted and tape recorded one month to six weeks after the training was completed. The intent was to allow time for each trainee to assimilate and integrate the content and training experience as well as to observe and reflect to what extent the training impacted their work.

Review of Data

The review of data included both process and outcome reviews. The process review utilized data sources to make adjustments during the field-test period and to determine the congruence between the intended activities and observed activities (Figure 5). The outcome review was conducted to determine the contingencies among the antecedent observations, transaction observations and outcome observations, and to determine the congruence between the module package intended outcomes and actual outcomes (Figure 6).

The process review incorporated feedback received during the presentation sessions. Data from the Assessment Sheets and Impact Questionnaires were reviewed on an item-by-item basis. Items were grouped according to the theme of the comment. No attempt was made to aggregate comments on these items. Data were reported in a descriptive manner.

Presentation sessions provided data about the occurrence of activities which were compared to module intents to determine congruence between module intents and occurrences. Data from the participant observer, anecdotal notes and session tape recordings were reviewed to determine if the intended activities occurred.

Themes of discussion were noted through the combined use of data sources. Concepts intended to be discussed to the extent planned were considered intended occurrences. Deviations from the intended occurrences were reported as unintended occurrences.

Module Satisfaction was determined through use of Module Evaluation Sheets. Some items required use of ratings. These items were weighted from five to one, with five as the most positive element on the scale and one as the most negative response. A mean score was determined for each item. Items requiring comments and short responses were reported in a descriptive manner.

Determination of the contingencies among antecedents, transactions and outcome observations was approached with an understanding that causality may exist, but the tools used in this project were not intended to measure these relationships.

The pre-test/post-test required short written responses for each question. Subjective judgments about the accuracy of each trainee's responses were made by the trainer, with no attempt to determine rater reliability.

The Follow-up Interview of each trainee was tape recorded. Trainee comments were noted, categorized and reviewed for common elements/themes. The comments were reported in a descriptive manner. In addition, interview data were reviewed in an attempt to determine relationships to the module package.

CHAPTER THREE

RESULTS

This chapter is divided into two sections. The
process review data section reports the results of data
gathered during the presentation of individual modules.
The outcome review data section reports the results of
data on the module package.

Process Review Data

The process review focused on individual modules with
the determination of congruence between the intended
transactions and the observed transactions. The observed
antecedents were reviewed in relation to the transactions
and outcomes for each Module.

Module I Occurrences - Session I

Thirteen service providers said they were committed
to participating in the advisor training. One week prior
to the beginning of the training, six of the prospective
trainees informed the researcher that they would be unable

to start on the intended day. Since these six people were unable to attend the first presentation session, a make-up session was scheduled for the following Monday.

The seven trainees who attended the first presentation session were identified as Group I. Two additional people made arrangements and joined the other six in attending the second presentation of Module I. These eight trainees were identified as Group II.

The pre-test was administered at the beginning of the Module I presentation session I. The module package was distributed and explained. An overview of the training occurred with an explanation of the modules and project. The reading of the People First Article did not occur.

The participant observer noted varied levels of intensity and involvement during the administration of the pre-test. She reported that some trainees needed support due to their lack of familiarity with terms and concepts used in the pre-test. Another observation was that Group I was aware of the trainer's disappointment of not enough trainees participating in the session. She felt this was an obstacle to the flow of events and the initial presentation of material.

The activity card exercise was conducted. A number of trainees expressed discomfort with pinning on the card. The feedback was used to modify the exercise for Group II.

The identifying issues of self-advocates exercise
resulted in sharing of many personal experiences. The
recording of examples did not occur due to time limitations
and trainees involvement in sharing their experiences.
This activity was allowed to continue for ten extra minutes.

Group I discussion focused primarily on advocacy and
self-advocacy. One trainee had her own view of self-
advocacy.

The discussion of self-determination did not occur,
but was briefly mentioned. This was due to time constraints.

The Impact Questionnaires, Module Evaluation Sheets
and Assessment Sheets were administered. Sixty-five
minutes of the first session were spent in the administration
of the test instruments.

Reading assignments for the following week were
distributed.

Module I Congruence of Presentation Intents and Occurrences - Session I

There was a discrepancy between the intended starting
date and the actual presentation of Module I. Fifty-three
percent of the trainees did not attend the first presentation
session. The presentation session for Module I was repeated.

The trainer's disappointment about the attendance at the
first presentation session was noticed by trainees.   He
did not intend to have his reactions to events affect the
flow of activities.

The reading of the People First Article was not read after the pre-test as intended.

Embarrassment was experienced by some trainees to the name card exercise. This was an unintentional occurrence.

The identifying issues of self-advocates exercise had the intended results, interaction and sharing of experiences. A written record of examples did not occur.

Group I discussion focused primarily on advocacy and self-advocacy. The self-determination discussion did not occur as intended.

The administration of data sources occurred after 5:30 p.m.

Module I Impact Questionnaire - Session I

Item 1: Differentiate between advocacy and self-advocacy.

All responses were brief definitions of advocacy and self-advocacy.

Item 2: Briefly explain self-determination.

One person wrote about motivation to act on wants and needs. Three commented on the ability to make decisions for self. Three others thought it was a right to determine one's own fate.

Item 3: What was your reaction to the People First Article?

All responded that they did not read the article.

Item 4: What do you feel about a national self-

advocacy movement?

Three people responded to the organizational

power of a social movement. Two commented

about the potential impact of the movement.

One person thought the question was too

broad. One person did not respond.

Module I Evaluation Sheet - Session I

Mean scores were reported for Items 1, 2 and 3.

(Table 2).

TABLE 2. MODULE I EVALUATION SHEET - SESSION I - WITH RESULTS.

Item 1: The presentation of the material was:

exciting	interesting	O.K.	dull	boring
5	4	3	2	1

Mean Score - 3.8

Item 2: The discussion on self-determination was:

very useful	useful	O.K.	not useful	a waste of time
5	4	3	2	1

Mean Score - 3.2

Item 3: The activities were:

rewarding	interesting	O.K.	dull	boring
5	4	3	2	1

Mean Score - 3.7

Item 4: What did you find most useful during this

session?

Three trainees found the group interaction

most useful, with two others who commented

on the discussion of values.

Item 5: What did you find least useful?

Two trainees found the name tag exercise

least useful, with another reacting to the

immediate evaluation. Four trainees com-

mented that the pre-test was least useful.

Item 6: What would you leave the same?

Three trainees liked the group interaction

and sharing of ideas. One person commented

on the name card exercise.

Item 7: What would you change in this module?

Three trainees commented on the lack of time.

One person wanted the content delivered faster.

Another wanted to eliminate the evaluation.

A sixth person would have liked to see more

people attend. The seventh comment was a

request to change the name card exercise.

Module I Occurrences - Session II

The second presentation of Module I occurred with

Group II. Group II attended on Monday at the same time as

originally scheduled.

The pre-test was administered in the same manner as with Group I. An orientation to the training and project was also given.

The activity card exercise was modified to reduce embarrassment. People were instructed to fill out the card as outlined then form triads and discuss what they were comfortable sharing. This allowed for more personal sharing without the difficulty associated with milling.

Four of the trainees were aware of a conflict of one of the trainees. This may have had impact on the group.

The identifying issues of self-advocates exercise had similar results as with Group I.

The discussion on advocacy and self-advocacy demonstrated a lack of clarity about advocacy roles. Consequently, self-advocacy was expressed as a vague concept.

The discussion on self-determination occurred. This was a difference between the content of the two Module I presentation sessions.

The session went fifteen minutes past the intended ending time.

The Impact Questionnaires, Module Evaluations and Assessment Sheets were administered. Again, sixty-five minutes were spent on the administration of the testing instruments.

The reading assignments were distributed as trainees were leaving.

Module I Congruence of Presentation Session Intents and Occurrences - Session II

Group II activity card exercise was modified and occurred as intended. The identifying issues of self-advocates exercise had similar results as Group I.

The discussion on advocacy and self-advocacy provided assessment information to the trainer. This was an intended result of using the discussion format.

The discussion on self-determination occurred but not to the extent sought. This was another difference between the presentation of the two Module I sessions.

It was not intended that the session went fifteen minutes overtime.

The data sources were administered as intended.

Module I Impact Questionnaire - Session II

Item 1: Differentiate between advocacy and self-advocacy.

All responses were brief definitions of advocacy and self-advocacy.

Item 2: Briefly explain self-determination.

Two respondents stated that self-determination was the basis for self-advocacy. Three commented on the motivation to control one's own life. Two discussed making choices and decisions for self. One wrote "filling your own needs."

Item 3: What was your reaction the People First

Article?

All respondents made positive comments about

the article. Seven wrote about the potential

effects of self-advocacy. One commented on

the historical perspective it offered her.

Item 4: What do you feel about a national self-

advocacy movement?

Five commented on the need for the movement.

One person wanted to know more. Two responses

focused on the organizational effort required.

Module I Evaluation Sheet - Session II

Mean scores were reported for Items 1, 2 and 3.

(Table 3).

TABLE   3.   MODULE I EVALUATION SHEET - SESSION II - WITH
             RESULTS.

Item 1:   The presentation of the material was:

exciting   interesting   O.K.   dull   boring

/_____/_____X_____/_____/

5   4   3   2   1

Mean Score - 3.0

Item 2:   The discussion on self-determination was:

very   not   a waste
useful   interesting   O.K.   useful   of time

/_____X_____/_____/_____/_____/

5   4   3   2   1

Mean Score - 4.3

Item 3:   The activities were:

rewarding interesting   O.K.   dull unfulfilling

/_____X_____/_____/_____/_____/

5   4   3   2   1

Mean Score - 4.4

Item 4:   What did you find most useful during this

          session?

          Five trainees found the discussion on self-

          determination most useful with two responses

          for the common concern for self-advocacy.

          One person liked the emphasis on group

          process.

Item 5: What did you find least useful?

Three trainees found the pre-test least useful. Another person commented on the short time for discussion.

Item 6: What would you leave the same?

One person said everything. Two others said the discussion. Another found the session very interest arousing. The fifth person enjoyed meeting others.

Item 7: What would you change in this module?

One person recommended an overview of the module package, with another requesting more time.

Module II Assessment

Item 1: Give an example of how you respected a mentally retarded person's dignity of risk. Two trainees gave examples that demonstrated the giving of support and respect for persons who sought new experiences. Four gave examples where failure for the mentally retarded person was anticipated. One trainee disagreed with the mentally retarded persons discussion but respected their choice. Five did not know of the concept.

Item 2: Why do you want to be an advisor to a
self-advocacy group?

Seven disclosed their desire to better the
lives of the disabled. Two saw the training
as an opportunity for self-improvement.
Three did not respond.

Item 3: What is a strength that you have that will
assist you in facilitating a self-advocacy
group?

Four trainees believed they had good listen-
ing and communication skills. Three believed
they could facilitate decision making. Two
commented on their leadership. One had a
strong desire to be an advisor. Another
wanted to see people happier.

Item 4: Do you feel competent to facilitate a self-
advocacy group?

Three responded yes, with two needing help
and seven said no.

Module II Occurrences

Refreshments were provided at the beginning of the
presentation session. This occurred in all subsequent
sessions. The intent was to provide trainees an opportunity
to relax and interact informally.

Individuals from both groups were introduced to each
other.

The discussion on the principles of self-advocacy was conducted in conjunction with the content of the reading materials. A lecture on the functions of the advisor followed. Definitions and examples of service providers as advisors were provided. The next topic was the role of the service provider as a change agent within an agency. Advisor skills were elaborated. The advisor skill assessment checklist was explained.

The self-advocacy group role play was conducted. Some trainees appeared to have difficulty participating in the role play activity. The participant observer noted that the advisor skill assessment checklist was threatening. Trainees did not want to evaluate each other. The activity needed more time as not everyone participated in each role. Processing of the role play provided an opportunity for trainees to share their experiences. The reactions of trainees to the role play activity was noted in the discussion with the participant observer.

One trainee held herself outside of the group. She repeatedly moved away from others and tended to sit behind others. She later withdrew from the training. Another shared conflicts and dilemmas she encountered in her work. A casemanager had deep insight about a client's perspective. A trainee expressed ambivalence in her role as advisor.

The participant observer noted in the review session the trainer's moderate position in bringing change into the system. A discussion followed about change strategies with a clarification of ideological positions.

It was noted that the advisor skill assessment checklist was incomplete. Directions were not clear and there was no place to put answers.

Module Evaluation Sheets and Assessment Sheets were administered. Readings were distributed.

Module II Congruences of Presentation Session Intents and Occurrences.

Module II refreshments were an added discrepancy from the original intents. This was generally well received except for those who were concerned about their weight.

Introductions between the two groups were not part of the intended presentation of Module II as outlined in the module package. This was an intended activity based upon the turn of events.

The discussion topics occurred as intended. One trainee observed that the content was similar to the concepts incorporated in community organization. She provided numerous resources to the trainer. This was an unanticipated occurrence that assisted in adding depth to the content.

The self-advocacy group role play occurred. Problems were noted with the advisor skill checklist. Everyone did

not participate in each of the roles as intended. The
activity required more time to enable each person to
participate in each role.

One trainee did not attend and withdrew from the
training.

The data sources were administered as intended.

The clarification of ideology between the participant
observer and the trainer was a welcomed unanticipated
occurrence.

Module II Skill Development Checklist

Fourteen trainees attended the Module II presentation
session. The Self Advocacy Group Role Play activity had
three groups, with five trainees in two and four trainees
in the other group. Each group had at least one role play
situation. One group completed two role plays. Six trainees
participated as advisors, representing forty-three percent
of trainees. Sixteen Advisor Skill Assessment Checklists
were returned.

A face value review of the checklist revealed
discrepancies between respondents when observing the same
trainee behavior In response to a question, one person
said yes, one said no, another said some and two did not
respond. Explicit directions and an explanation of terms
used were not provided. Consequently further review of
results of this instrument were considered fruitless.

Module II Evaluation Sheets

Mean Scores were reported for Items 1, 2 and 3.

(Table 4).

TABLE 4. MODULE II EVALUATION SHEET - WITH RESULTS
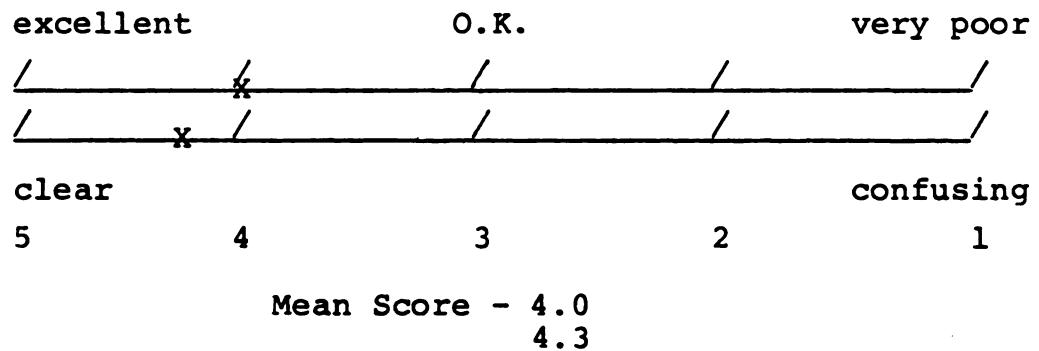
Item 1: The presentation of the material was:

excellent   O.K.   very poor

/_____X_____/_____/_____/_____/

/____X____/_____/_____/_____/

clear   confusing

5   4   3   2   1

Mean Score - 4.0
4.3

Item 2: The discussion on the Principles of Self-Advocacy
was:

excellent good   O.K.   poor   very poor

/_____X/_____/_____/_____/

5   4   3   2   1

Mean Score - 4.2

Item 3: The role play activity was:

helpful   good   harmful

/____X____/_____/_____/_____/

5   4   3   2   1

Mean Score - 4.3
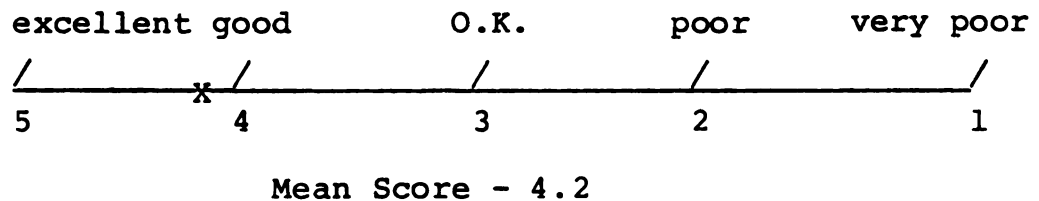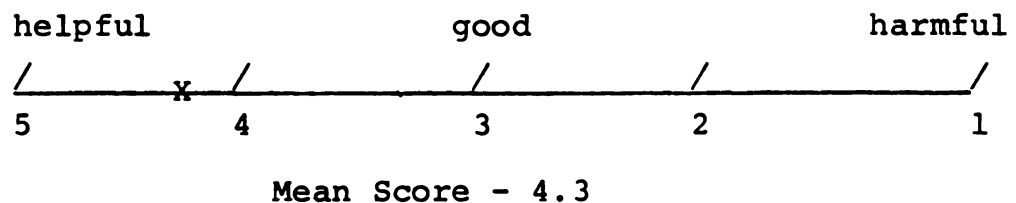
Item 4: What did you find most useful about this

session?

Five trainees found the lecture   most useful.

Two people found the discussion most useful.

Four others enjoyed the role play exercise.

One person enjoyed the entire session.

Item 5:   What did you find least useful?

Four trainees noted a lack of time to follow

through with group process. One person did

not like the role play exercise. One person

was disappointed that everyone did not

participate as an advisor in the activity.

One person reacted to another trainee's

comments. A trainee suggested that the other

trainees could be utilized more as teachers.

Item 6:   What suggestions or recommendations do you

have?

Seven wanted more time and directions for

the role play exercise. One person wanted

more group discussion. Another suggested the

group lead itself. A trainee thought there

was too much content for the session. Another

said the material was presented too fast and

wanted the meeting to end on time.

Module III Assessment Sheet

Item 1:   List three commonly held myths about the

developmentally disabled and mentally

retarded.

Seven trainees responded to the theme of the

retarded as a diseased organism. Ten

responded to the eternal child theme. Four

responded to the theme of a menace to society.

Four others responded to the theme of the sub-

human organism. Six used variations of the

theme as an object of dread.

Item 2: Write an example from your own experience

where a disabled person has expressed their

need to be a self-advocate.

Nine trainees responded with clear examples.

One gave an opinion and not an example. One

person did not respond to the question.

Item 3: Describe how you are perceived by the people

you are seeking to advise.

Six thought they were perceived as authority

figures. Two saw themselves as advocates.

Two felt as friends. There was one helper,

a social worker, a staff person, an expert

and two did not respond.

Item 4: Have you started working with people as an

advisor?

Yes___7___   No___3___   Don't Know___1___

If yes, do you feel more confident as a

result of what you have learned in this

training? Please explain.

Three were clearer about principles and

limits of advisor role. Three felt more

sensitive and empathic. One person broadened

their view of people.

If no, do you feel more confident to start as

a result of this training? Please explain.

One person felt more confident but wanted to

learn more. The other two only felt slightly

more confident.

Module III Occurrences

Twenty minutes was spent on discussions of assignments.
Some trainees expressed difficulty in completing assignments.
They did not expect to do homework and wanted work time to
complete training tasks, including readings. One trainee
resented the course structure of the training. This trainee
became defensive.

