Chapter 1

Philosophic Orientation

THIS TEXT BEGINS with a discussion of the motivational influences that are found in well-organized, resident-oriented agencies that provide a full range of home-living experiences. Each agency possesses a character or set of values that are perceived by public and professional persons alike. The development and operation of a set of values or philosophic orientation is a necessary first step in providing the framework for a quality existence for individuals with severe handicaps.

A philosophy of operation is a set of *guiding principles* that forms the underlying reasons why we function as we do with individuals with severely handicapping conditions. Even beyond our work in this human service area "a central guiding principle is needed in all human activities." (Dubos, 1981, p 202) Schumacher (1973) emphasizes this orientation:

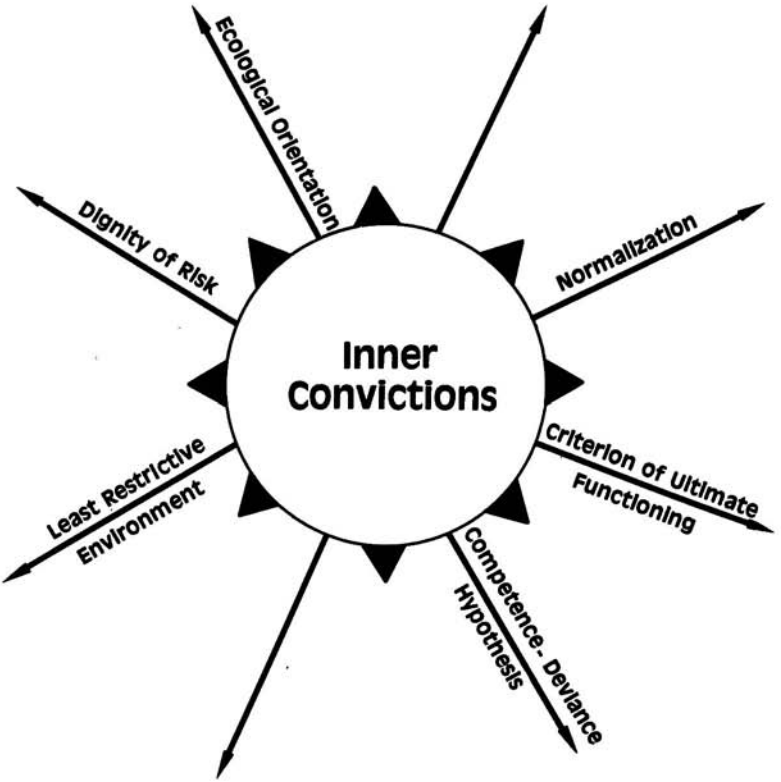
> All subjects, no matter how specialized, are connected with a centre; they are like rays emanating from the sun. The centre is constituted by our most basic convictions, by those ideas which really have the power to move us. (p. 94)

In relation to community planning of residential options for persons with severe handicaps, what are these rays made of? The following philosophic orientations will be highlighted in this opening chapter as representing the current guiding principles in residential planning for persons with severe handicaps.

- Normalization

- Criterion of Ultimate Functioning
- Competence-Deviance Hypothesis
- Least Restrictive Environment
- Dignity of Risk
- Ecological Orientation

Figure 1 contains an illustration of how Schumacher (1973) might have envisioned the previously enumerated philosophic orientations as they emanate from a core area of each person's inner convictions.