The discussion on developmental disabilities and mental
retardation was conducted. The discussion focused on the
myths and stereotypes society has placed upon the mentally
retarded. A historical perspective was offered that the
lowest bidder was given responsibility for taking care of
societies deviants. A few trainees supported this system
as being the most cost and personnel efficient. The partici-
pant observer noted that some did not question the system
because alternatives were not apparent.

The issue of consumerism was discussed. It was
pointed out that consumers often fear raising questions
about the services provided for fear of losing those limited

services. An example was given of a consumer who said in effect, "If I question this service they will send me back to the institution."

The development of a list of self-advocacy skills did not occur. Trainees did not have a broad picture of self-advocacy and tended to focus on behavior of individuals. It became apparent to the trainer that generalizing behavior to a list of skills was beyond the scope and time constraints of the training, and was the responsibility of the trainer.

The self-advocacy role play exercise occurred. When trainees role played self-advocates they were more submissive. Trainees role played the advisor as a stronger, more knowledgeable, authority person. The participant observer raised the question: "How strong can a self-advocate feel if they are reminded of their subservience?" The activity was not completely processed.

Module evaluation sheets were administered. The leadership style questionnaire was distributed with readings. The session ended ten minutes late.

Module III Congruence of Presentation Session Intents and Occurrences

Module III trainee reactions to the module assignments was a discrepancy between module intents and occurrences.

The discussion on developmental disabilities and mental retardation occurred. The participant observer noticed

that some of the trainees did not challenge the system because alternatives were not apparent.

A list of self-advocacy skills was not developed. The task of identification and categorization of behavior into skills was beyond the scope of the presentation session.

The role play exercise occurred. Trainees role played the advisor as a strong, knowledgeable, authority person and the self-advocate as submissive. This behavior was interpreted as a maintenance of the dependency relationship service providers may have with mentally retarded adults.

The data sources were administered. Three trainees asked for directions to be repeated.

The session ended ten minutes late, an unintended occurrence.

Module III Advisor Skill Checklist

Ten trainees attended the Module III presentation session. The Self-Advocacy Role Play Exercise had trainees organize themselves into three groups of three. Each person had the opportunity to function as the recorder once in the exercise. Ten Advisor Skill Checklists were returned.

A face value review of the checklist revealed that the trainees did not have enough exposure to the checklist to respond accurately or consistently to items. Directions

and explanation of terms were not adequate for the use of this instrument. Consequently, further review of results of this instrument would be fruitless.

Module III Evaluation Sheets

Mean scores were given for items 1, 2 and 3. (Table 5).

TABLE 5. MODULE III EVALUATION SHEETS - WITH RESULTS.

Item 1: The presentation of information was:

excellent	clear	O.K.	vague	confusing
/	/	/	/	/
5	4	3	2	1

Mean Score - 3.6

exciting	interesting	O.K.	dull	boring
/	/	/	/	/
5	4	3	2	1

Item 2: The practice interventions activity was:

rewarding	interesting	O.K.	vague	confusing
/	/	/	/	/
5	4	3	2	1

Mean Score - 4.3

Item 3: My satisfaction with this module is:

great	fine	O.K.	low	poor
/	/	/	/	/
5	4	3	2	1

Mean Score - 4.3

Item 4: What did you find most useful in this session?

Four trainees found the discussion of ideas with development of new attitudes as most

important. Three trainees stated the role
play most useful. One person believed the
group process was the most useful aspect of
the session.

Item 5: What did you find least helpful?

Two commented on the discussion of assignments
as least helpful. One person did not like to
fill out the assessments. Two trainees
thought the group discussion was dominated
by a few trainees and felt they lost an
opportunity to gain more information from
the trainer. One person found the entire
session to be interesting.

Item 6: I would recommend these changes:

More time for role play and discussion in
small groups was one person's recommendation.
Another suggested more snappy and direct
facilitation. Two people commented that
they enjoyed the session.

Module IV Supervisory Attitudes: The X-Y Scale

Eleven trainees completed the Supervisory Attitudes,
The X-Y Scale. All eleven trainees placed themselves be-
tween thirty and forty on the Theory Y assumptions side of
the scale. This would indicate that they were more demo-
cratic leaders. The training promoted democratic leadership
styles. There may have been a training effect that could

have biased the trainees responses. This instrument did not provide useful information for planning the Module IV presentation session.

Module IV Occurrences

Session opened with a lecture on group development. Questions of motivation were raised with respect to the conflict stage of group development. The issue of motivation was presented as a perceptual problem, with the advisor as a facilitator to the self-advocacy group in the establishment of constructive norms to resolve conflicts.

One trainee pointed out that she had been in a women's group for seven years and the stages outlined fit her experience.

A trainee brought up the power roles as professionals. This power position results in promoting the deficiency needs of consumers. From this perspective, some professionals find the promotion of interdependence between the professional and service recipient threatening to their professional role image.

An example was given that demonstrated empowering self-advocacy group decision making. A group was given a donation of $1,500.00. The decision making process was democratic with all decisions being discussed and voted upon. The group was secure in its norms for voting on issues. The self-advocacy group deliberated at it's own pace. The interaction over a period of time resulted

in greater cooperation and an increased confidence of self-advocates. The wisdom of their judgement was noted.

The stages of decision making were listed along with a brief discussion on problem solving.

The practice intervention activity occurred. Only three trainees had an opportunity to function as the advisor. After each role play, a discussion occurred that focused on the previous lectures and discussion. These feedback and discussion sessions brought out issues that individual trainees were having with the people they were serving.

The last ten minutes focused on four assumptions of groups and three types of leadership style. This presentation of content was rushed.

The Impact Questionnaire, Module Evaluation Sheets and Assessment Sheets were administered.

Three trainees did not attend. A trainee withdrew from the training.

Module IV Congruence of Presentation Session Intents and Occurrences.

Module IV, a lecture on group development was presented as intended. The issue of motivation was an unintended occurrence. This issue suggested that the concept of self-advocacy as a felt need may not have been understood by those trainees.

The elaboration on the power position of professionals assisted the group to develop a perspective toward their roles as advisors. This was an unanticipated occurrence.

The presentation on decision making and problem solving occurred but was not developed adequately. Ten minutes were provided for the dissemination of this content.

The practice intervention activity occurred. Each trainee was intended to function as advisor. Three trainees participated as advisors.

Ten minutes were given for a lecturette on groups and leadership styles. This was not enough time to develop the content.

The data sources were administered. Three trainees wanted to leave and asked if they could mail their question-naires. This was agreed upon by the trainer and represents an unintended occurrence.

Module IV Impact Questionnaire

Item 1: Label and briefly describe the stages of group development.

Three trainees correctly labeled and explained the four stages of group development that were presented. Two trainees correctly de-scribed the stages of group development. Two correctly labeled the stages of group development. One person wrote only three

labels. Two others did not appear to understand the concept.

Item 2: Identify the steps in the problem solving approach.

Eight trainees had correct responses to this item. One person did not find her reference to the material presented in the module readings. One person had a short criptic response to this item.

Item 3: Identify the steps in decision making.

Nine trainees had correct answers to this question. One person had her own answer that did not reflect the readings or the presentation session. One person did not answer this item.

Item 4: Fill in and explain: I believe my skills as an advisor to facilitate self-advocacy groups have _____ during this session. Explain.

Eight felt their skills had improved. One person was the same, and one person did not answer the item. Seven trainees felt more aware and conscious of the task of being an advisor. They all felt more confident as expressed in their remarks. One person worked through some conflicts she was having

and found many positive suggestions from the group. One person found too much philosophy of groups and desired concrete examples.

Module IV Evaluation Sheets

Mean scores were presented for Items 1, 2 and 3 (Table 6).

TABLE 6. MODULE IV EVALUATION SHEET - WITH RESULTS

Item 1:   The presentation of information was:

excellent	clear	O.K.	vague	confusing
/	/x	/	/	/
5	4	3	2	1

Mean Score - 3.9

exciting	interesting	O.K.	dull	boring
/	/x	/	/	/
5	4	3	2	1

Mean Score - 3.8

Item 2:   The practice interventions activity was:

rewarding	interesting	O.K.	vague	confusing
/x	/	/	/	/
5	4	3	2	1

Mean Score - 4.7

Item 3:   My satisfaction with this module is:

great	fine	O.K.	low	poor
/	/x	/	/	/
5	4	3	2	1

Mean Score - 4.0

Item 4: What did you find most useful in this session?

Seven people found the role play activity most useful. Two others like the discussion about group dynamics.

Item 5: What did you find least helpful?

There were only four responses to this item. One person wanted more information on group dynamics. Two felt the didactic information was excessive. One person did not like the role play exercise.

Item 6: I would recommend these changes:

Two trainees wanted more group problem solving and interaction with each other. One person suggested more time for practice and discussion.

Module V Assessment

Item 1: Due to this training my ability to work with disabled people has increased in these areas: Six trainees mentioned an increased sensitivity to the needs of the disabled. Four commented that they were encouraging self-direction and decision making. Three said that they had increased their empathy skills. Three had gained in group problem solving facilitation. Two gained a new perspective on the rights of

the disabled. Two increased their leadership
skills. Two commented that they were more
acceptant of assertive behavior by the dis-
abled and one person gained confidence.

Item 2: List five assertive beliefs you have.

Four trainees wrote five assertive beliefs.
One person wrote four assertive beliefs.
Two trainees had three assertive beliefs.
Two people wrote two assertive beliefs.
One person wrote five personal beliefs about
the disabled. One person commented that
she had not formulated any assertive beliefs.

Item 3: List two laws that have had an impact on
changing the rights of the developmentally
disabled.

Five trainees correctly identified two laws.
One person listed a law and the consequence
of a law. One person commented on the
effects of laws but did not mention any
laws. Two stated that they did not know
any laws. Two did not respond to the item.

Module V Occurrences

The first ten minutes of the session focused on the
trainer's data collection problems.

A discussion on assertiveness was started with a
trainee defining assertiveness. Trainee perceptions of

self-advocates being assertive was explored. This issue
was intertwined with the issue of civil rights and rights
for the disabled. It was discovered that many of the
trainees were unaware of many laws and rights of the dis-
abled. The issue of proposed federal cutbacks was dis-
cussed. Rights were perceived as moral and ethical issues.

Concern was expressed about consumer's questioning
rules. The suggestion was made to facilitate people to
negotiate for new rules. Also, that consumers become an
integral part of the rule making process. It was pointed
out that the questioning attitude was a constructive sigh
of growth and showed the consumer wanted responsibility.
The advisor could legitimize the questioning and communicate
openly to bring about change. The advisor with the system
had the function to cultivate the environment to open the
system to consumer criticism and consumer directed change.

There was some confusion on a trainee's part about the
non-normalizing quality in granting rights to the disabled.
She commented that the disabled had enough rights and any
efforts to grant "additional" rights further stigmatized
them.

A strong point was made by a trainee of the negative
consequences of supporting the deficient view of mentally
retarded people as being irresponsible. The concern was
expressed that caring was equated with control.

The impact Questionnaire, Module Evaluation Sheets and Assessment Sheets were administered.

Readings for the following session were distributed.

Module V Congruence of Presentation Session Intents and Occurrences.

The first ten minutes of the session focused on the trainer's data collection problems, an unintended occurrence.

The discussion developed as intended with relevant points. An observation was made that assessed many of the trainees lack of awareness of laws and rights of the disabled.

Though trainees did not know laws, in fact, they did support the principle of the law. There was a deep commitment ot the growth and development of the mentally retarded. Trainee response to consumers becoming part of the decision making process was an indication learning had occurred.

The trainee who questioned the normalizing qualities of special rights for the disabled, appeared to the trainer that she did not accept the rights of the disabled. The participant observer thought the comment was more of an attempt to understand and explore the concept of normalization and human rights.

The comment on the negative effects of supporting the deficient view of mentally retarded people was a repeated theme through the training. The potential for human growth and the identification of the caring relationship was

valuable and useful content, but was not intended to the extent that it occurred.

The administration of data sources occurred as intended.

Module V Impact Questionnaire

Item 1: Explain how human rights are associated with responsible assertive behavior.

Three trainees commented that non-assertive behavior impedes access to one's human right because it entails denying one's self. Another two discussed rights as a basis to justify assertive behavior. Two people commented on the necessity to understand rights as a means to be heard. Two differentiated between assertiveness and aggression. Two comments did not link either concept.

Item 2: I am questionning and seeking to change a non-assertive belief that I hold:

Yes __8__   No __2__   Does Not Apply __1__

Item 3: I am considering to add _____ assertive beliefs to my belief system.

Two people commented that their growth did not equate in numbers of beliefs. The other six filled in numbers but did not comment.

Item 4:   What would you say to a client you work

with who expressed this belief to you:

"I know it's wrong to hurt people and I

don't ever want to hurt anyone."

There were two distinct approaches to this

question. Seven people responded by show-

ing concern for the person and their need

to be aware of their own wants and feelings.

The other four responses were exploratory

questions about the persons sense of hurt,

their feelings about themselves and the

need to resolve conflicts.

Module V Evaluation Sheets

Mean scores were reported on Items 1 and 2 (Table 7).

TABLE 7. MODULE V EVALUATION SHEET - WITH RESULTS.

Item 1:   I found the content of the material:

simple	easy	appropriately challenging	difficult	too hard
1	3	5	3	1

Mean Score - 4.6

Item 2:   The discussions were:

exciting	useful	interesting	dull	boring
5	4	3	2	1

Mean Score - 4.1

Item 3: What did you find most useful in this
module?

Three trainees found the discussion on
normalization, rights and responsibilities
the most useful part of this module. One
person commented on the conflicting
philosophical systems operating in the com-
munity. Another person mentioned the
implications of law and legislative decisions
that had an impact on the consumer's rights
movements. A trainee found the readings on
assertive belief systems useful. Another
person commented on the discovery that she
denied mentally retarded people credibility
in their assertiveness. Two commented on
the general discussion.

Item 4: What did you find least useful?

One reacted negatively to the P.L. 94-142
and Section 504 article.

Item 5: What changes would you recommend?

One person suggested the inclusion of
Chapter Seven of Michigan's Mental Health
Code, instead of the P.L. 94-142 and Section
504 article. One person would not change
anything in the module.

Module VI Assessment

Item 1: Describe your feelings about starting a self-advocacy group.

Three trainees were excited and interested in working with self-advocacy groups. Four commented that they supported the concept of self-advocacy but did not feel they had the time to get deeply involved with a self-advocacy group. Two were excited by the concept but had a fear of failure. One person was planning leaving his job and would not be available to continue a group.

Item 2: Discuss ways to implement a self-advocacy group.

Two trainees did not respond to the question. The other eight made suggestions that started with an assessment of the need for a self-advocacy group. Three suggested to wait for an event to happen and start discussions at that time. Three suggested that they would promote the idea and develop interest in the group concept. They all saw the advisor as the critical person in the formation of a self-advocacy group.

Module VI Occurrences

Ways to change the job situation was the opening discussion. Three trainees presented problems of becoming advisors. One was negative in all her responses during the session.

A trainee suggested the need for administration and residential change to promote self-advocacy.

A trainee discussed the possibility of promoting self-advocacy on an individual level. Another suggested the effective use of incident reports and recipient rights complaints.

The trainer gave an example of self-advocates at a work activity center who formed a rights committee to question the procedures used to remove an aggressive client to the quiet room. This committee had meetings and con-fronted the staff and supervisor about the policy and procedures. They requested and held meetings with the rights advisor. The person who was being given this special treatment was included by the committee in meetings. This example demonstrated the legitimacy of the complaint and an effective use of the recipient rights advisor.

An example was given by a trainee that staff were being required to develop program plans for themselves as a means to sensitize them to the experience of consumers. He reported that the staff felt threatened by the experience.

Another example from Moore Living Center focused on some staff attempting to remove a hierarchical organizational structure thus equalizing the roles of staff and creating an atmosphere of equality as a cooperative organization.

An election process was explained that could be used at work activity centers. Another model was discussed for residential programs.

A suggestion was made to continue to meet as an advisor support group. The trainees voted to continue to meet on a monthly basis. The trainer was to gain administrative approval and time for the continued meetings.

The Impact Questionnaires and Module Evaluations were administered.

Module VI Congruence of Presentation Session Intents and Occurrences.

The discussion on ways to alter work situations for advisors reflected an ambivalence about change and trainees' capacity to effect change.

Some trainees gave examples that indicated they understood the principles of the training.

A trainee proposed to continue meeting on a monthly basis. All of the trainees agreed to the proposal. Some may have voted to go along with the group. Of the fourteen people (trainer included) who attended the sixth presentation session, ten have continued to meet on a monthly basis. The inclusion of an advisor support group was an unintended occurrence.

The administration of the data sources were completed as intended.

Module VI Impact Questionnaire

Item 1: Outline a plan to start a self-advocacy group.

Nine respondents had at least four steps in their plans. The key points covered were: to discuss ideas with people interested in organizing a group, assess needs and problems of potential group members, identify natural leaders, assist in the organization of an initial meeting, assist in the formation of a group, involve others in the community who have been involved in self-advocacy groups.

Item 2: List resources that you and self-advocates have available.

Some of the comments included other staff, Protection and Advocacy office, Recipient Rights Advisors, Greater Lansing Association for Retarded Citizens, Association for Retarded Citizens, parents, People First, other self-advocacy groups.

Item 3: What will you look for when assessing the
needs of self-advocates?

Seven responded to the expressed needs of
the person. Three were sought to assess
the level of interest shown by the person.
One suggested to observe how a person leaves
options open for themselves. Skills possessed
and skills needed combined with an understand-
ing of the person's self-awareness were
dimensions suggested by a trainee. Five
were not sure of the question.

Item 4: Write a statement reflecting your belief
about the need for self-advocacy.

Twelve trainees responded to the question.
Eleven were very positive about self-advocacy
and saw the concept had affected their work.
Each of these people were concerned for the
mentally retarded and sought to improve
the living conditions of these people as
well as they could. One person did not see
self-advocacy as a need by some people.
This person commented that agencies will
still monitor the goals and objectives of
self-advocates.

Module VI Evaluation Sheets

Mean scores were given for Items 1, 2 and 3 (Table 8).

TABLE 8. MODULE VI EVALUATION SHEET - WITH RESULTS.

Item 1: I found the discussions to be:

exciting informative interesting redundant irrelevant

/_____/x_____/_____/_____/

5   4   3   2   1

Mean Score - 3.9

Item 2: The content for this module was:

too easy simple   challenging   difficult   too hard

/_____/____x___/_____/_____/

1   3   5   3   1

Mean Score - 4.7

Item 3: As of this module my commitment to be an advisor to self-advocacy groups has:

increased   stayed
greatly   increased   the same   decreased   plummeted

/_____/____x___/_____/_____/

5   4   3   2   1

Mean Score - 3.8

Item 4: What did you find most useful in this module?

Two commented on starting a group. One person found the group support most useful. Another liked the challenge to be an advisor. One person found the discussion on political radicalism most useful. Three liked the group discussions.

Item 5: What did you find least useful?

One person did not like the time spent on resolving issues of beginning a group. Another person was distressed because of the three cookies he ate. A trainee did not like the Warren article.

Item 6: What would you change?

One person suggested to include a bibliography. Another did not care for Warren article, felt the author saw the parents as consumers of services.

Item 7: What would you leave the same?

Discussions was one comment. The other comment was the flexibility of the group to explore situations that arose in the training.

Outcome Review Data

The Outcome Review determined the congruence between intended outcomes and observed outcomes, and observed antecedents were reviewed in relation to the observed out-comes (Stake, 1967). Data were sought to determine the over-all impact the module package had upon each trainee. The intent of the Pre-test/Post-test was to give an indication of trainee growth in comprehension of content. The Follow-up Interview was designed to determine the relevance of con-tent and identify recommendations for product improvement.

Pre-Test/Post-Test Occurrences

Pre-test/Post-test face value review revealed that the construction of the instrument was not adequately developed for aggregation of data. The subjective judgement of the trainer was used to determine the extent of comprehension of trainee knowledge of test items. A methodology was not developed for rater reliability. This negated the possibility of determining test validity, which precluded the determination of trainee gains in comprehension.

The test was useful as an advanced organizer. The Pre-test provided the trainer with an impression of trainee familiarity with training content.

Follow-up Interview Occurrences

The purpose of the Follow-up Interview (Appendix G) was to determine the relevance of the content of the instructional materials and to elicit recommendations for product revisions.

Ten of the twelve trainees who completed the training participated in the Follow-up Interview. Ninety percent of those interviewed had recommended the training to others. Those interviewed included: Two casemanagers, one residential casemanager, two therapists, one physical therapist, two residential counselors and two residential aides.

Consciousness raising was reported by five trainees to have been the most important effect of the training. Three people reported a change in attitude toward their clients. The consciousness raising concerned the movement of mentally retarded people as an oppressed minority who are seeking their human rights. Three trainees stated they were more aware of the rights of the disabled. A deeper understanding of the advocacy relationship was discussed by one trainee.

Four trainees discussed their increased awareness of their role in working with the disabled. The value of gaining the disabled persons perspective was reported by five trainees. Four trainees stated that they learned alternative approaches in working with the disabled. Four people discussed the facilitation of independence. Seeking self-control rather than relying on external or environmental controls was a perspective valued by four trainees. The dignity of risk was a unifying concept for three trainees.

Three trainees explored methods to develop opportunities for the disabled to be responsible. These methods involved opening the system to change and included the legitimizing of the disabled persons input.

Four trainees reported that they facilitated problem solving. Two of these people stated that the training had an effect that allowed them to take the time to listen

to the person and allow the person to complete the task for themselves. These trainees resisted an urge to solve the problem for the disabled person. Both trainees commented that they realized the person could follow through and solve the problem. Two people disclosed their tendency to rescue others. Two of the trainees who assisted with problem solving also realized that they facilitated the disabled person to be assertive. They gave examples of these occurrences.

The discussions of philosophy were important to four trainees. The concept of caring in the helping relationship was clarified by three of the trainees. Two people commented about the conflict of competing philosophies with a vast difference between those who seek independence for the mentally retarded and those who they see as seeking the maintenance of dependency relationships. One person found the discussions of philosophy distasteful.

That the phenomonological approach was an important perspective to consider when working with the disabled, was a view held by five trainees. Four found this a new perspective while one trainee appreciated the support for an orientation she had promoted. Two people discussed the implication that the phenomonological approach established a new criterion for intervention and judgement about people and programs.

The view of the service provider's role to determine the cultural norms for the mentally retarded to conform

to a middle class view of acceptable behavior was altered by four trainees. The trainees were concerned that some service providers assume the responsibility to control the behavior of their clients and limit opportunities for the client to exercise judgement, responsibility and self-control. The value of people gaining the power to make decisions about their lives was noted by one trainee as an alternative approach to the development of self-control.

Three trainees were assisting staff and disabled persons at their sites to start self-advocacy support groups. One of these trainees was starting a support group for severely physically disabled people. The people this trainee was working with had expressed a need to become a self-advocacy group.

House meetings were the forum used to develop a self-advocacy group in a residential program. Two trainees shared their perceptions and expectations for the development of a residential group. One trainee had difficulty in accepting the level of discussion of the group. She preferred the exploration of issues. Both trainees were concerned about their expectations and influence with the residents of the home.

Six trainees reported that they were working with individuals to develop self-advocacy skills. Three trainees stated that they never intended to be involved in self-advocacy groups. They preferred to work on a

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one-to-one basis with people. One person could not envision
how to gain the time necessary to advise a self-advocacy
group and maintain her current position. She did not
think it was feasible to alter her work load. A resident
counselor saw herself as a role model to other staff at
the site where she worked. For her the training provided
ideas for staff development. She was specifically inter-
ested in developing problem solving and assertiveness among
the residents, and these residents expressed no interest in
forming a support group.

Staff presentations were discussed by four trainees.
These trainees were interested in developing conditions for
the acceptance and encouragement of self-advocacy. They
talked about their supervisors' favorable reaction to the
content they were planning to present.

Three people commented that the sequence of the
presentation was good. One said that she was not sure at
times how the different concepts fit together but they
fit perfectly. Two trainees stated that occasionally the
discussion lost direction and consequently they had dif-
ficulty following the development of concepts.

One trainee did not alter her perceptions about the
mentally retarded.

One trainee saw value in close personal relationships
based on natural affinities.

Trainee interaction was perceived as an important process of the training. Five trainees commented that the sharing of everyday experiences allowed them an opportunity to think through situations. One person stated that she enjoyed listening to the ideas of the others. Two other trainees wanted more structure in the discussions. Another person commented that the frank discussions and exploration of ideas was a real eye opener for her. The interaction with other trainees provided one person an opportunity to re-evaluate her role in working with others. She stated that she felt a common bond with the other trainees.

Two people discussed trainee frustrations that were expressed during the presentation sessions. They felt the frustrations were barriers being encountered to open themselves and the system. One person who was willing to express and discuss her frustrations suggested another forum for this disclosure and that some trainees did not separate their job frustrations from the training goals.

The trainees commented on the value of the reading material. Two people were critical of the P.L. 94-142 and Section 504 article.

The module design was commented on by seven of the trainees. Seven did not like the Assessment Sheets, Impact Questionnaires and Module Evaluation Sheets. Five commented that they just filled them out for the trainer and found

little learning in the experience. Three commented that the directions were confusing. Two remarked that they were tired and by the end of the presentation session did not feel like concentrating. One found the goals and rationale useful to organize her thoughts.

Five trainees suggested to provide more direction to assist trainees to use materials. One person wanted more role playing exercises; one person wanted less. Another suggested an increase in intimacy exercises. One person wanted more structure.

Five people suggested an increase in the amount of time for the training, with specific suggestion of two hours a day, two days a week. Another person recommended a two or three day retreat. Two people would have preferred the training in the morning.

Table 9 summarizes the Self Report of Theme Application. As can be seen, ten trainees acted to promote self-advocacy at their work sites. All of the trainees stated in the interview that they did something to demonstrate that they functioned as an advisor to a mentally retarded person. Eight trainees interviewed assisted a Self-Advocate to speak on their own behalf. Four of the trainees had facilitated a self-advocacy group, while six did not act on this theme. Nine of the trainees made claims that they promoted consumers rights. There were no data for the tenth person. Seven trainees acted to develop opportunities for mentally

TABLE 9.   SELF REPORT THEME APPLICATION

Module	Theme	Acted On	No Action	No Data
I	Self-Advocacy at the Service Site. Trainee promoted Self-Advocacy at work site.	10		
II	Role of Advisor to Self-Advocates. Trainee demonstrated an advisory role.	10		
III	Facilitating the Self-Advocate. Trainee worked with a Self-Advocate to speak for self.	8		2
IV	Facilitating Self-Advocacy Groups. Trainee facilitated a Self-Advocacy Group	4	6	
V	Developing Rights and Responsibilities. Trainee promoted consumer rights.	9		1
	Trainee developed opportunities for consumers to be responsible.	7		3
VI	Starting a Self-Advocacy Group. Trainee was involved as an advisor to a self advocacy group.	4	6	

retarded people to be responsible.   There were no data for three trainees.   Four trainees were advisors to self-advocacy groups.   Six trainees were not involved with self-advocacy groups.

The extent of involvement was not determined.   The reliability of the claims was not varified.   Measurement devices were not developed for those purposes.

CHAPTER FOUR

SUMMARY, DISCUSSION, RECOMMENDATIONS FOR REVISIONS AND IMPLICATIONS FOR FUTURE RESEARCH

Summary

The general purpose of this project was to develop instructional materials to be used in the training of service providers as advisors to self-advocates. In order to accomplish this purpose, three tasks were identified: Product Development, Product Implementation and Product Evaluation.

Product Development

The background for the development of materials involved a review of the literature in the field of mental retardation. The literature review, integrated with personal experience, provided the philosophical foundations for this project with supporting social, psychological and legal evidence.

Expert opinion was sought to identify the contents. Two events were planned to gain the ideas and perspectives of self-advocates, self-advocacy advisors and advocates.

The first event was a National Survey of self-advocacy advisors and self-advocates. The results of the survey were used to identify content ideas and resources.

The second event was a workshop of advocates and one self-advocate who reflected upon the results of the survey. Their task was to refine and identify ideas and issues to be included in a package of instructional materials.

A module format was chosen for organizing the instructional materials. Each module had a theme, rationale, goals, objectives, activities and readings. There were six modules developed to reflect the themes of the identified content. The six modules comprised the module package.

Product Implementation

The module package was implemented in six presentation sessions. Each presentation session corresponded to the module with the related theme, objectives and activities. The presentation sessions were conducted weekly for six weeks. Each session was designed to be two hours long.

Product Evaluation

The objectives for Product Evaluation were to make recommendations for product revision. The Product Evaluation was conducted during and after the field-test of the module package.

A number of data sources were designed to field-test
the instructional materials (Module Package). A Pre-test
and Post-test were developed to measure selected content
knowledge. Each module contained an Assessment Sheet,
either an Impact Questionnaire or Skill Sheet and a
Module Evaluation form. Other data sources included:
anecdotal notes and a participant observer. These data
sources were used to determine: the appropriateness of
individual module content, the impact of the seminar
session on trainees, the continuity of content design
and trainee gains.

A Follow-up Interview was conducted with each trainee
one month to six weeks after completion of the training.
The purpose of the interview was 1) to determine how or
to what extent the trainees applied the content of their
respective work situations, and 2) to determine what aspects
of the content was most relevant to the trainees.

A Process Review was conducted on the presentation
sessions to make comparisons between the intended module
goals and activities with session occurrences. The Out-
come Review was an attempt to determine the relationship
between test gains, comprehension of content and application
of content made by trainees to their work situation.

Results of Product Evaluation

The results of the Review Process indicated that the presentation session occurred as intended, suggesting congruence. Discrepancies of the intents and occurrences, when they appeared, were due to time constraints, excessive testing and the desire of trainees to include content that was beyond the intended scope of the presentation session.

The data sources for comprehension were not adequately developed to provide reliable data. These measures were useful in identifying additional aspects of the instructional materials to be evaluated. Attitudinal measures may be a better indicator of trainee gains than cognitive gains.

The Follow-up Interview provided data about the application of content to the work situation. Only four of ten trainees were involved with self-advocacy groups at the time of the Follow-up Interview. Application of content to start a self-advocacy group did not occur for seven of the trainees interviewed. However, trainees reported that they had promoted self-advocacy on individual levels and sought to encourage co-workers to embrace the concepts of self-advocacy.

Discussion

Philosophical Issues

Understanding mental retardation from a phenomonological perspective requires a suspension of one's own assumptions and beliefs (Taylor and Bogdan, 1977). This perspective was important for many of the trainees. They discussed an alternative approach that assisted them to transcend their assumptions (Blatt, 1977). There was the realization that this perspective could facilitate independence (Goldenberg, 1978).

Wolfensberger (1972) discussed the seven myths of mental retardation. A review of the presentation sessions and follow-up interviews gave indications of the insidious nature of these myths. Infantilizing actions perpetuate the myth of the eternal child. Treatment and programming could have the effect of maintaining the image of the diseased organism. Efforts aimed exclusively to control behavior may maintain the myth of a menace to society.

The process of the training sought to bring about changes in how trainees perceived the mentally retarded. Perceptions did change for some but the stigmatizing effects of cultural myths were also prevalent.

Social Issues

Consciousness raising about the mentally retarded as an oppressed minority occurred for five trainees. They

expressed an understanding of the stigma of being labeled mentally retarded (Barber, 1968); Wolfensberger, 1972; Blatt, 1977; Katz, 1976). Three people stated they had a change in attitude toward the disabled.

Wolfensberger (1972) discusses the difficulty most people have with change, often reacting to change rather than taking a pro-active role. The mentally retarded person has two limitations to overcome. One is the disabling condition itself and the other is imposed by society. Changing the perceptions of those who provide services of the disabled is part of the change process. Perceptions held by service providers make it difficult for them to see an opportunity to promote change. Two trainees discussed their frustration with opening themselves and the system.

Goldenberg (1978) discussed the difficulty he encountered in training community organizers. He attributed part of the difficulty to the background and formative experience of the trainee. These early experiences generate many perceptions (Combs and Snygg, 1959). A trainee may embrace the ideas and ideals of empowering the disadvantaged yet may not be able to apply what has been learned. For example only two trainees had started new self-advocacy groups.

The above perspective places the responsibility for change on the trainee. This may be unfair since the Module Package content or the process of

instruction may not have been adquately developed to enable the trainee to learn what was necessary to bring about change to the system.

Role of Advisor

The service provider may not be in a suitable position to be an advisor to self-advocates. They may have too many conflicts of interest to enable them to facilitate groups of people to assert their rights and provide a service. This concern was expressed by two respondents to the National Survey and a workshop participant. It also appears in the literature (Woodyard, 1980).

Five trainees stated that the training provided them an alternative perspective in their relationships with disabled persons. The necessity to rescue, control, treat or program was challenged. A new role was offered that could assist service providers and consumers to free themselves of the cultural myths of mental retardation.

Service providers who viewed their role as an advocate for the disabled are more likely to be in a position to promote self-advocacy. Self-advocacy groups represent one form of advising and may be limiting in terms of the needs and learning styles of individuals. Some service providers can facilitate groups and can alter their job role sufficiently to follow the self-advocacy group model, while others cannot. Service providers can promote self-advocacy

with individuals resulting in effective ways to gain services, employment, housing or recreation. For example, all of those interviewed had at least once worked with an individual to assist them to advocate for themselves. Case-managers can cultivate self-advocacy by encouraging partici-pation of the person in their own program planning. This would include meeting with the person prior to the meeting and working with them to identify their goals and objectives. Service providers in day programs can facilitate resource development and utilization. Those in residential programs can work with individuals or groups for house meetings.

The desire for democratic principles to be applied to the treatment of the disabled was evident with those inter-viewed. Four trainees saw the value in the development of self-control. This is viewed as the recognition for self-determination of the disabled (Goldenberg, 1978; Rank, 1956; Nirge, 1972).

Recommendations For Product Revision

Recommendations for this project are organized according to the three major tasks, namely: Product Development, Product Implementation and Product Evaluation. Each of these tasks had areas where revisions were found to be necessary.

Product Development

An introduction and orientation to the Module Package is needed. This will provide an explanation of the uses of the modules and assist trainees in their planning. Included will be the overall goals, a rationale for the complete package, an explanation about data collection will also be a clarification of the expectations of trainees.

One function of the Module Package was to guide the trainer in the presentation of the training sessions. The modules served as a general guide, but greater specificity was desired. Presentation notes were developed to serve this function. These notes further defined and outlined the content. The development of presentation notes utilized the concepts and activities in the modules along with data from the module evaluation instruments. These notes represent the beginning of a trainer's manual. Further work is required to develop a trainer's manual.

Reading materials could be included in each module, and not listed as indicated in the Module Package. This would enable trainees to read at their own rate.

Discussions, group interaction and role play activities were positively reacted to in each module. This suggests that the presentation sessions were useful to the trainees.

The training could be individualized for each trainee. This would assist the trainees in their attempts to apply the content to their work situation, a difficulty noted in the results.

The goals, rationale, objectives and activities of each module could be reviewed to make corrections in language and content. Additional objectives need to be written such as: In Module I, the first objective listed under the first goal statement was not congruent. The second paragraph in the rationale was found to be vague.

The inclusion of a bibliography in the Module Package was recommended by a trainee. A bibliography would allow trainees to explore areas of interest.

A recommendation that did not result from the data sources, but was realized in conducting the field-test, was that adjunct audiovisual materials could have been useful. Movies, slide tape sets, photographs and tape recordings would be sought or developed to elaborate and exemplify concepts.

The Follow-up Interview provided data that suggested administrators and supervisors were seeking information about self-advocacy. A module could be developed to facilitate the change process within an organization. Such a module could include statements of philosophy, psychology and an activity that would assist in the generation of ideas to implement the conditions that would allow for the development of self-advocacy.

The Pre-test should be removed from the Module I presentation session. Sufficient time was needed for the elaboration of content. Modifications were made to the activity card exercise.

Module II could be expanded into two sessions. This would allow sufficient time for the presentation of the content. Additional materials could be included in this module on the qualities of a caring relationship. A differentiation needs to be made between the concepts of caring about another and taking care of another. The negative consequences of infantilization could be explored in a discussion with examples of adult-to-adult communication.

Content could be developed that further separates the concepts of taking care of people and exhibiting care for another person. The first example is infantilizing, which places care takers in a controlling, domineering and power-ful position over another person. The second position is showing care for the well-being of another, which reflects an attitude of compassion. Showing care for another places people in an equal role with the message that people exhibit care in an adult-to-adult manner, not parent-to-child. The participant observer expressed this as the relationship of friends meeting together over common concerns.

Module III could be expanded into two presentation sessions. This would provide enough time for the presentation of information and the completion of activities. A handout on skills of self-advocates needs to be developed. This will facilitate trainees in their understanding and identi-fication of the needs of self-advocates. An activity could be developed to further learning. An assessment instrument

could be developed to enable service providers to make referrals or advice to their clients when they express a need to be self-advocates.

Module IV could be expanded into two presentation sessions for the same reasons as stated above. An activity on problem solving could be developed so trainees would differentiate between problem solving and decision making. Further elaboration needs to be made on the ways a self-advocacy group facilitates the development of judgement.

Laws that effect the rights of the disabled could be presented in Module V in a sufficient manner. A list of consumer rights would also be added to this module. The recipient process would also need to be elaborated in this module.

In Module VI, a handout on suggestions for starting a self-advocacy group would provide trainees step-by-step directions. The inclusion of trainees in an advisor support group would be an option offered in this module.

Product Implementation

The results of the Site Interest Survey were negligible. The system used to disseminate information about the training relied upon personal contacts and supervisors sharing information about the training. Another system needs to be developed that would contact a larger audience. A flyer and training brochure could be developed to provide prospective trainees an opportunity to participate in the training.

A number of options were suggested for revision to the time schedule. The nature of the group could determine the time frame for the next presentation of the Module Package. Prospective trainees could express a preference for training time when responding to the flyer, at which time they would be making a commitment to participate in the training. Some of the options include: One and one-half hour sessions from 3:30 to 5:00 p.m., morning two hour sessions, one-half day sessions and day long sessions. A weekend retreat may also be an option.

Other options could be to develop the Module Package as an inservice course that could be given on a credit/non-credit basis. This would possibly increase the numbers of potential trainees. A pre-service college course could be developed from the Module Package. This could become an elective for students in education, social work and psychology. This would enable students to become familiar with alternative roles before they enter the field. The course structure would also structure the time and direction of presentation sessions.