At the core of our imaginary sun are our personal beliefs, convictions, commitments and priorities, that alter the operation of surrounding rays of light. We must begin with our own personal changes, convictions, and goals before we attempt to guide other people's lives; especially the lives of residents who are severely handicapped. For change to occur we must begin with ourselves (Blatt, 1981; Buscaglia, 1982). "Before I ask the world to change, I must change. I am the beginning step." (Blatt, 1981, p. 12)

One man, greatly respected by Burton Blatt, was Dick Hungerford who wrote a beautiful essay commemorating the first meeting of the then National Association for Retarded Children (circa. 1950). The following is a quote from this presentation:

> My office window looks out on a near-tenement street. In the main there are curtains awry at the windows; there are rusted fire escapes with half-filled milk bottles precariously perched on them. The pavement is littered with papers, listlessly moving in the March dusk. And at the end of the street there is Bellevue, a city hospital. In general it is not pleasant.
>
> Two apartments, however, are different. The same kind of fire escape breaks the view; the same dirty pavement is beneath. But in these apartments the windows are clean, the curtains are starched and white, the Venetian blinds are evenly drawn. And a light has been lit. They have met a common problem and found dignity.
>
> So I think it must be with each one of us. This is our street. We can be ruined by it, or we can bring meaning to it and to ourselves.
>
> And perhaps that is the sameness for which our hearts long. All streets have grayness, at one end of every street there is a Bellevue. All problems are difficult, it is always hard to work in the half-light, the partially understood, which encompasses so much of living. We cannot run away from life. We cannot pick up all the empty milk bottles or isolate all the derelicts. We must not judge harshly Man-or God. We must be kindly. We must work with everything that we have for the betterment of the street where we are placed. And we must keep our windows clean and turn on the lights against the common twilight. (Hungerford, 1950, p. 418)

The main question becomes: How do I become the best person that I am capable of becoming in order to affect more positively the lives of people I come in contact with?

Three suggestions are provided to begin the process of solidifying our inner convictions.

First, we must acknowledge that what each of us perceive in the world around us are approximations of what is really there. We all possess uniquely different sensory perceptors and process information at different speeds and with different background references to evaluate this input. Therefore, no one can claim to have all the answers on any given topic. Michel (1981) relates that "For every expert, there's an equal and opposite expert." We need to begin thinking less in dichotomies (either-or) and more in combinations of relationships that are possible when evaluating a particular problem. Thus, the first proposition is to consent that none of us know the truth, but we may be able to lay claims on approximations of the Truth as we perceive it to be.

Secondly, each of us needs to keep a personal journal. Included in a journal are thoughts about various events you've experienced during the day, observations, uncollected thoughts, excerpts from books that have had a positive impact, creative manipulations of ideas, setting goals and priorities (of both short and long duration). In essence, it's a written communication to oneself expressing thoughts that ordinarily would not resurface without confronting them again days, weeks, or years later in a journal. A journal should be a chronology of growth toward resolving issues of both philosophic and pragmatic origin.

Third, we must actively participate in discussions of ethical dimensions. Sample topic areas might include:

- What is the role of a profoundly mentally retarded member of society?
- What happen after we die? (You may not be right, but this perception provides a catalyst for existing choices.)
- How do you feel toward parents of severely handicapped students?
- What are your feelings on terminating a pregnancy when it's known that the unborn child will have Down's Syndrome?
- Why do bad things happen to good people?

These are just a few topics that should be discussed in college courses and residential in-services that are preparing persons to work with individuals with severe handicaps.

A detailed explanation now follows addressing the prevailing philosophic principles that appear to be at the forefront of the residential movement for the severely handicapped. The day-to-day operation of these guiding principles will be affected by each individual's personal beliefs and inner convictions.

Normalization

Wolfensberger (1972) is the author who is given credit for expanding the principle of normalization from previously enunciated definitions by Bank-Mikkelsen and Nirje from the Scandanavian countries. Recently, Wolfensberger (1980) offered the following revision:

> The use of means which are culturally normative to offer a person life conditions at least as good as the average citizen's and to as much as possible enhance or support personal behaviors, appearances, status, and reputation to the greatest degree possible at any given time for

each individual according to his or her development needs.