Product Evaluation

Trainee criticism of the Pre-test/Post-test, Assessment Sheets and Impact Questionnaires (Appendix D), suggests major revisions are needed on these instruments. Standard measurement techniques are needed so that data could be

aggregated. This would make computation easier and allow for reliability and validity studies. The same information would be gathered in less time.

The value of cognitive gains may be secondary to changes in attitudes of the trainees. Three trainees discussed their difficulties in applying the content to the field situation. Attitudinal measures could provide data that would assist in understanding the difficulties trainees were experiencing.

The Pre-test could be used as an assessment instrument for the trainer and trainee to plan an individualized training format for the trainee. Data from the present Pre-test/ Post-test could be used to develop an effective assessment instrument which would be administered before training. The Post-test would be eliminated from the evaluation process because it's emphasis would be on assessment with joint planning.

The Impact Questionnaire, Module Evaluation Sheets and Assessment Sheets could be incorporated into one data source. Such a Module Satisfaction Checklist could incorporate the useful items from the previous data sources, compiled in a manner that would allow for the aggregation of data. This would decrease confusion and time required for data collection. Certain items could be standardized on each Module Satisfaction Checklist to allow for module comparison.

The Skill Development Checklists should be replaced with more reliable checklists. The same checklist should be used in each module so trainees would have an opportunity to become familiar with the instrument.

The Supervisor Attitudes Assessment from Module IV did not prove to be useful as a measure of leadership style. It may be more suitable as a training aid and could be incorporated into a training activity.

The participant observer had an effect on the trainer. Reviews of each session heightened the trainer's awareness and understanding of the experiences of the trainees. The discussion by the trainer and participant observer involved, at times, the exploration of assumptions and beliefs. Understanding the difference in perspective was helpful in creating an effective learning environment.

A less intrusive use of a participant observer is recommended. The role in relation to focus on congruence of intents and occurrences would be changed. Feedback would not occur after each session. The trainer would not be privy to the data until the field-test was complete. The participant observer and trainer would be less likely to influence each other during the process of instruction. This could result in a deeper understanding of the effects of staff development activities and specifically these instructional materials.

The uses of participant observers and anthropological research methodologies are well suited to the study of staff development in assisting staff to go beyond cultural myths of mental retardation.

The Follow-up Interview provided some interesting data. The results, largely self-report data, indicated that trainees accomplished many of the major purposes of the training. Although not measured, there appeared to be changes in attitude and in the perspective the trainees took when working with the disabled. Unfortunately, there was no way to determine the motivation or accuracy of trainee claims. Additional data sources are needed to determine the validity of the Follow-up Interview.

A Satisfaction with Readings Checklist could be developed to determine trainee reactions to the specific reading material. Feedback would be needed to determine whether the reading material was adequately suited to the learning needs of the trainees.

Attitude change measures are needed to determine if there is a change in how trainees perceive the disabled. Perceptions of ownership, dependency and need to control others could be useful in understanding the dynamics of the advisor's relationship with the disabled. This may be a more important measure of growth than skill development or cognitive gains.

The problems of service providers initiating and becoming involved with self-advocacy groups may have been related to the limited context in which the training took place. The training was conducted on a group basis with a pre-determined structure that did not provide for individualization. The trainer did not assess the conditions of trainee work situations. There were no demonstrations in the field of self-advocacy groups for trainees to model. Transfer of learning should have been designed into the project, thus providing service providers with assistance in their efforts to initiate self-advocacy groups.

Follow-up Questionnaires could be developed to determine how trainees applied the content of the Module Package to their work situation. In addition to the trainee, such questionnaires could be given to supervisors, service recipients and other service providers for purposes of validation.

Implications

Differences in learning styles and teaching styles suggests that those service providers who prefer individual work could be matched with self-advocates who preferred to work on an individual level. The conditions for learning to be an advisor and a self-advocate would be different.

Would those self-advocates who chose to become a self-advocate independent of a group develop different self-advocacy skills? Does the self-advocacy group maintain the disabled person in stigmatizing roles and relationships? What effect does the group experience have that can not be matched by an individual experience?

Personal experience in working with self-advocacy groups for three years has indicated that self-advocacy groups go through various stages of development. These stages are not determined by time, but demonstrate the growth the self-advocates experience as they learn to conduct their own affairs. Research to bring about an understanding of the stages of self-advocacy group development may be useful for the group in their planning and development.

Heath (1978) claims that self-advocacy develops group identity and independence. Observations made while working with people as they became self-advocates supports Heath's contention. (Further research is needed to elaborate more specifically on those conditions that increase group identity. Additional research is needed to determine those aspects of independence developed through self-advocacy.)

A Self-Advocacy Assessment scale would give service providers and advocates another method to identify the needs of a self-advocate. There are pros and cons to the use of an assessment device when applied to the concept of

self-advocacy.   An instrument like this could assist a
person to make the necessary decision to allow a disabled
person to develop as a self-advocate.   An instrument of
this nature could be used to program self-advocacy and
remove the chance for a disabled person to make their
own choice about becoming a self-advocate.

What happens when a number of service recipients
become self-advocates?   What is the effect on the service
agencies?   Are there changes in policy and practice in the
treatment of the mentally retarded when there is a self-
advocacy group in a program?   Does self-advocacy bring
about better service provisions?   These questions seek
to determine the effect self-advocacy has upon service
agencies.

The Module Package was presented as an inservice to
service providers.   The design of the materials did not
allow for individualization.   It became apparent in the
training that the trainees had different needs and styles
of learning.   Staff development efforts need to be designed
to accommodate for these individual differences.   These
instructional materials were presented to the trainees
and they were expected to implement the content.   A more
effective approach would be for the trainer to assist the
trainees to apply the materials.   This would involve
individual and group work with trainees.   Individualizing
staff development efforts may increase the effectiveness of
the group process.   These two approaches have the potential
to be combined.

Looking ahead to potential uses of these instructional materials it should be noted that service providers, administrators of service agencies, and professors of Education, Social Work, Human Ecology, Sociology, Psychology, and Anthropology could incorporate aspects of the content.

These materials could be modified for continuing education courses for inservice staff development, and designed to addressed the developmental needs of administrators, staff, and volunteers.

Residential programs could use these materials to promote democratic practices in group homes. Home operators could provide opportunities for residents to choose to participate in the operation of the home. This could include: meal planning and preparation, determination of cleaning and house keeping duties, interior decoration, and participation in leisure and recreation activities. Negotiation and compromise are some skills this environment could foster.

Service providers who assume an advocacy role may increase service recipients level of independence. Responsibility for planning and decision making gradually shift as the disabled person chooses to take greater control of their life. The advocate as advisor facilitates growth and change. An understanding of the context in which change occurs is important. For example: If a service provider facilitates an individual to become more assertive and that individual encounters others who wish to maintain dependency

relatonships, the disabled individual is at risk. This could result in repercussions to the service provider. On the other hand if a service provider is aware of a disabled person's need to become a self-advocate and does not respond to the need then they have avoided an opportunity to grow, as well as denying others that opportunity.

There are risks inherent in the development of self-advocacy. This is a relatively new concept and there will be trial and error. Yet, we cannot shirk the responsibility to promote growth and independence. The fear of conflict is no reason to avoid the development of democratic practices for the mentally retarded. The encounter of the conflict if handled with sensitivity, tact, and understanding can result in the advancement of the field, as well as, agencies, systems, and individuals.

The advisor does not own the self-advocate or the group. The advisor cannot become so dedicated to the promotion of self-advocacy that they lose their perspective. Demands placed on self-advocates to live up to the expectations held by advisors become counterproductive to the growth of the self-advocate.

Administrators of human service agencies can provide support and resources for the inclusion of self-advocacy. Support and resources are necessary to develop the attitudes and skills of advisors. Administrative support may be necessary to reduce the risk to individual advisors and self-advocates. Administrative resources are necessary to

maintain a commitment and continuation of opportunities for self-advocacy.

Advocates and service providers can rely upon self-advocates to alert them of violations of recipients' rights. The service recipient must be included to eliminate abuse and neglect. Their complaints are legitimate and can be used to improve the service system.

The concepts within the instructional materials could be useful to students in the social sciences. They can become sensitized to issues faced by the disabled as they seek their rights. The problem of a student understanding the relevance of law and legislation can be clarified through an exploration of service recipients' struggle to live as respected members of society.

Coursework could be incorporated that would provide students an opportunity to appreciate the difference between teaching and facilitation of learning. From this perspective college students could begin to conceptualize the complexity of roles they may assume.

Self-advocacy is a felt need. Agencies designed to meet the needs of the disabled can provide conditions that allow self-advocates to direct the course of their lives.

BIBLIOGRAPHY

BIBLIOGRAPHY

Addison, Max R. Special Report, Advocates on Advocacy:
    Defining Three Approaches. Citizen Advocacy
    1979.

Alinsky, Saul D. Rules for Radicals: A Pragmatic Primer
    for Realistic Radicals. New York: Vintage Books,
    Random House, 1971.

Ballard, J., Jeffery Zettel. Public Law 94-142 and
    Section 504: What They Say About Rights and
    Protections. Exceptional Children. November, 1977,
    pp. 177-184.

Biklen, Douglas and Robert Bogdan. "Handicapism in
    America." In Burton Blatt, Douglas Biklen, and
    Robert Bogdan (eds.), An Alternative Textbook In
    Special Education: People, Schools and Other
    Institutions. Denver, Co.: Love Publishing Co., 1977,
    pp. 205-216.

Blatt, Burton. "Issues and Values." In Burton Blatt,
    Douglas Biklen and Robert Bogdan (eds.), An Alterna-
    tive Textbook In Special Education: People, Schools
    and Other Institutions. Denver, Co: Love Publishing
    Co., 1977, pp. 3-28.

Bogdan, Robert and Steven Taylor. The Judged, Not the
    Judges. An Insider's View of Mental Retardation.
    In Burton Blatt, Douglas Biklen and Robert Bogdan
    (eds.), An Alternative Textbook In Special Education:
    People, Schools and Other Institutions. Denver, Co.:
    Love Publishing Co., 1977, pp. 217-232.

Brager, George and Harry Specht. Community Organization.
    New York and London: Columbia University Press, 1973.

Combs, A.W. and Donald Snygg. Individual Behavior: A
    Perceptual Approach to Behavior, revised edition.
    New York, Evanston and London: Harper and Row
    Publishing Co., 1959.

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Cronbach, Lee J. Course Improvement Through Evaluation.
    In Worthen, Blaine R. and James R. Sanders (eds.),
    Educational Evaluation: Theory and Practice. Charles
    A. Jane Publishing Co., 1973, pp. 43-59.

Cunio, Heath, Kaplan, Scott, Price, Schaaf. People First:
    A Manual. 1976.

Curtis, Charles K. Social Studies for the Slow Learner.
    The Clearing House, April, 1974, pp. 456-460.

Diamond, Sondra. "Developmentally Disabled Persons."
    In Wiegernik, Ronald and John W. Pelosi (eds.),
    Developmental Disabilities: The DD Movement.
    Paul H. Brooks Publishers, 1979.

Dick, Walter. "Formative Evaluation." In Leslie J. Briggs
    (ed.), Instructional Design: Principles and Applica-
    tions. Englewood Cliffs, N.J.: Educational Technology
    Publications, 1977, pp. 311-336.

Disabled Peoples' Bill of Rights and Declaration of
    Independence. The Center View, Vol. 3:2. November,
    1979.

Dybwad, Gunner. "The Community Responsibility for Mentally
    Disabled Individuals." Community Mental Health Board.
    Hilton Inn, Lansing, Michigan, May 9, 1980.

Edgerton, Robert B. and Sylvia M. Bercovici. The Cloak
    of Competence: Years later. American Journal of
    Mental Deficiency. Vol. 80, No. 5, 1976, pp. 485-
    497.

Farber, Bernard. Mental Retardation: Its Social Context
    and Social Consequence. Boston, MA.: Houghton Miffin
    Co., 1968.

Freire, Paulo. Pedagogy of the Oppressed. A Continuum
    Book. New York: The Seabury Press, 1970.

Freire, Paulo. Pedagogy in Process: The Letters to
    Guinea-Bissau. A Continuum Book. New York: The
    Seabury Press, 1978.

Gardner, Nancy. The Self Advocacy Workbook (The SAW).
    A product of the Technical Assistance for Self-
    Advocacy Project, UAF - University of Kansas,
    Lawrence, KS 66045. Kansas Center for Mental
    Retardation and Human Development, 1980.

Goldenberg, I. Ira. Oppression and Social Intervention. Essays on the Human Condition and the Problems of Change. Chicago, IL: Nelson-Hall, 1978.

Gooler, Dennis D. and Ardon Grotelueschon. "Process Accountability in Curriculum Development." In Blaine R. Worthen and James R. Sanders (eds.), Educational Evaluation: Theory and Practice. Worthington, OH: Charles A. Jones Publishing Co., 1973.

Hallgren, B., and A. Norsman. Life, Liberty, and the Pursuit of Happiness. Madison, WI, and Middleton, WI: Wisconsin Coalition for Advocacy and Wisconsin Association for Retarded Citizens, 2 West Mifflin, Madison, WI 52703, 1977.

Halpern, J., K. L. Sackett, P.R. Binner and C.B. Mohr. The Myths of Deinstitutionalization: Policies for the Mentally Disabled. Westview Press, Inc., 1980.

Haskins, James, with J.M. Stifle. The Quiet Revolution: The Struggle for the Rights of Disabled Americans. Crowell, New York, 1980.

Heath, Dennis. "People First Develops Group Identity, Independence." Polestar, 1977.

Heath D., V. Schaaf, and L.W. Talkington. People First: Evolution Toward Self-Advocacy. Deficience Mentale/ Mental Retardation, Vol. 28, No. 2, April, 1978, pp. 3-8.

Herr, Stanley S. From Rights to Realities: Advocacy By and For Retarded People in the 1980's. U.S. Department of Health, Education and Welfare, Office of Human Development Services. The President's Committee on Mental Retardation, 1980.

Hurvitz, N. The Origin of the Peer Self-Help Psychotherapy Group Movement. The Journal of Applied Behavioral Science, Vol. 12, No. 3, July-August-September, 1976.

Ihide, Don. Experimental Phenomenology: An Introduction. Capricorn Books, New York: G.P. Putnam's Sons, 1977.

Jakubowski, Patricia, Arthur J. Lange. Responsible Assertive Behavior Cognitive/Behavioral Procedures for Trainers. Research Press, 1976.

Katz, Alfred H. and Eugene L. Bender. Self-Help Groups
     in Western Society: History and Prospects. The
     Journal of Applied Behavioral Science, Vol. 12,
     No. 3, July-August-September, 1976.

Kramer, Beth. Silent Minority. President's Committee
     on Mental Retardation, Washington, D.C., Department
     of Health, Education and Welfare, Washington, D.C.,
     1974.

Kugel, R. and Ann Shearer. The Changing Patterns in
     Residential Services for the Mentally Retarded.
     President's Committee on Mental Retardation, Washington,
     D.C., 1976.

Leonard, Leo D. Building Skills for Competency-Based
     Talking. New York, 1974.

Mamula, R.A. and Nate Newman. Community Placement of
     the Mentally Retarded: A Handbook for Community
     Agencies and Social Work Practitioners. Springfield,
     IL: Thomas, 1973.

McIndless, John. Being Labelled Deficient Mentale/Mental
     Retardation, Vol. 28, No. 2, April, 1978, pp. 15-17.

Menolascino, F.J. The Future of the Handicapped Person
     and His Community. Paper presented at the World
     Congress on Future Special Education. (First,
     Stirling, Scotland, June 25-July 1, 1978.)

Meyer, Edward L., Alan R. Frank and Myron Rodee. Field-
     Testing: A Source of Evaluation in Developing
     Instructional Materials. Exceptional Children,
     Vol. 8, No. 1, February, 1970, pp. 31-36.

Neufeld, G. Ronald. "The Advocacy Role and Functions of
     Developmental Disabilities Councils." In Ronald
     Wiegernik and John W. Pelose (eds.), Developmental
     Disabilities: The DD Movement. Paul H. Brooks,
     Publishers, 1979.

Nirge, Bengt. The Normalization Principle and It's Human
     Management Implications. In R. Kugel and W.
     Wolfensberger (eds.), Changing Patterns in Residential
     Services for the Mentally Retarded. President's
     Committee on Mental Retardation, 1969, pp. 179-195.

Nirge, Bengt. The Normalization Principle. In R. Kugel
     and Ann Shearer (eds.), The Changing Patterns in
     Residential Services for the Mentally Retarded.
     President's Committee on Mental Retardation,
     Washington, D.C., 1976.

Perske, Robert.   The Dignity of Risk and the Mentally
     Retarded.   Mental Retardation, February, 1972,
     pp. 24-27.

Perske, Robert and Martha Perske.   New Life in the
     Neighborhood.   Nashville, TN: Parthenon Press,
     1980.

Rank, Otto.   "Fate and Self-Determination."   In Clark
     E. Moustakas (ed.), The Self: Explorations in
     Personal Growth.   New York, Hagerstown, San
     Francisco, London: Harper Colophon Books, Harper
     and Row Publishers, 1956, pp. 70-75.

Rogers, Carl.   Freedom to Learn.   Columbus, OH: Charles
     E. Merrill Publishing Col, 1969.

Roos, Philip, E.G. Patterson and Brian M. McCairn.
     "Expanding the Developmental Model."   Unpublished
     manuscript, no date.

Scriven, Michael.   The Methodology of Evaluation.   AERA
     Monograph Series on Curriculum Evaluation, No. 1.
     Chicago, IL: Rand McNally, 1967, pp. 39-89.

Scriven, Michael.   The Methodology of Evaluation.   In
     Blaine R. Worthen and James R. Sanders (eds.),
     Educational Evaluation: Theory and Practice.
     Worthington, OH: Charles A. Jones Publishing Co.,
     1973, pp. 60-104.

Segal, R.M.   Mental Retardation and Social Action: A
     Study of the Association for Retarded Children as a
     Force for Social Change.   Springfield, IL: Charles
     C. Thomas, 1970.

Shearer, Ann.   The Caring Staff.   In R. Kugel and Ann
     Shearer (eds.),   The Changing Patterns in Residential
     Services for the Mentally Retarded.   President's
     Committee on Mental Retardation.   Washington, D.C.,
     1976.

Stake, Robert E.   The Countenance of Educational
     Evaluation.   Teachers College Record, Vol. 68,
     No. 7, April, 1967, pp. 523-540.

Stake, Robert.   Evaluation Design, Instrumentation, Data
     Collection and Analysis of Data.   In Blaine R.
     Worthen and James R. Sanders (eds.), Educational
     Evaluation: Theory and Practice.   Worthington, OH:
     Charles A. Jones Publishing Co., 1973.

Stedman, Donald J. and Ronald Wiegerink. "Future of Service Delivery Systems." In Wiegerink, Ronald and John W. Pelosi (eds.), Developmental Disabilities: The DD Movement. Paul H. Brooks, Publishers, 1979.

Steer, Michael and Paul C. Jennings. The Meaning of an Alternative Movement in Service Delivery to Mentally Retarded People. Deficience Mentale/Mental Retardation, Vol. 28, No. 2, pp. 13-15, 78.

Steinman, Richard and Donald M. Traunstein. "Redefining Deviance: The Self-Help Challenge to the Human Services." Journal of Applied Behavioral Science, Special Issue/Self-Help Groups, Vol. 12, No. 3, July-August-September, 1976.

Taylor, Steven and Robert Bogdan. "A Phenomenological Approach to 'Mental Retardation.'" In Burton Blatt, Douglas Bidden and Robert Bogdan (eds.), An Alternative Textbook in Special Education: People Schools and Other Institutions. Denver, CO: Love Publishing Co., 1977, pp. 193-204.

Turnbull, H. Rutherford and Ann P. Turnbull. "Examining Consumer's Assumptions." In Wiegerink, Ronald and John W. Pelosi (eds.), Developmental Disabilities: The DD Movement. Paul H. Brooks, Publishers, 1979.

Varela, Rita A. "Self Advocacy and Changing Attitudes." In Public Awareness Viewpoints. Richman, Gary and Trohanis, Pascal (eds.). Chapel Hill: Developmental Disabilities Technical Assistance System, University of North Carolina, 1978.

Warren, Frank. "The Role of the Consumer in Planning and Delivering Services." Developmental Disabilities: Themes and Issues. University of North Carolina, Vol. 5, February, 1976.

Wiegerink, Ronald and John W. Pelosi (eds.). Developmental Disabilities: The DD Movement. Paul H. Brookers, Publishers, 1979.

Wolfensberger, W. The Principle of Normalization in Human Services. Toronto, Canada: National Institute on Mental Retardation, 1972.

Woodyard, J.J. An Advisor's Guidebook for Self-Advocacy. A product of the Technical Assistance for Self-Advocacy Project: UAF - University of Kansas, Lawrence, Kansas, 1980.

APPENDICES

APPENDIX A

National Survey of Advisors

618 Forest
East Lansing, Michigan 48823
(517) 694-5098

    I am developing instructional materials to train advisors to
self-advocacy support groups. This project is being conducted be-
cause of my belief in the psychological and social benefits these
groups provide to developmentally disabled and mentally retarded
people as they become integrated into society. The development
and evaluation of these instructional materials fulfill the require-
ments for a doctoral dissertation in the field of Curriculum and
Instruction at Michigan State University.

    In order to determine the content for these instructional
materials, I am surveying self-advocacy group advisors. Your
input is needed in the quest to further understand and delineate
the skills and knowledge used by advisors. You can provide valued
information about materials, readings and experiences useful in
the training and development of advisors and self-advocacy groups.

    The Association for Retarded Citizens has recently distributed
a listing of self-advocacy groups. Your name and address is included
with the suggestion for a sharing of ideas that could facilitate the
formation of other self-advocacy groups.

    Please take a few minutes and read the enclosed position paper
considering the question, "What would be useful in a training program
for advisors of self-advocacy support groups?" Note your salient
ideas and return in the self-addressed envelope.

    If you desire any information, please feel free to write or
call. Thank you for your time and energy.

                    Sincerely,

                    John S. Rowlson

Enclosures

THE EFFECTIVENESS OF INSTRUCTIONAL MATERIALS FOR

ADVISORS OF SELF-ADVOCACY SUPPORT GROUPS

POSITION PAPER

Legal and social science principles have converged in Section 504 of the Rehabilitation Act of 1973 and P.L. 94-142. Both have provisions that the least restrictive alternative should be provided to the handicapped, including work, educational and residential settings (Kiley, 1981). The values inherent in these laws are consistent with those espoused in the Normalization Principle, stressing the value of handicapped persons being able to live as much like the rest of society as possible (Kramer, 1974). Conditions are being created where disabled persons experience the normal respect entitled any human being (Wolfensberger, Nirge, 1972). Their choices, wishes, desires and aspirations are considered in order for them to determine direction for their lives.

Advocacy

The right to life, liberty and pursuit of happiness may be self-evident, but has never been self-enforcing. (Hallgren & Norsman, 1977)

The struggle to protect and exercise basic human rights is dependent upon the economic and human resources available. Members of the advocacy movement believe in the need to provide these resources to people with developmental disabilities, establishing systems to protect and safeguard the rights and interests of the disabled. Advocates are those persons who intend to represent and advise regarding the rights, interests, and needs of people with disabilities (Addison, 1976). Advocates attempt to bring about social justice for those who have been or represent the potential to be treated unjustly. The advocates' goal is to provide the kind of involvement that results in persons becoming self-advocates. Their focus is on facilitating the learning of self-advocacy skills for an independent as possible lifestyle (Dybwad, 1980).

Self-Advocacy

Self-Advocacy is that component of the advocacy movement which is directed toward increasing the knowledge and understanding of basic human/civil rights and responsibilities and is a pre-condition to meaningful citizenship. . . . Self-Advocacy is defined as advocacy by an individual whose rights, interests or needs are at risk of being diminished, in order to represent his/her own rights and interests and speak on his/her own behalf. (Hallgren & Norsman, 1977)

Asserting one's personal rights involves expressing thoughts, feelings and beliefs in direct, honest and appropriate ways which do not violate another person's rights (Jakubowski, 1976). Assertive behavior by persons seeking their rights are the interpersonal skills of the self-advocate. Appropriate assertiveness is learned, and requires a relevant social context. Individuals can become socialized by being able to communicate and protect their self-interest. Socialization increases the potential to relate with others in society, as well as developing self-respect and identity (Heath, 1977).

Self-Advocacy Support Groups

Individuals may need the support and encouragement of others to be self-advocates. Support groups provide additional power and resources to the individual. The group is useful in maintaining continuity of affective outcomes including increased motivation, self-respect, and self-acceptance. The development of cognitive skills (problem solving, memory, retention), organizational abilities, and leadership are also increased (Heath, 1977).

The development of effective citizenship is brought about through the interaction of people facing concrete, real life problems with each other at a site location that has meaning and is easily accessible. The identification self-advocates have with the site provides a context for participation in real life problems (Curtis, 1974). The issues the support group deal with are relevant to their lives and stem from the dynamics of the site. The involvement by persons in their own programs and sites increases their skills as self-advocates through participatory democracy. The sense of efficacy, competence, and personal power is developed and strengthened as self-advocates participate in meetings and on committees, defining the group's purpose and goals, choosing leaders, planning activities, and providing one-an-other emotional support. The organization of the mentally retarded into support groups and coalitions is a way to self-representation and self-advocacy. They can exercise their rights as citizens, and gain direct access to needed services (Menolascino, 1976).

Advisors to Self-Advocacy Support Groups

The advisor has an important role in assisting in the formation and organization of a self-advocacy support group. People desiring to become self-advocates often do not have the knowledge and skill needed to facilitate the group process. The advisor is a member of the group with similar rights and obligations, and serves as a model for others to observe and learn from in developing a supportive atmosphere. An advisor may make suggestions to assist in moving the group process along, to clarify communication, to insert structure, to teach group members to be self-advocates and to be sensitive to the needs and direction of the group and its members.

The Need for Advisor Training

The challenges encountered as a result of discovering what is necessary to do as an advisor is rewarding, and painful. In many programs around the country there are people, who in responding to the needs of the disabled, have chosen to facilitate the development of self-advocacy support groups; sometimes feeling alone, without a clear direction. Heath (1978) discusses the time spent on defining the role of the advisor. This is a way to determine responsibility and purpose, but requires the ability to withstand ambiguity. The specialized talents of those who can respond in such a way while involved in creating support groups must be lauded. They have broken through a frontier in the field of mental retardation.

The idea of self-advocacy is being disseminated, with many persons desiring to become involved. Some, with their "hearts in the right places," do not know where or how to proceed. They may need to be able to "tap" on the collective experience of those who have gone before them, and learn from the trials and tribulations of others.

There are few materials presently available to assist in the training and development of advisors to self-advocacy support groups. Information, ideas, techniques and skills must be shared between and among advisors, and passed on to others seeking this knowledge. Instructional programs are needed to enable people to become advisors thus increasing the number of developmentally disabled and mentally retarded persons becoming self-advocates.

BIBLIOGRAPHY

Addison, Max R. Special Report, Advocates on Advocacy: Defining Three Approaches, Citizen Advocacy, 1979.

Dybwad, Gunner. "The Community Responsibility for Mentally Disabled Individuals." Community Mental Health Board, Hilton Inn, Lansing, Michigan, May 9, 1980.

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Heath, Dennis L., Advisor. People First: Develops Group Identity, Independence. Polestar, 1978.

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Jakubowski, Patricia & Arthur J. Lange. Responsible Assertive Behavior Cognitive/Behavioral Procedures for Trainers. Research Press, 1976.

Kiley, Michael. Community Mental Health Board, State Police Training Center, Workshop, Lansing, Michigan, February 6, 1981.

Kramer, Beth. Silent Minority. Presidents Committee on Mental Retardation. Washington, D.C.: Department of Health, Education and Welfare, 1974.

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Wolfensberger, Wolf; Nirge, B.; Olshansky, S.; Perske, R.; & Ross, P. The Principles of Normalization in Human Services. Toronto: National Institute on Mental Retardation, 1972.

"What would be useful in a training program for advisors of self-advocacy support groups."

MICHIGAN STATE UNIVERSITY

COLLEGE OF EDUCATION

DEPARTMENT OF ELEMENTARY AND SPECIAL EDUCATION

EAST LANSING · MICHIGAN · 48824

TO: Self Advocacy Group Advisors

FROM: Donald Burke

The enclosed position paper and request for input is being sent to you because of your interest in self advocacy for the developmentally disabled. This request for assistance is an initial step in a dissertation project designed by John Rowlson which has been approved by his doctoral committee.

As dissertation advisor, I thank you in advance for your interest and cooperation.

DB:jb

Enclosure

APPENDIX B

Letter of Workshop Intent

2365 Jarco Dr.
Holt, MI 48842
(517) 694-5098

     I am pleased and honored that you are willing to share
your time and energy by participating in a workshop to identify
the content of an instructional program to train advisors to
self-advocacy support groups. There are eight people from
around Michigan who have made a commitment to attend. This
is an opportunity to engage in a meaningful dialogue to
expland our views in determining a well thought out training
program.

     This workshop is the third and final step in the process
of developing content, resources, goals, and activities for
the advisor instructional materials. The first step began
with a review of the literature and ended in a position
paper. The second step was a national survey of 85 advisors
designed to ascertain "What would be useful in a training
program for advisors of self-advocacy support groups?"
The content will be field-tested in April and May, 1981.

     I foresee an exciting and rewarding day and am looking
forward to working and creating with you. Thank-you for
your interest and support.

          Sincerely,

          John Rowlson

WHAT WOULD BE USEFUL IN A TRAINING PROGRAM

FOR ADVISORS OF SELF-ADVOCACY SUPPORT GROUPS?

WORKSHOP AGENDA

DATE: March 27, 1981   TIME: 9:00 AM to 5:00 PM

LOCATION:

BRETTON SQUARE INDUSTRIES
2365 Jarco Dr.
Holt, MI 48842

8:45 to 9:00 Coffee and Rolls

9:00 to 9:15 Introductions

9:15 to 10:30 PART I   IDENTIFYING CONTENT
                         A synthesis of information from survey of
                         Advisors.

10:30 to 10:45 Break

10:45 to 12:00   Continue identifying and developing content
                         At the end of this session we will have a
                         categorized and prioritized list of the
                         ideas to be included in the training program.

12:00 to 12:30 LUNCH PROVIDED

12:30 to 12:45 PART II ORGANIZING CONTENT
                         A review and revision of goals of training
                         program

12:45 to 2:00   A review of materials and resources
                         Please bring your materials and other
                         resources. The results of this session
                         will be a list of materials and resources
                         with recommendations.

2:00 to 2:30   Presentation of Module design and format

2:30 to 2:45 Break

2:45 to 4:00   The creation of training activities.
                         Our product for this session will be train-
                         ing activities congruent with content, and
                         utilizing materials.

4:00 to 4:45	"Etcetera" An open discussion to "tie-up loose ends."
4:45 to 5:00	Closing

APPENDIX C

Workshop Packet

618 Forest
East Lansing, Michigan   48823
(517) 694-5098

        I am developing instructional materials to train advisors to self-advocacy
support groups. This project is being conducted because of my belief in the
psychological and social benefits these groups provide to developmentally
disabled and mentally retarded people as they become integrated into society.
The development and evaluation of these instructional materials fulfill the
requirements for a doctorial dissertation in the field of Curriculum and
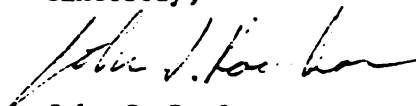Instruction at Michigan State University.

        Inorder to determine the content for these instructional materials, I am
surveying self-advocacy group advisors. Your input is needed in the quest to
further understand and delineate the skills and knowledge used by advisors.
You can provide valued information about materials, readings and experiences
useful in the training and development of advisors and self-advocacy groups.

        The Association for Retarded Citizens has recently distributed a listing
of self-advocacy groups. Your name and address is included with the suggestion
for a sharing of ideas that could facilitate the formation of other self-advocacy
groups.

        Please take a few minutes and read the enclosed position paper considering
the question, "What would be useful in a training program for advisors of self-
advocacy support groups?" Note your salient ideas and return in the self-
addressed envelope.

        If you desire any information, please feel free to write or call. Thank
you for your time and energy.

                                        Sincerely,

                                        John S. Rowlson

Enclosures

THE EFFECTIVENESS OF INSTRUCTIONAL MATERIALS FOR

ADVISORS OF SELF-ADVOCACY SUPPORT GROUPS

POSITION PAPER

Legal and social science principles have converged in Section 504 of the Rehabilitation Act of 1973 and P.L. 94-142. Both have provisions that the least restrictive alternative should be provided to the handicapped, including work, educational and residential settings (Kiley, 1981). The values inherent in these laws are consistent with those espoused in the Normalization Principle, stressing the value of handicapped persons being able to live as much like the rest of society as possible (Kramer, 1974). Conditions are being created where disabled persons experience the normal respect entitled any human being (Wolfensberger, Nirge, 1972). Their choices, wishes, desires and aspirations are considered in order for them to determine direction for their lives.

Advocacy

The right to life, liberty and pursuit of happiness may be self-evident, but has never been self-enforcing. (Hallgren & Norsman, 1977)

The struggle to protect and exercise basic human rights is dependent upon the economic and human resources available. Members of the advocacy movement believe in the need to provide these resources to people with developmental disabilities, establishing systems to protect and safeguard the rights and interests of the disabled. Advocates are those persons who intend to represent and advise regarding the rights, interests, and needs of people with disabilities (Addison, 1976). Advocates attempt to bring about social justice for those who have been or represent the potential to be treated unjustly. The advocates' goal is to provide the kind of involvement that results in persons becoming self-advocates. Their focus is on facilitating the learning of self-advocacy skills for an independent as possible lifestyle (Dybwad, 1980).

Self-Advocacy

Self-Advocacy is that component of the advocacy movement which is directed toward increasing the knowledge and understanding of basic human/civil rights and responsibilities and is a pre-condition to meaningful citizenship. . . . Self-Advocacy is defined as advocacy by an individual whose rights, interests or needs are at risk of being diminished, in order to represent his/her own rights and interests and speak on his/her own behalf. (Hallgren & Norsman, 1977)

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Individuals may need the support and encouragement of others to be self-advocates. Support groups provide additional power and resources to the individual. The group is useful in maintaining continuity of affective outcomes including increased motivation, self-respect, and self-acceptance. The development of cognitive skills (problem solving, memory, retention), organizational abilities, and leadership are also increased (Heath, 1977).

2

The development of effective citizenship is brought about through the interaction of people facing concrete, real life problems with each other at a site location that has meaning and is easily accessable. The identification self-advocates have with the site provides a context for participation in real life problems (Curtis, 1974). The issues the support group deal with are relevant to their lives and stem from the dynamics of the site. The involvement by persons in their own programs and sites increases their skills as self-advocates through participatory democracy. The sense of efficacy, competence, and personal power is developed and strengthened as self-advocates participate in meetings and on committees, defining the group's purpose and goals, choosing leaders, planning activities, and providing one-an-other emotional support. The organization of the mentally retarded into support groups and coalitions is a way to self-representation and self-advocacy. They can exercise their rights as citizens, and gain direct access to needed services (Menolascino, 1976).

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The advisor has an important role in assisting in the formation and organization of a self-advocacy support group. People desiring to become self-advocates often do not have the knowledge and skill needed to facilitate the group process. The advisor is a member of the group with similar rights and obligations, and serves as a model for others to observe and learn from in developing a supportive atmosphere. An advisor may make suggestions to assist in moving the group process along, to clarify communication, to insert structure, to teach group members to be self-advocates and to be sensitive to the needs and direction of the group and its members.

The Need for Advisor Training

The challenges encountered as a result of discovering what is necessary to do as an advisor is rewarding, and painful. In many programs around the country there are people, who in responding to the needs of the disabled, have chosen to facilitate the development of self-advocacy support groups; sometimes feeling alone, without a clear direction. Heath (1978) discusses the time spent on defining the role of the advisor. This is a way to determine responsibility and purpose, but requires the ability to withstand ambiguity. The specialized talents of those who can respond in such a way while involved in creating support groups must be lauded. They have broken through a frontier in the field of mental retardation.

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There are few materials presently available to assist in the training and development of advisors to self-advocacy support groups. Information, ideas, techniques and skills must be shared between and among advisors, and passed on to others seeking this knowledge. Instructional programs are needed to enable people to become advisors thus increasing the number of developmentally disabled and mentally retarded persons becoming self-advocates.

BIBLIOGRAPHY

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    A Self-Advocacy Curriculum. Wisconsin Coalition for Advocacy, 1977.

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Heath, Dennis and Others. People First: Evolution Toward Self-Advocacy;
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Wolfensberger, Wolf; Nirge, B.; Olshansky, S.; Perske, R.; & Ross, P. The
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"What would be useful in a training program for advisors of self-advocacy support groups."

Dear Mr. Rowlson,

I'm happy to have the opportunity to reflect for you on the one activity that finally gives a long life as a teacher its ultimate meaning and purpose; ie. helping developmentally disabled people learn how to speak for themselves.

Your question above was not easy at first to answer, for a number of unrelated reasons. First because I arrived at the role of advisor by my own life-long route (53 years), and because I have found it necessary to develop my own basic rules for the role, since I hadn't learned that there were many others travelling parallel paths and pursuing identical ideals out there somewhere. Another reason your question was difficult to answer was because I suspect that this kind of role might still be unique enough to need a hybrid individual to fill it; rather than someone, for example, who is beginning a career in social work and still has an array of options to choose from, I think it requires someone who has already chosen a wide range of commitments and who now finds this work almost as a calling or as a mission. In other words, I don't think you can train a good advisor for a self-advocacy group. I believe you have to find the person already formed.

I believe that is important, at this stage of the development of the art of advising in this area, because the very act of urging a developmentally disabled person to do something which the social system has, for so many years, has done for them, inevitably brings on both the d.d person and the advisor some very powerful responses from service providers within that same social system. Very often, the more confident and eloquent and effective the disabled person becomes, the more he and the advisor and the group are opposed and obstructed. To carry on in such an environment, both for the group and for the advisor, there needs to be more than just anger, or wild shouting and striking out. What is needed is a calm determination to press on in positive, legitimate ways based on fundamental rights and a courage to be able to take a beating along the way.

Now, while I could illustrate those convictions with many experiences I've had as a teacher and a self-propelled advocate who "had his heart in the right place", perhaps I should summarize an answer more directly related to your question.