Nirjie (1977) very beautifully incorporates eight basic tenets of normalization into the following poem:

> Normalization means... a normal rhythm of the day.
> You get out of bed in the morning, even if you are profoundly retarded and physically handicapped;
> you get dressed,
> and leave the house for school or work, you don't stay home;
> in the morning you anticipate events,
> in the morning you think back on what you have accomplished;
> the day is not a monotonous 24 hours with every minute endless.
> You eat at normal times of the day and in a normal fashion;
> not just with a spoon, unless you are an infant;
> not in bed, but at a table;
> not early in the afternoon for the convenience of the staff.
>
> Normalization means ... a normal rhythm of the week.
> You live in one place,
> go to work in another,
> and participate in leisure activities in yet another.
> You anticipate leisure activities on weekends,
> and look forward to getting back to school or work on Monday.
>
> Normalization...a normal rhythm of the year.
> A vacation to break the routineness of the year.
> Seasonal changes bring with them a variety of types of food, work, cultural events, sports, leisure activities.
> Just think...we thrive on these seasonal changes.
>
> Normalization means...normal developmental experiences of the life cycle.
> In childhood, children, but not adults, go to summer camps.
> In adolescence, one is interested in grooming, hair styles, music, boyfriends, and girlfriends.
> In adulthood, life is filled with work and responsibilities.
> In old age, one has memories to look back on, and can enjoy the wisdom of experience.
>
> Normalization means...having a range of choices, wishes, and desires respected and considered.
> Adults have the freedom to decide
> where they would like to live,
> what kind of job they would like to have, and can best perform.
> Whether they would prefer to go bowling with a group, instead of staying home to watch television.
>
> Normalization means...living in a world made of two sexes.
> Children and adults both develop relationships with members of the

opposite sex.
Teenagers become interested in having boyfriends and girlfriends.
And adults may fall in love, and decide to marry.

Normalization means...the right to normal economic standards.
All of us have basic financial privileges and responsibilities.
are able to take advantage of compensatory economic security means, such as child allowances, old age pensions, and minimum wage regulation.
We should have money to decide how to spend; on personal luxuries or necessities.

Normalization means...living in normal housing in a normal neighborhood.
Not in a large facility with 20, 50, or 100 other people because you are retarded.
And not isolated from the rest of the community.
Normal locations and normal size homes will give residents better opportunities for successful integration within their communities.

Additionally, included in the *Way to Go* publication is a list of eight "clangers" associated with normalization. A "clanger" is an internal bell that should signal to us that an observed situation is counter to the principle of normalization.

Clangers

1. Does what we see seem to fit the circumstances?
2. Is what we see appropriate for us? For our children?
3. Would something we see make us feel strange or out of place if it were happening to us?
4. What image is probably conveyed to others by what we see?
5. Does what we see give evidence of growth, warmth, and caring?
6. Would we like to live there, work there, play there?
7. Could we improve what we see?
8. Can we think of a better way to do it? (Cooney, 1978).

In summary, normalization is a modus operandi, the backbone of our relationship with individuals with severely handicapping conditions. It is an often abused term when merely renaming cottages and rearranging furniture is the extent of an adherence to a normalization philosophy (McCord, 1982). Normalization can be a powerful defense toward developing more acceptable and enlightened interactions with "different functioning" individuals.

Criterion of Ultimate Functioning

The criterion of ultimate functioning was a phrase coined by Brown, Nietupski, and Hamre-Nietupski (1976) and "...refers to the ever changing expanding localized, and personalized cluster of factors that each person must possess in order to function as productively and independently as possible in socially, vocationally, and domestically integrated community environments." (p. 11)

Eight questions emerge from the above statement relating to the choice of activities for severely handicapped residents.

The Value of Certain Instructional Practices

1. Why should we engage in this activity?
2. Is this activity necessary to prepare residents to ultimately function in complex heterogeneous community settings?
3. Could residents function as adults if they did not acquire the skill?
4. Is there a different activity that will allow residents to approximate realization of the criterion of ultimate functioning more quickly and more efficiently?
5. Will this activity impede, restrict or reduce the probability that residents will ultimately function in community settings?
6. Are the skills, materials, tasks, and criteria of concern similar to those encountered in adult life?