At this point, I think there are two things that are most useful if someone would be trained to be a good advisor to a self-advocacy group. 1) The advisor or the group should not work or function officially under the aegis of a service agency, or in many cases even under the umbrella of another advocacy organization. Our experience in Colorado has been disastorous in trying to form a State group within the State A.R.C. We have also received strong opposition from the Community Centered Board in Boulder which provides services for many of our local

page 2

members. In fact, our Boulder County ARC is heavily infiltrated and
controlled by the two main administrators of services in the community,
so that both the ARC and the Citizen Advocacy programs are no support
to the self-advocate group what-so-ever. That is in spite of the fact
that I, the advisor, have been active with the ARC on both the county
and the state level for many years. I've been advocating more and
more vocally and effectively for more visibility and participation in
all activities inside and outside of the ARC. As a result I have been
progressively ostracized. It has only been a long life of involve-
m ent in educational, labor union and political advocacy that has made
it possible to continue to work with our group without being crushed
myself. Infact, our State People First group seems to flourish in
spite of all the opposition. Independence is essential!

2) An advisor must be highly creative, tuned in to the human
nuances of the personalities of disabled people (able to recognize
that most of them are identical with so-called normal people), have a
charisma for disabled people (ie. see that one's self is disabled
too so that it is easier to identify with the disabled group) and
be able to learn how to relate all experiences, which challenge a
disabled person, to the everyday world of so-called normal people.
The advisor has to know that everyday world fairly well and feel
comfortable with most of it, though not necessarily accepting of
what is not acceptable.

But let me quickly emphasize this. Since I am a teacher of
children and developmentally disabled children and adults, and
only by accident and by role modelling am I an educator of my peers,
most of what I have said above comes from my own subjective life,
experiences and point of view. It is a basic assumption of mine now
that most important roles which require human interaction require
also a particular type of person. What is needed is to find that
very person, open the door to the challenges of the role and let
personal creative ability and self-propulsion carry on from there.
That's a very subjective training program, probably one that is dif-
ficult to fund at a university special education department. But
that is how I see it (stage at this).

Now, on a personal level. I suspect, and would be very pleased
to know, that you first heard about our People First of Colorado and
our self-owned magazine, The C.U. Citizen, from two friends of ours
Jan Black and Alice Roeloffs, who are now directing a fine program
in Detroit and who had started the College for Living program at Metro-
politan State College in Denver. If that is true, give them our greet-
ings. We love them dearly. If you heard of us from some other route,
then, I hope you eventually get to know Jan and Alice. They are worth
the experience.

Sincerely,

Paul Davinroy

April 5, '81

The development of effective citizenship is brought about through the interaction of people facing concrete, real life problems with each other at a site location that has meaning and is easily accessible. The identification self-advocates have with the site provides a context for participation in real life problems (Curtis, 1974). The issues the support group deal with are relevant to their lives and stem from the dynamics of the site. The involvement by persons in their own programs and sites increases their skills as self-advocates through participatory democracy. The sense of efficacy, competence, and personal power is developed and strengthened as self-advocates participate in meetings and on committees, defining the group's purpose and goals, choosing leaders, planning activities, and providing one-an-other emotional support. The organization of the mentally retarded into support groups and coalitions is a way to self-representation and self-advocacy. They can exercise their rights as citizens, and gain direct access to needed services (Menolascino, 1976).

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Very good position paper, I would however put additional statements for the need for self advocacy training and support of parents and professional in the field of M.R. Good luck

Kevin Patrick Dracey

CITIZEN ADVOCACY
905 -9th Ave. Box 515
Sidney, Ne 69162
Phone: 254-7052

in a training program for advisors of self-advocacy

I attempted to start a self-advocacy group. However, I encountered parent resistance and apathy. I intend to to try again in the near future.

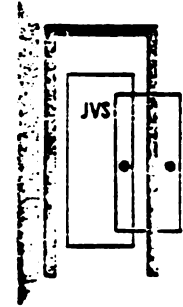I would recommend that your training program include an area dealing with parent resistance and apathy.

Good luck with your research!

Beth Grant

Jewish Vocational Service

1339 North Milwaukee Street — Milwaukee, Wisconsin 53202 — (414) 272-13-.

Michael M. Galazan, Executive Director

3/12/81

Dear Mr. Rowlson:

Interestingly enough, your request for ideas with regard
to needs of self-advocate advisors comes at a time when I
am also reaching out for help and exploring possibilities.

In 1976, I began a club for my clients who were/are living
independently in apartments and working in outside employment
throughout Milwaukee County. In visiting these clients in
their homes, I found a trend of isolation, skill and emotional
deterioration. In order to correct this debilitating situation
I formed the organization 1776'ers based on a 4-H Club program,
incorporating educational and recreational components.

In 1978, I was approached by Annette Norsman of ARC to in-
corporate the approximately 70 members of the organization
in a pilot project of self-advocacy skill building. Because
of individual disinterest, etc, only about ½ of the member-
ship has attained specific self-advocacy/assertiveness to date.

A major problem in getting people through the program is
motivation of the individual through natural parents, house
parents, foster parents, workshop/rehabilitation staff etc.
The other monumental problem comes after the individual attains
the skills in self-advocacy and begins to implement his know-
ledge within the rehab. setting and/or community.

The first time one of the individuals tried to assertively
mediate a wage dispute at a sheltered workshop, he was sus-
pended. Examples are too numerous to describe.

The problem as I have experienced it, is one of community education
and education within the social service fields which supposedly
service the developmentally disabled population. Wide spread
dissemination of available materials to rehab. agencies would (con't)
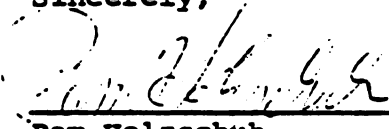
CASPER BUILDING: 263 North Jackson Street — Milwaukee, Wisconsin 53202 — Phone 276-6622
SCHOOL—WORK SERVICES: 2601 North Third Street — Milwaukee, Wisconsin 53212 — Phone 272-1344
SOUTHEAST CAMPUS: 100 West Wilbur Avenue — Milwaukee, Wisconsin 53207
SOUTHWEST CAMPUS: 6015 West Forest Home Avenue — Milwaukee, Wisconsin 53220 — Phone 545-6666
PLACEMENT SERVICES: 819 North Sixth Street, Third Floor — Milwaukee, Wisconsin 53203 — Phone 224-4201
EDUCATIONAL AND VOCATIONAL GUIDANCE INSTITUTE: 1360 North Prospect Avenue — Milwaukee, Wisconsin 53202 — Phone 271-3844

Page: 2

be a step in the right direction. We as a group of rehab.
counselors at the Jewish Vocational Service in Milwaukee,
would welcome lists of speakers for inservice training, ex-
panded bibliographies on the subject and audio-visual aids
for inservice.

Please note I am the advisor for the 1776'ers group. Bill
Lucht is the president of the organization. I can be reached
at the above number.

                                          Sincerely,

                                          Pam Holzschuh
                                          Advisor-1776'ers

M.D.I. Sheltered Workshop
Route #3
Otter Creek, Maine 04665

I'm sorry that I am not going to be much help to you. Although you found our name on a Self-Advocacy listing we do not have an active body because of a lack of a coordinator. I have three staff members to supervise 25 workers and there is just not enough time in the day to do everything we would like to. I'm sure this has to be a common problem with small facilities. As for volunteers- they are few and far between; further, their commitment to a cause is governed by interest so if that idea doesn't appeal to them you can't get them to do it. The problem of inadequate funding touches more than just direct service and this is one area. Before I could even consider training, I'd have to get some time to devote to the concept. Best of luck on your project.

Sincerely yours

Richard Sprague, Ex. Director

March 13, 1981

John S. Rowlson
618 Forest
East Lansing, Michigan 48823

Dear John,

I'm sorry I couldn't take more time giving you some ideas on training of advisors. You caught me at a really busy time. I enclosed a Merry Mac pamphlet and a short history of the group. As their Advisor, I'm responsible for their P.R. (I also like to brag about them.)

John, when I read things like "Training and Development of Advisors" I immediately become anxious. My fears are somewhat realistic. if advisors are trained or "professionalized" we're instituting a new profession that might eventually try to "control" rather than support retarded citizens.

I am well aware of the rewards, the frustrations and the pain a new advisor must experience when organizing a self-advocacy group. I wouldn't have missed it for the world! The results of that experience taught me that I wasn't as democratic as most of the members, that I wasn't as sensitive as most of the members and that I didn't give the members enough credit for the good judgement they possessed. That experience made me more a part of their hopes, dreams and the future of their club. The Merry Macs are my friends and co-workers and I

plan to be with them for many years.

Well John, I'll get off my soap box now and hope the meager information I gave you will help you in some way.

Sincerely,

Kathy Tessitore

Kathy Tessitore
Advisor: Merry Macs

"What would be useful in a training program for advisors of self-advocacy support groups."

1. Knowledge of retardation.

2. Sensitivity to slow speakers, persons with speech impediments.

3. A long term commitment to consistency and continuity.

4. A _clear_ explanation that an Advisor is a friend and a resource person, not a staff person or a boss.

5. A firm belief in the rights of disabled persons and a deep respect and understanding of each member's potential.

6. An ability to sit back and let members work things out for themselves.

7. Have every decision voted on, _never_ make a decision for the group.

8. The advisor never imposes rules such as who can join, how many persons can join, or influence members to be selective.

9. The advisor explains the importance of being on local advisory board committees and encourages members to be active in their community.

10. The advisor should let the members know that they have the right to ask the advisor not to participate in the meeting or not to attend a meeting. It should be made clear to the members that it is _their_ club and not an extension of a "program."

11. The advisor should keep a record of names and addresses of all members so information, public relations, notices, etc., can easily be disseminated.

MERRY MACS

2 Year Old February 20, 1980.

Had Mohawks and Squaws for guest speakers.

Members suggested letter be written to institution regarding discrimination against retarded persons serving as volunteers.

Six members attended anti-discrimination conference sponsored by another self-advocacy group.

Members gave input to Socio-Ed program regarding evening courses they would like to take. Also made suggestions for summer recreation programs.

Discussed guardianship and what it means.

Members sent letter to state senator/chairperson Senate Ways and Means Committee expressing their concern over the Mental Health budget and its effect on their lives.

Members attended "Yes We Can" conference planned by developmentally disabled persons. A Merry Mac member (Alice) was on planning committee.

Some members have discussed violations of their rights with community residence staff persons.

Members plan their social activities. For example, Christmas party, Anniversary party, etc.

Members formed Political Committee which will gather information concerning presidential candidates.

Club held a voter registration training meeting. Members practiced using voting machine and ballot box. City Election Commission members attended and a representative from the League of Women voters.

Club had guest speaker about proper sexual behavior in public. Slide show was seen and discussed. Fee was paid out of treasury.

member attended self-advocacy conference in Kansas City.

President gave presentation to local program to recruit new members,

4 members spoke at MARC convention on self-advocacy.

Merry Macs

Self Advocacy Group

****
Legal Rights of
Mentally Retarded Persons
****

1. The same basic rights as every other citizen.

2. The right to live as normally as possible and the right to quality care in residential facilities.

3. The right to economic security and the right to perform productive work.

4. The right to protection from exploitation and abuse.

5. The right to proper medical care and physical restoration.

6. The right to equal educational opportunity and sufficient training to develop to the fullest potential.

7. Above all, the right to respect.

****

GOALS

The Merry Macs are dedicated to the idea that every handicapped person is more like other people than he is different from them.

A handicapped person has the same basic rights as every other citizen.

Most of the members want the opportunity to participate in community affairs and to give consumer feedback to agencies who deal with the handicapped.

All members want to develop to their fullest potential, whether that is advocating for themselves in public places or observing their peers advocate for the members who, for some reason, cannot advocate for themselves.

The ultimate goal of the Merry Macs is to function independently and no longer need an advisor.

We would like to raise funds for our organization so that it can promote the common cause of self-advocacy to new groups.

****

CONSTITUTION OF THE MERRY MAC CLUB

****

What our club stands for:

1. Learn how to fight for our rights.

2. Meeting new friends.

3. Getting along and controling ourselves with new people.

****

RULES OF THE CLUB

1. No fighting
2. No screaming
3. No cigarette butts on floor
4. Help clean up after meetings
5. Bring weekly dues of 25 cents
6. No interrupting the speaker
7. Raise your hand to speak
8. Staff people may attend when invited, substitute for advisor is O.K.
9. Be careful of fire

****

WEEKLY MEETINGS

Time: 7:00 P.M. to 9:00 P.M.

Day: Tuesday

Place: Christ Church United
1 Bartlett Street
Lowell, Mass.

Date: September thru June

(Summer meeting place to be announced)

POSITIONS HELD BY MERRY MAC MEMBERS

Alice Monahan: LARC Board of Directors and MARC Consumer Advisory Board

Mary Tousignant & David Irwin, Lowell Human Rights Committee

Judy Huard: L.R.T.A. Advisory Board

Julia Hartnett: LARC Socio-Education Advisory Board

Mary Devlin: G.L.O.V.E. Advisory Board

Doug Smith: MARC Consumer Advisory Board

Judy Huard-McCB Advisory Board

****

CONCEPT OF SELF-ADVOCACY GROUP

Proposed by Alice Monahan

First Official Meeting
February 20, 1979

OFFICERS:

President: Judy Huard
V. President: Wayne Gagne
Secretary: Mary Tousignant
Treasurer: Judith Kinney

ELECTIONS: Held Annually

For Information contact:

Advisor -- Kathy Tessitore
145 Lexington Ave.
Lowell, Ma., 01854

Tel: 459-6179
459-0122

Association for Retarded Citizens, Dade County

A Voluntary Organization Dedicated to the Welfare of Mentally Retarded People of All Ages.

8672 Bird Road, Suite 211. Miami, Florida 33155   Phone: 553-1602

March 11, 1981

John S. Rowlson
618 Forest
East Lansing, Michigan
48823

Dear John,

I received your letter regarding your dissertation project to develop materials to assist advisors of self-advocacy groups. This is very much needed. During the past two years, I have served as the advisor to People First of Dade County, and I now serve as the Project Director for a Developmental Disabilities Grant in which we are assisting consumers and advisors in starting nine self-advocacy groups throughout Florida. We have developed some training materials and resource manuals for use by consumers and professionals. Jeff Woodyard's, <u>Advisor Guidebook For Self-Advocacy</u>, is also very helpful. If you want these materials, please let me know and I'll send them to you.

The following are some topics that I think you may want to include:

1) Basic overview of developmental disabilities and laws.
2) Group process and development—generic and application to self-advocacy groups.
3) Understanding government - how to influence legislation.
4) Obtaining resources - funding, training, volunteers.
5) Maintaining the balance between doing too much and too little for the group.
6) How to be an advisor if you work for an agency providing services and keep your job.
7) Resolving transportation problems.
8) Working with other advocates
9) Goal planning and follow-up with the group.

A United Way Agency

Member of Florida Association for Retarded Citizens and National Association for Retarded Citizens

2

Good luck on your project. Please let me know if
I can be of further assistance.

Sincerely,

Nina Cohen
Self Advocacy
Project Director

NC: br

Casey Clark — NARC
Community Rg. Bld.
Concord. MA. 01742

il in a training program for advisors of self-advocacy

In my opinion, in order to be a successful advisor one should first understand the population one will be working with. People are products of their environment, therefore, one needs to explore the community the folks live in, their family situation, residential setting, work environment and social situation. Much of this can be done in an interview with the individuals on a 1-1 basis. Once you have acquired the basic information you can pull together a group.

In order to have a successful group you have to set up guidlines and a structured environment in which the issues of self- advocacy can be highlighted and addressed. Above all you must be consistant in your approach. The structure will help avoid confusion and is helpful in insuring that no one is left out of discussion and they have a frame work to comply with limiting inappropriate behaviors, such as speaking out of turn, and tangents etc.

It is also important that advisors are well informed as to events that will directly or indirectly effect the group as a whole or as individuals. Keep up with past and currant legislation, and community affairs. You might also want to go out to existing self-advocacy groups and note how they approach issues.

Above all one must be committed to the concept of self-advocacy and be willing to put in a lot of man hours, availability to your population is a key to success, as an advisor one must be open to the needs of the folks before, during, and after the meeting, it is an ongoing responsibility, if one is not sure how much time they want to devote to a group they should put off organizing until they are able to clarify in their own minds how important being an advisor to a self-advocacy group is.

Thats about it in a "nut-shell". If I can be of further service to you please feel free to contact me.

Sincerely,

Casey Clark.
Minute Man Recreation Coordinator

People First of Washington

P.O. Box 381
Tacoma, WA. 98401
PHONE (206) 272-2811

March 17, 1984

Dear Mr. Robertson,

Thank you for writing to Washington People First concerning your doctoral dissertation and concern for self advocacy and People who are developmentally disabled.

I am currently involved with Dennis Heath of People 1st International in Oregon and the staff of the Research and Training Center at the University of Oregon in Mental Retardation (a UAF facility) in writing a Helpers Manual for helpers in self advocacy movement. This manual is ~ 1/2 done and includes chapters on 1) History of Self Advocacy Movement and People who are Developmentally Disabled 2) Short History of People First and Self Advocacy 3) Personal Characteristics of Helpers 4) Gaining Access to Systems to start self advocacy movements 5) Gaining access to consumers to start self advocacy movements 6) agencies for starting self advocacy movements (resourcebooks) 7) Roadblocks to anticipate in starting self advocacy movement 8) recruiting other helpers 9) Case examples 10) what consumers say they want from helpers 11) an extensive bibliography on groups, group dynamics, advocacy, self advocacy, communication skills, changing/influencing systems etc.

Your project sounds great

~ over ~

I would Suggest that you contact
Cindy Rhoades / Jean Lehmann
% Rehabilitation Research and Training
Center in Mental Retardation
Center on Human Development
University of Oregon
Eugene, OR 97403

Regarding our helpers manual
I would also Suggest that you attend the
People 1st International Convention, July 4-5-6 in
Portland Or and See ~~IIILINE~~ 1750 People First self advocates
and helpers in all Stages of development from across
the United States and Canada. You might find that
attending this convention and all the self advocates &
helpers present could form a large part of the body of
your dissertation.

Keep in touch with your progress & let me know
how I can help.

Sincerely,

Bob Furman
People 1st Helper
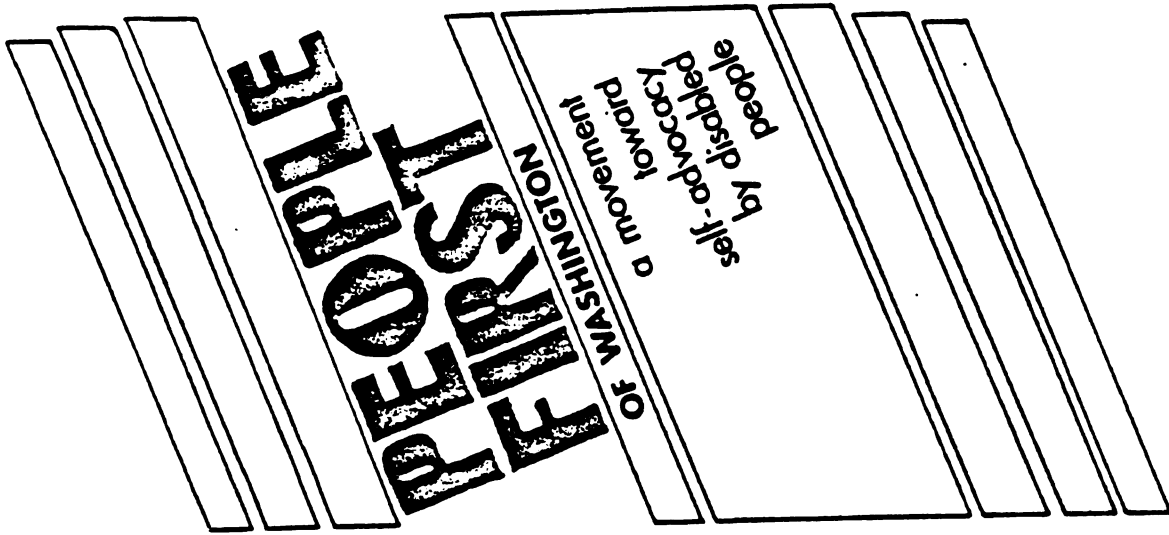
PEOPLE FIRST
P.O. Box 381
Tacoma, WA. 98401

Information
PEOPLE FIRST
P.O. Box 381
Tacoma, WA. 98401

(206) 272-2811

Resources
People First Movie (Oregon)

People First Handbook

People First Officer's
Handbook

List of Washington People
First Chapters

People First of Washington
Brochures

What is People First ?

People First means that we are like everyone else and we don't want to be called retarded.

People First is a support group where we share and grow and solve problems with friends.

People First is learning our rights, meetings and social events, and helping others.

What are the goals of People First ?

To help each other.

To learn new skills.

To learn to talk for ourselves. To tell people what we want.

To show people we can do things for ourselves.

To help other handicapped people start People First Chapters.

To make decisions and be as independent as possible.

What do we do at meetings ?

Work as a group to solve our problems.

Learn about our community.

Plan activities.

How to start a People First chapter

Handicapped people and helpers get together from workshops, group homes and the community to talk about People First... being independent...being a part of a group...doing things on our own.

Invite members and helpers from a nearby chapter to share information with you.

Make a decision on when and where your meetings will be. Most chapters meet once or twice a month.

When you are ready, elect officers for your chapter.

Keep in touch with other People First Chapters and share information.

How do we raise money for People First

Each Chapter collects dues.

We have car washes, dances, re-cycling projects.

Helpers Role

Helpers learn to listen and help members speak and do things on our own.

Helpers are resource people who help us when we need it.

They should let us go at our own pace.

Helpers do not get to vote.

The Future

We hope that more People First Chapters will be started in Washington.

Since 1978, Washington People First Conventions have been held each year. The Convention is a time when all the members of all the chapters and interested people get together to meet each other and share People First experiences.

"What would be useful in a training program for advisors of self-advocacy support groups."

John — Dave William now works in a Regional Center. I am the regional peoples first advisor at SSH. I would I have a lot to say that you could find in your reading. But I feel there are already a number of Self Advocacy training manuals out. Contact Geff cwood and at U. of Kansas in Lawrence. Haworth Hall he is winding up the head of a 3 year grant to train + start up Self Advocacy groups nation wide. He Sandy Fitch, and Nancy Gardner could give you tons of great advice, if they don't convince you to rewrite do the manual. True the advocacy movement need advisors - advisors are always needed to backup consumer groups. I guess I really don't have a lot to say. I'll present your letter to the People First group via the listening board there. I too & see if they could be more positive. Sorry Robin Sargent

c/o CPS
Sonoma State Hospital
Eldridge Ca. 95431
days 707 833 6477

Ideas from class about a good advisor

1) should know about different communication systems so they can communicate with non verbal (non-speech) people, like, Bliss symbols, sign language, electronic communication boards.

2) be helpful, just a little help, don't spoil them, don't help all the time
   DON'T HELP TOO MUCH !!

3) let us run things, don't do all the organizing for the groups, let them run meeting, do minutes organize time, place.

4) members should push wheelchairs, get to meetings on time and not fool around advisors shouldn't do these things, members should set up tables + chairs

5) don't help too much, let us do things our way + make our own mistakes

6) help members understand things that happen at other meetings & on committees, if we can't understand what people are talking about

7) if there is something the members can't do, teach them, don't do it for them everytime, teach us so next time they don't have to help

8) help get forms in on time, reminding us about time limits or when things need to be done by.

9) help with transportation to advisory Board meetings

APPENDIX D

Module Package

MODULE I

INTRODUCTION AND ORIENTATION TO

THE SELF-ADVOCACY MOVEMENT

<u>GOALS</u>:

To increase application of knowledge about self-advocacy.
To increase sensitivity and acceptance of self-advocates.
To develop environments that foster self-advocacy groups.

<u>RATIONALE</u>:

This module is intended to inform you about self-advocacy groups that
are being formed around the country. These groups are being formed in
this community and one may be starting at the site where you work. You
will learn what can be done to assist in creating conditions that allow
self-advocacy groups to evolve.

Your involvement with people from other programs in a cooperative and
creative environment will increase resources for you and others. The
diversity of ideas and options for self-advocacy groups will become
apparent as you learn the conditions that exist in the many sites rep-
resented. The blending of resources and ideas can strengthen your
program.

Your knowledge and understanding of the issues of advocacy and self-
advocacy will be explored and shared. In this process you will realize
the relationship advocacy has to self-advocacy, and clarify your role
as an advocate.

The need for self-determination by the disabled will be discussed.
You will learn how self-advocacy groups satisfy many personal and
social needs. The benefits an individual can achieve by making choices
can lead to greater independence and integration in a democratic society.

OBJECTIVES:

To increase application of knowledge about self-advocacy.
   A. Given the definition of advocacy, you will identify and
       record those times you acted as an advocate, continue for
       one week or until you have ten examples, analyze the data
       and set yourself an advocacy objective.

To increase sensitivity and acceptance of self-advocates.
   A. Given an introduction to self-advocacy, you will share
       perceptions and experiences about beliefs you hold related
       to the satisfaction of disabled persons needs.
   B. Given an introduction to self-advocacy, you will identify
       and discuss self-advocacy issues observed at various sites
       in this community.

To develop environments that foster self-advocacy groups.
   A. After the first session, you will discuss with the people
       you work with the ideas involved in starting self-advocacy
       groups in this community and at your site.

ACTIVITIES:

I.   Participate in name card exercise.

II.   Participate in identifying issues of Self-Advocates exercise.

III. Record for one week those instances you have acted as an advocate.
      Look for patterns, omissions, or insights which you can use to
      increase the times you are an advocate. Write yourself an advocacy
      objective.

IV.   Discuss the ideas in the People First article with another person
      from your site. Note how some of these ideas may be implemented
      in your program.

V.   During free time observe the people you serve. Be aware of cul-
      tural differences and similarities. Determine who the group
      likes, respects, the leaders, followers, outsiders. Note norms
      that may be similar to and different than agency norms.

VI.   The addition of a self-advocacy group will effect the ecological
      balance of your program. Brainstorm with your staff what the
      effects might be and develop a plan to reduce the negative effects
      and increase the positive aspects of a self-advocacy group.

VII. Use a Journal to record observations, activities, projects, and
      your progress made during this training. The journals will be
      collected at the end of the training to be used to analyze the
      effectiveness of the instructional materials. They will be re-
      turned to you one month after training has been completed, during
      a follow-up interview.

ACTIVITY

TITLE: Name Card Exercise

GOALS:

To state position during inservice.
To be an impetus for interaction.
To clarify values about self in relation to the disabled.

MATERIALS:

1.   One 4" x 8" card.
2.   One safety pin.

STEP-BY-STEP PLAN:

1.   On a 4" x 8" card write name in upper right hand corner.
2.   Write work site under name.
3.   Choose the appropriate title for your role in this inservice and
     place in upper left hand corner;

         a) interested staff,
         b) administrator,
         c) prospective advisor,
         d) advocate,
         e) other (fill in own term).

4.   On back of card, write one expectation you have for this inservice.
5.   Also on back of card, write a need the disabled have that you
     believe is being adequately addressed at your site.
6.   Follow this by an inadequately met need.
7.   Pin card on name side out.
8.   The facilitator will direct the following activity:

         a) silently mill around and identify a person who you do
            not know and pair up,
         b) identify speaker and listener, you will switch roles,
         c) share in one minute your role in this inservice and
            why you are here,
         d) share one of the two answers to the questions on the
            back of the card. Be aware of your criteria for selection,
         e) revise roles and repeat.

9.   Processing:

         a) assess level of comfort and depth of responses,
         b) determine various criteria used in sharing.

ACTIVITY

TITLE: Identifying Issues of Self-Advocates (exercise)

GOALS:

To become acquainted with others.
To reflect upon your clients and their needs.
To gain an understanding of what others perceive and value.
To increase your awareness of self-advocacy.

MATERIALS:

Paper and pencil.

STEP-BY-STEP PLAN:

1. Form group of four to six people.
2. One person at a time share an example of a client seeking to be
    a self-advocate.
3. Briefly discuss each example to be certain each person is sharing
    an issue if needed.

        a) clarify definitions,
        b) explore perceptions,
        c) piggy-back experiences.

4. Expand example and make generalizations about Self-Advocates.
5. Record.
6. Process in large group:

        a) sharing examples,
        b) clarifying perceptions,
        c) check out feelings.

7. Facilitator collects examples.

MODULE I

IMPACT QUESTIONNAIRE

This questionnaire seeks to determine the impact this module has had upon your growth along the dimensions of: knowledge, skills and attitudes/beliefs.

1. Differenciate between advocacy and self-advocacy.

2. Briefly explain self-determination.

3. What was your reaction to the People First article?

4. What do you feel about a national self-advocacy movement?

MODULE I

EVALUATION

The purpose of this evaluation is to determine your reactions to the instructional materials along the dimensions of: content, format, structure, and presentation.

1. The presentation of the material was:

    exciting   interesting   O.K.   dull   boring
    /_____/_____/_____/_____/

    Comment:

2. The discussion on self-determination was:

    very   not   a waste
    useful   useful   O.K.   useful   of time
    /_____/_____/_____/_____/

    Comment:

3. The Activities were:

    rewarding   interesting   O.K.   dull   unfulfilling
    /_____/_____/_____/_____/

    Comment:

4. What did you find most useful during this session?

5. What did you find least useful?

6. What would you leave the same?

7. What would you change in this module.

MODULE II

<u>ASSESSMENT</u>:

1. Give an example of how you respected a mentally retarded persons dignity of risk.

2. Why do you want to be an advisor to a self-advocacy group?

3. What is a strength that you have that will assist you in facilitating a self-advocacy group?

4. Do you feel competent to facilitate a self-advocacy group?

MODULE II

THE ROLE OF ADVISOR TO SELF-ADVOCACY GROUPS

GOALS:

To increase knowledge and application of principles of self-advocacy
    advising.
To identify and define advisor skills.
To develop alternative methods for determining the role of advisor.

RATIONALE:

The purpose of this module is to provide a philosophical base of beliefs
that define the role of advisor. Knowing the proper function of advisor
to self-advocates will assist in maintaining clarity and purpose.

The conditions of the mentally retarded lives must be appreciated. Many
have been treated as dependent and incapable, with many of their needs
being taken care of by others. The transition from dependency to in-
creased independence requires changes in how the disabled and advisors
perceive help. Often old patterns of interacting and ways of maintaining
a dependency position is reinforced by both parties. It is difficult for
an advisor and the self-advocate to move from a superior to subordinate
interaction pattern; from being dominating and dominated; from the helper
and the helpless; to seeing each other as resources; to establishing
equality of influence; to cooperation and mutual respect; to being able
to know when to "back off" and observe people work problems out for
themselves.

You will be given the opportunity to discuss, clarify, and practice
various roles of advisors. You will then be more skilled and knowledge-
able and in a better position to advise.

The skill of being able to discriminate your needs from the self-advocate
will be strengthened as you participate in the discussions and activities.
This skill is important in keeping your role as advisor in perspective
and modeling integrity with the group.

You will be introduced to the skills advisors need to facilitate self-
advocacy groups. You will learn to identify and when these skills are
exhibited; this will allow you to put theory into practice and begin
to integrate principles with your skills.

MODULE II

OBJECTIVES:

Principles.
    A. Given four basic principles of self-advocacy, you will
        develop and implement a written plan that will heighten
        your comprehension and sensitivity of each principle.
        The results of this plan will be turned in at the completion
        of the training.
    B. Given the opportunity to role play a self-advocacy group
        defining the role of the advisor, you will participate in
        various roles focusing on application of the principles
        of self-advocacy.

To identify and define advisor skills.
    A. After completion of each role play situation, you will fill
        out an advisor skill assessment sheet checklist and provide
        each person with constructive feedback.
    B. After receiving feedback from the group, you will identify
        those advisor skills that are your strengths and those that
        may be limitations.

To develop methods for determining the role of the advisor.
    A. During discussions about various self-advocacy groups, you
        will describe the conditions that exist at the site where
        you will be an advisor and problem solve with the group
        various ways you may be able to determine your role as an
        advisor.

ACTIVITIES:

I.   Participate in discussion on Basic Principles of Advising Self-
      Advocates.

      Materials: a) "The DD Bill of Rights"
                 b) Self Advocacy: "What does it mean"
                 c) Guidelines for Advisors

II.   Participate in discussion and explanation of Advisor Skill
      Assessment Check-list.

III. Participate in Self-Advocacy Group role play.

ACTIVITY

TITLE: Self-Advocacy Group Role Play

GOALS:

To practice applying the principles of self-advocacy.
To increase awareness and understanding of advisor skills.
To give and receive feedback.

MATERIALS:

1.   Role descriptors of self-advocates.
2.   Skill assessment sheet.

GROUPS: Four to six people in a group.

STEP-BY-STEP PLAN:

1.   Request a volunteer to be the advisor, informing the group that
     each person will have an opportunity to have both roles of
     advisor and self-advocate.
2.   Have participants draw a role descriptor from hat.
3.   Read descriptor but do not share with others.
4.   A self-advocate announces an issue to be discussed.
5.   After everyone has an idea of their role, announce that the role
     play will last five minutes with processing, and then we will
     switch roles.
6.   Begin role play for five minutes.
7.   Stop - process at seven minutes.
8.   Fill out assessment sheet.
9.   Repeat exercise until all participants have had an opportunity
     to be an advisor.

MODULE II

EVALUATION

1. The presentation of the material was:

excellent   O.K.   very poor

/_____/_____/_____/_____/

/_____/_____/_____/_____/

clear   confusing

Comments:

2. The discussion on the Principles of Self-Advocacy was:

excellent   good   O.K.   poor   very poor

/_____/_____/_____/_____/

Comments:

3. The role play activity was:

helpful   O.K.   harmful

/_____/_____/

Comments:

4. What did you find most useful about this session? Why?

5. What was least helpful?

6. What suggestions or recommendations do you have?

MODULE III

ASSESSMENT:

1. List three commonly held myths about the developmentally disabled
    and mentally retarded.

2. Write an example from your own experience where a disabled person
    has expressed their need to be a self-advocate.

3. Describe how you are perceived by the people you are seeking to
    advise.

4. Have you started working with people as an advisor? Yes___ No___

    If yes, do you feel more confident as a result of what you have
    learned in this training? Please explain.

    If no, do you feel more confident to start as a result of this
    training? Please explain.

MODULE III

PARTICIPATING IN THE GROWTH OF

SELF-ADVOCATES

GOALS:

To increase knowledge of developmental disabilities.
To develop a perceptual view of self-advocates.
To increase knowledge about self-advocacy skills.
To facilitate problem solving and decision making.

RATIONALE:

The purpose of this module is to link knowledge of developmental dis-
abilities with an understanding of what a person must do to be a
self-advocate. People often limit their perceptions of the persons
potentials by stigmatizing and stereotyping through the assumptions
held to be "true". There are many myths about retardation,
Wolfsenburger speaks clearly about seven myths commonly held which
result in devaluing the person. You will be provided information
that can assist you in distinguishing fact from myth. In this process
you will recognize opportunities to go beyond your own preconceptions
about human potentials and appreciate the striving for dignity and
equality motivating self-advocates.

Person's beginning their journey as self-advocates may not know how
to communicate their needs. They may be tentative in attempting to
pursue their emerging awareness. Your task is to gain the ability
to hear their subtle expressions, and respond in ways fostering growth
in self-reliance, self-confidence, assertiveness, reality orientation,
problem solving, and decision making.

The self-advocate must make their own decisions and act on them.
This requires judgement and motivation. Facilitating this process
is a function of the advisor. You will practice posing questions,
options and alternatives so that people can make decisions.

You will role play a person you know becoming a self-advocate. This
will sensitize you to their thoughts, feelings and allow you to gain
an appreciation of their inner world. The responses of others to
your role play will provide you with different ways to intervene.

MODULE III

OBJECTIVES:

To increase knowledge of developmentally disabled.
  A. Given the opportunity to explore myths about mental retardation, you will choose a method that will allow you to respond in a non-stigmatizing manner.

To develop a perceptual view of self-advocates.
  A. Given the opportunity to role play a self-advocate you know well, you will discuss with the group the insights, thoughts, feelings and perceptions you have about the person role played.
  B. After the role play, you will provide feedback to other advisors about their interventions.

To increase knowledge about self-advocacy skills.
  A. During a discussion on self-advocacy skills, you will develop a list of skills needed by the self-advocate you are familiar with.
  B. As an observer recorder during the role play, you will make notes of times when the self-advocates used an advocacy skill.
  C. Given the opportunity to discuss, practice and observe self-advocacy skills, you will record those instances within one week when you observed a disabled person exercising a self-advocacy skill.

To facilitate problem solving and decision making.
  A. Given the opportunity to role play, you will practice using questions, options and alternatives.
  B. After the role play, you will receive feedback about the impact your interventions had on others.

ACTIVITIES:

I.   Participate in discussion Developmental Disabilities and Mental Retardation.

II. Read Handouts:

        a) Mental Retardation
        b) Myths of Mental Retardation
        c) Dignity of Risk
        d) Self-Advocacy and Changing Attitudes

III. Participate in discussion on self-advocacy.

ACTIVITIES: (cont'd.)

IV. Develop a list of self-advocacy skills.

V. Participate in discussion on facilitating self-advocacy.

VI. Participate in self-advocacy role play exercise.

VII. Record those instances within a one week period where you observe a disabled person exercising a self-advocacy skill.

MODULE III

ADVISOR SKILL CHECKLIST

_____
Name of Advisor

_____
Name of Assessor

Advisor Skill Area:	Often	Occasionally	Never	Comments
Decision Making Skills:				
Pose Questions				
Offer Options				
Develop Alternatives				
Assist to Discuss Pros and Cons of various alternatives				
Explore Consequences				
Advisor Focused on:				
Own Need				
Own Solution				
One Idea				
Many Ideas				
Self-Advocates Needs and Ideas				

ACTIVITY

TITLE: Self-Advocacy Role Play Exercise.

GOALS:

To identify and respond to the needs of people becoming self-advocates.
To become more sensitive to people with disabilities.
To practice posing questions, generating options and alternatives.

ROLES:

3 people as: 1 self-advocate - communicate as a person you know in
                   their manner who is beginning to be a self-
                   advocate.
               1 advisor - facilitate self-advocate in problem solving
                   situation.
               1 observer/recorder: 1. watch and record interaction
                                      2. assist both parties to process
                                          experience
                                      3. keep time

STEP-BY-STEP PLAN:

1. Identify each person and their initial role.
2. Self-advocate presents a problem, situation or a decision they are
    seeking the advisor to resolve.
3. Advisor respond to self-advocate.
4. Observer/Recorder maintains time for eight minutes, maintains
    silence until time limit has expired.
5. Observer has self-advocate share thoughts, feelings, insights,
    and perceptions. Three minutes.
6. Observer has advisor share experience. One minute.
7. Observer and self-advocate provide advisor feedback on inter-
    ventions. Five minutes.
8. Advisor shares meaningful feedback.
9. Change roles and repeat.

MODULE III

EVALUATION

1. The presentation of information was:

excellent   clear   O.K.   vague   confusing
/   /   /   /   /

Comments:

exciting   interesting   O.K.   dull   boring
/   /   /   /   /

Comments:

2. The practice interventions activity was:

rewarding   interesting   O.K.   vague   confusing
/   /   /   /   /

Comments:

3. My satisfaction with this module is:

great   fine   O.K.   low   poor
/   /   /   /   /

Comments:

4. What did you find most useful in this session?

5. What did you find least helpful?

6. I would recommend these changes:

MODULE IV

FACILITATING A SELF-ADVOCACY GROUP

GOALS:

To understand aspects of group dynamics.
To increase knowledge about group problem solving and decision making.
To further develop group facilitation skills.

RATIONALE:

You will learn the assumptions held by many Group Dynamicists, that
provide for the basis for the study and uses of groups. With this
orientation to groups you will explore leadership styles and as a pre-
test to this module learn about your leadership style. You will then
delve into the possible implications this style has upon you and the
groups you may facilitate. This discussion will be conducted with an
awareness of the purpose for self-advocacy (Module I) and the role of
the advisor (Module II). Dissonance theory will be presented as a
tool to assist you to integrate learning.

Groups tend to go through various stages and phases. You will be
presented with a model that may be useful in understanding the inter-
actions and behavior of the group. The knowledge of the stage of
group development will allow you to make interventions appropriate
to the developmental level of the group.

Self-Advocacy groups seek to solve their own problems and make decisions
for themselves. Effective problem solving and decision making involve
learnable skills that you as an advisor will facilitate. You will be
presented material that can assist you to process various steps in a
problem solving situation.

One difficulty many people have is identifying and owning that a problem
exists. The less adequate a person is or believes himself/herself to be,
the risk is greater to accept a problem and to begin to imagine the pos-
sibility to solve the probelm for themselves. You will explore various
techniques and develop skills to change peoples perceptions about the
nature of problems and the individuals capacity to work things out for
themselves.

Many people have difficulty making and following through with decisions.
This malaise can be overcome through practice and environmental supports
that allow people to make decisions and "deal" with their feelings re-
garding their judgment. The group provides a form of insulation from
having to assume "all" the responsibility for decisions, making choices
safer. Another advantage a group has is that more alternatives can be
generated representing various points of view, allowing for more
effective decisions.

RATIONALE: (cont'd.)

You will learn steps effective decision makers use. This knowledge
will assist you to intervene in developing the groups capacity to
make effective decisions.

Advisor skill building will be developed through rehearsal of inter-
ventions that evolve through discussions about the content covered
in this module.

MODULE IV

OBJECTIVES:

To understand aspects of group dynamics.
   A. Given the test of leadership styles, you will identify your
       style and discuss the implications this leadership style
       may have on a self-advocacy group.
   B. Given information about group stages of development, you will
       practice making interventions appropriate to the level of the
       group.

To increase knowledge about group problem solving and decision making.
   A. Given the problem solving approach, you will practice making
       responses that facilitate people to change their perceptions.
   B. Given steps effective decision makers use, you will generate
       with others optional interventions to develop the groups
       capacity to make effective decisions.

To further develop group facilitation skills.
   A. During practice interventions while an observer, you will
       provide feedback to the advisor.
   B. After making a practice intervention you will receive feed-
       back from others and share with the group the most meaningful
       feedback.

ACTIVITIES:

  I. Participate in discussion on group dynamics and leadership style.

 II. Participate in group problem solving and decision making discussion.

III. Practice making interventions to the group in response to examples
      generated through discussion.

 IV. Read Handouts:

           a) Steps In Decision Making.
           b) Authority Cycle In Small Group Development.
           c) Stages of Group Development.

ACTIVITY

TITLE: Practice Interventions.

GOAL:

To practice group facilitation skills.

MATERIALS:

Stages of Group Development.
Steps in Problem Solving.
Steps in Decision Making.

STEP-BY-STEP PLAN:

1. Presentation and discussion of material.
2. An example situation will be described that dramatizes a concept.
3. A person will volunteer to be an advisor, the remainder of the group will act as self-advocates.
4. The self-advocate will provide one minute of dialogue (warm-up and set-the-stage).
5. The advisor will make an intervention.
6. The group will provide feedback.
7. The advisor will respond to most meaningful feedback.
8. Optional responses will be generated.

*Optional steps used after group becomes efficient with process.
Use steps 1, 2, 6 and 8.

ASSESSMENT

McGreggor Theory X, Theory Y of Leadership

MODULE IV

IMPACT QUESTIONNAIRE

1. Label and briefly describe the stages of group development.

2. Identify the steps in the problem solving approach.

3. Identify the steps in decision making.

4. Fill in and explain: I believe my skills as an advisor to facilitate self-advocacy groups have _____ during this session. Explain:

MODULE IV

EVALUATION

1. The presentation of information was:

excellent   clear   O.K.   vague   confusing
/_____/_____/_____/_____/

Comments:

exciting   interesting   O.K.   dull   boring
/_____/_____/_____/_____/

Comments:

2. The practice interventions activity was:

rewarding interesting   O.K.   vague   confusing
/_____/_____/_____/_____/

Comments:

3. My satisfaction with this module is:

great   fine   O.K.   low   poor
/_____/_____/_____/_____/

Comments:

4. What did you find most useful in this session?

5. What did you find least helpful?

6. I would recommend these changes:

MODULE V

ASSESSMENT:

1. Due to this training my ability to work with disabled people has increased in these areas:

2. List five assertive beliefs you have.

   a.

   b.

   c.

   d.

   e.

3. List two laws that have had an impact on changing the rights of the developmentally disabled.

   a.

   b.

MODULE V

SEEKING HUMAN RIGHTS THROUGH DEVELOPING RESPONSIBILITY

GOALS:

To review civil and human rights legislation.
To understand how human rights are associated with responsible
    assertive behavior.
To increase options for people to be responsible.

RATIONALE:

Since 1954 Brown vs. Topica Board of Education the civil/human rights
issue has had a profound impact on American society. In twenty seven
years many of societies disenfranchised groups have obtained previously
denied rights.

The developmentally disabled have been ostracized by society as re-
flected in social policy. Court decisions and laws have paved the way
for the "silent minority" to gain a voice in the democracy. You will
discuss some of the major laws and court decisions and their implica-
tions to increase your understanding and appreciation of the impact
newly gained rights can have on an individual.

An individual aware of their rights also needs to be able to communicate
effectively so that they do not alienate themselves and stigmatize their
group. A belief in responsible assertive behavior can be developed to
improve communication. Rights without responsibility is license.
Denying people rights is unjust and undemocratic. The concepts are
associated with each other and need to be linked when facilitating a
self-advocacy group. You will clarify and explore assertive beliefs
that are useful in developing responsibility. You will also discuss
fears and concerns associated with devalued people behaving assertively.
Within this process you will strengthen your belief in responsible
assertiveness by the disabled.

The environment that people live, work and play in can limit or expand
options people may have in behaving responsibly. You will brainstorm
various environmental adjustments that could be made that would facili-
tate people being responsible. If you want people to be responsible
for their actions then they must have opportunities to be responsible.
You may need to provide them opportunities.

MODULE V

OBJECTIVES:

To review civil and human rights legislation.
   A. Given a summary of civil and human rights legislation, you
       will discuss the implications these laws have had on the
       developmentally disabled.

To understand how human rights are associated with responsible
assertive behavior.
   A. Given basic beliefs about responsible assertiveness, you will
       discuss and clarify your own beliefs and note in your journal
       ways to increase your own assertiveness.
   B. After clarifying assertive beliefs, you will discuss fears
       and concerns associated with the disabled being assertive.
       This discussion will lead to developing strategies that can
       be used to overcome those fears and concerns.

To increase options for people to be responsible.
   A. Given the opportunity you will brainstorm options that provide
       opportunities for people to be responsible.

ACTIVITIES:

 I. Participate in discussion on Laws and Rights.

II. Participate in clarification of assertive beliefs as a way toward
     responsibility.

III. Participate in discussion to overcoming obstacles due to fears
     and concerns about the disabled being assertive.

IV. Participate in brainstorming on ways to expand opportunities for
     people to be responsible.

 V. Read Handouts:

        a) Developing An Assertive Belief System.
        b) Advocacy Programs for the Disabled.
        c) Verbal and Non-Verbal Components of Behavior.
        d) Focus: Laws, Civil Rights Acts.
        e) Public Law 94-142 and Section 504 - "What They Say About
           Rights and Protections."

MODULE V

EVALUATION

1. I found the content of the material:

                        appropriately
    simple   easy   challenging   difficult   too hard
    /_____/_____/_____/_____/

    Comments:

2. The discussions were:

    exciting   useful   interesting   dull   boring
    /_____/_____/_____/_____/

    Comments:

3. What did you find most useful in this module?

4. What did you find least useful?

5. What changes would you recommend?

MODULE VI

ASSESSMENT:

1. Describe your feelings about starting a self-advocacy group.

2. Discuss ways to implement a self-advocacy group.

MODULE VI

STARTING AND CONTINUING A SELF-ADVOCACY GROUP

GOALS:

To explore ways to implement self-advocacy groups.
To develop systems that provide for the continued existence of self-
    advocacy groups.

RATIONALE:

The need for self-advocacy groups must be expressed by the disabled.
If having a group is the advisors ideas and imposes this "service"
on clients then it will be "treatment" and not self-advocacy. Self-
advocacy is a felt need and the sensitive advisor can listen to the
messages that communicate this need. This assessment of need to be-
come self-advocates can be useful in starting a group or finding a
group for a person.

The various sites where people work, live, and play can provide a
consistent and relevant context for the development of self-advocacy
groups. Each site has its own unique characteristics that effect the
purpose and direction of the groups. In this module you will be
provided a step-by-step guide of "Getting a Self-Advocacy Group
Started". The format for self-advocacy group meetings has become
fairly consistent, with officers being elected and parliamentary
procedures being employed. It must be remembered that each group
is different and they must make their own decisions about the function-
ing of the group.

You will be provided information from people around the country who
have already been involved in self-advocacy. Established groups are
resources for you and your group, and you can review their materials.

A commitment needs to be made to people desiring self-advocacy groups.
This commitment is to insure the continued existence of the structures
and resources provided by the advisors as long as the group needs an
advisor. It is irresponsible to start a group and not provide for
its continued existence. We will plan ways to insure the continued
resources for self-advocacy groups.

MODULE VI

OBJECTIVES:

To explore ways to implement self-advocacy groups.
    A. After completing the first five modules, you will develop a
        self-advocates assessment guide.
    B. In conjunction with other advisors, you will discuss the
        characteristics of various sites and the potential for starting
        and continuing self-advocacy groups.
    C. After completing session six you will have the opportunity
        to review resources from other self-advocacy groups.

To develop systems that provide for the continued existence of self-
advocacy groups.
    A. Given the opportunity you will develop a list of potential
        resources for self-advocacy groups.
    B. After developing a resource list, you will develop plans
        that insure self-advocacy groups of advisors and other resources.
    C. After completing this module, you will assist in the development,
        implementation, and continued existence of a self-advocacy group.

ACTIVITIES:

I.   Participate in the development of "A Self-Advocates Assessment
     Guide."

II. Participate in discussion on "Implementing Self-Advocacy Groups."

III. Review these materials:

        a) People First Handbook.
        b) Life, Liberty and the Pursuit of Happiness: A Self-
           Advocacy Curriculum.
        c) A guidebook for Self-Advocacy Advisors.

IV. Participate in developing a resource list.

V. Participate in planning a system to insure the continued existence
    of self-advocacy groups.

VI. Participate in supplementing and continuing a self-advocacy group.

VII. Read Handouts:

        a) Letters From Advisors Describing Their Experiences.
        b) "The Role of the Consumer in Planning and Delivering
           Services."
        c) Doug Biklen cites eleven methods of advocacy techniques.

MODULE VI

IMPACT QUESTIONNAIRE

1. Outline a plan to start a self-advocacy group.

2. List resources that you and self-advocates have available.

3. What will you look for when assessing the needs of self-advocates.

4. Write a statement reflecting your belief about the need for self-advocacy.

MODULE VI

EVALUATION

1. I found the discussion to be:

exciting   informative interesting   redundant   irrelevant
/_____/_____/_____/_____/

Comments:

2. The content for this module was:

too easy   simple   challenging   difficult   too hard
/_____/_____/_____/_____/

Comments:

3. As of this module my commitment to be an advisor to self-advocacy groups has:

increased   stayed
greatly   increased   the same   decreased   plummeted
/_____/_____/_____/_____/

Comments:

4. What did you find most useful in this module?

5. What did you find least useful?

6. What would you change?

7. What would you leave the same?

APPENDIX E

Site Interest Survey

COMMUNITY MENTAL HEALTH BOARD
CLINTON-EATON-INGHAM

MEMO

To: Supervisors   Date: April 22, 1981

From: John Rowlson

Re: Advisor Training for Self-Advocacy Support Groups

The human and civil rights of the mentally retarded and developmentally disabled need to be protected. In order for any disinfranchised group to become independent from paternalistic and stigmatizing stereotypes, in seeking justice and equality they must speak for themselves. They must become self-advocates.

The tasks of mentally retarded and developmentally disabled persons speaking on their own behalf are especially great when considering the social and historical conditions endured. Their lives are restricted and controlled with few opportunities for personal expression. Yet we profess to be a democratic nation that values "freedom and justice for all." Learning to participate in democracy requires opportunities to practice democratic decision making, risk taking and self-determination.

Self-advocacy is a felt need and emanates out of the persons desire to improve their lot in life. This represents a profound and meaningful choice.

The conditions to bring about opportunities for self-advocates to develop are being created around the country. Many small groups have formed and are organizing themselves in an attempt to be heard.

The advisor to people becoming self-advocates is critical. Democracy, decision making, law, assertiveness and self-determination are learned; and the astute advisor facilitates this learning, without being controlling. The advisor assists in arranging the necessary conditions for people to become self-advocates.

I have prepared instructional materials to train advisors to Self-Advocacy Support Groups as part of my doctoral dissertation. These materials are being field tested through training staff and advisors from programs in the tri-county area.

The training for advisors consists of six two hour sessions, once each week. The first and last session are for the entire staff from participating sites. This will assist people in understanding and implementing self-advocacy groups. Session two through five are for the advisors training and focus on the roles, skills and knowledge needed to facilitate a self-advocacy group.

The sessions are designed as instructional modules, with a pre and post test, to assess and evaluate participant growth. The module design, content, format and presentation are evaluated after each session. A follow-up interview is planned to determine how the content of the materials is applied and to evaluate the overall effectiveness of the training.

Enclosed is the agenda for the trainings and a site interest survey. Please fill out the survey and return. This will assist me in preparing for the training.

If you have any questions, please call 694-5098.

People who choose to go thru the training must make a commitment to attend every session. This will facilitate intergrating theory and practice during skill building exercises. Each session builds upon the previous session.

I will be making follow-up phone calls later this week.

njw

TIME: 3:30 to 5:30   LOCATION: Bretton Square Industries

Module I   Introduction and Orientation to the Self-Advocacy Movement
                        Date: Monday, May 4, 1981

Module II   The Role of the Advisor to Self-Advocacy Groups
                        Date: Wednesday, May 13, 1981

Module III   Participating in the Growth of Self-Advocates
                        Date: Wednesday, May 20, 1981

Module IV   Facilitating a Self-Advocacy Group
                        Date: Wednesday, May 27, 1981

Module V   Seeking Human Rights Through Developing Responsibility
                        Date: Wednesday, June 3, 1981

Module VI   Starting and Continuing Self-Advocacy Groups
                        Date: Wednesday, June 10, 1981

SITE INTEREST SURVEY

Agency Name_____

The purpose of this survey is to identify those persons who are interested in receiving Self-Advocacy training for Advisors.

1. Have participants in your program expressed an interest in forming self-advocacy support groups?

YES_____ NO_____

2. Is there an interest on the part of staff to be involved with a self-advocacy support group?

YES_____ NO_____

3. Are there any staff at your program who would like to receive training as an advisor to a self-advocacy support group?

YES_____ NO_____

4. Please list the names and telephone numbers of all persons who are willing to participate in the advisor training program.

A. _____

B. _____

C. _____

D. _____

5. Do I have your permission to contact these persons prior to the training?

YES_____ NO_____

APPENDIX F

Pre-Test/Post-Test

ADVISOR TRAINING

Pre-Test/Post-Test

_____

Name

Directions: The purpose of this test is to determine your growth
     as an advisor due to the training you are about to receive.
     This test will be administered prior to the introduction of
     the instructional materials and again after you have completed
     the six modules included in these materials. The dimensions
     of growth include: Knowledge, Skills, Attitudes/Beliefs.
     The results of this test will be treated in a confidential
     manner. At the end of the training analysis, you may have
     the test returned to you or they will be destroyed.
     Please fill out each question to the best of your ability.
     You will be allowed 40 minutes to complete 20 questions.
     Use your time wisely, and work quickly.

1.   Define Advocacy.

2.   What does Self-Advocacy mean?

3.   Give an example of how you respected a developmentally disabled
     persons dignity of risk.

4.   List three commonly held myths about the developmentally disabled.
     1.

     2.

     3.

5. Give an example from your own experience where a disabled person has expressed their need to be a self-advocate. How did you respond to that need?

6. Briefly describe the relationship self-advocacy has to normalization.

7. Identify the steps of decision making.

8. List three styles of leadership.
    1.

    2.

    3.

9. List two laws that have had an impact on the rights of the developmentally disabled.
    1.

    2.

10. List five assertive beliefs.
    1.

    2.

    3.

    4.

    5.

11. List five rights of the disabled.
    1.

    2.

    3.

    4.

    5.

12. Explain how human rights are associated with responsible assertive behavior.

13. What would you include in a plan to start a self-advocacy group?

14. Write a statement reflecting your belief about the need for self-advocacy.

15. Describe your feelings of competence to facilitate a self-advocacy group.

16. What skills do you have that may be necessary for an advisor of self-advocates?

17. What is the value of self-determination?

18. List and explain the stages of group development.

19. Outline the role of the advisor to a self-advocacy group.

20. Give a rationale for including consumers in the decision making process.

APPENDIX G

Follow-Up Interview Format

FOLLOW-UP INTERVIEW FORMAT

I.   Purpose of Follow-Up Interview:

To determine the relevance of the training with each trainee.

To elicit from each trainee recommendations for revisions to module package.

II. Follow-Up Interview Questions:

A.   What did you find most important about the training?

B.   What salient points of the training stand out in your mind?

C.   How have you applied the training content to your work situation?

D.   What impact has the training had upon you?

E.   What differences have you noticed in your work since participating in the training?

F.   What differences have you noticed in your clients since participating in the training?

G.   What would you change about the training?

H.   What would you change about the module package?

I.   What did you like in the training?

J.   Would you recommend the training to others?