Competence-Deviance Hypothesis

Gold (1980) proposes that the more competence an individual has, the more deviance will be tolerated in him/her by others. He describes deviance as those aspects of an individual which cause negative attention. He describes competence as those attributes and skills which not everyone has, and which are appreciated and needed by someone else.

We all have some unique, deviant behavior but we can readily distinguish private from public environments. Some of our behaviors would cause negative attention if observed outside the confines of our home, i.e., eating habits, behavior while viewing a sports event or singing loudly in the shower are but a few examples.

Let's take a look at potential deviant behavior and how it can be acceptable in one situation and unacceptable under a different set of circumstances. Marc Gold was a human being who was eminently respected in and out of the field of Special Education because of his

immense contributions to his discipline. Marc Gold also wore his hair in a pony tail and had a very pronounced moustache. If Dr. Gold had decided to make a midlife career change and seek a job as a salesperson for Xerox or IBM, these same physical attributes would not be tolerated. In other words, his competence would not be of such a magnitude that his deviant (negative attention) behavior would be tolerated.

Another example of dubious deviance is chewing tobacco and spitting. To many people, this is obnoxious behavior but when the manager of a recent world series baseball team is seen on national television exhibiting this deviant behavior, it is easily tolerated. His competent behavior far overshadowed behavior which did cause negative attention from some baseball fans...but it was tolerated!

How do the above two examples relate to residents who are severely handicapped? These residents display many behaviors which are apt to evoke negative reactions from people, i.e., drooling, incontinence, lack of mobility, hand flapping, etc. Our task as trainers is not to rid each resident of all deviant behavior (that would be impossible!), but to enable that individual to possess competent behavior so that the remaining deviant behavior will be more tolerated by others. Examples of competence can range from learning how to be an excellent swimmer or being able to assemble a complex circuitry board to the ability to be pleasant when someone is talking to you (this behavior is surely valued and appreciated and certainly something not everyone has).

Least Restrictive Environment

The derivation of the concept of the least restrictive alternative will be discussed as it relates to residential placement for persons with severe handicaps. In the area of mental health, the first legal opinion addressing this concept occurred in 1966 in the *Lake v. Cameron* court of appeals decision. Mrs. Cameron had been committed to a mental hospital because of a history of wandering away from her home. In the opinion of the court, less restrictive means could have been employed by the state without resorting to commitment. Examples of less restrictive alternatives mentioned in this opinion included the use of an indentification card, public health nursing care, and foster care (Mickenberg, 1980). Six years later, Judge Johnson, in *Wyatt v. Stickney*, defined the least restrictive alternative as including the movement of residents from: (a) more to less structured living, (b) larger to smaller facilities, (c) larger to smaller living units, (d) group to individual residence, (e) segregated from the community to integrated into

community living, and (f) dependent to independent living.

The previous two court decisions, in conjunction with several similar opinions throughout the country, paved the way for Section 504 of P.L. 93-112. Often cited as a mandate for the right of all persons with handicaps to live in the least restrictive environment, Section 504 states that:

> No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from participation, be denied the benefits of, or be subjected to discrimination under any program or activity, receiving federal financial assistance.

Laski (1980) concludes that as a result of the language of Section 504, the committee proceedings concerning the law, the history of related enactments, its administrative construction, and several judicial opinions that Section 504: (a) required that the segregation of disabled people be ended, (b) prohibited unnecessary separate services and required that services be provided in the most integrated settings, (c) required that disabled people be admitted equally to all services and to the equal benefit of all services, and (d) required that disabled people be provided services equally effective as those provided to the general population.

An additional statement concerning the least restrictive alternative can be found in the Developmentally Disabled Assistance and Bill of Rights Act of 1975. In part, this law "...provides that persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities...(services) should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty."

The previous statements from court opinions and federal laws do not contain adequate descriptions for defining the parameters of the concept of a least restrictive alternative. Many members of human service planning agencies interpret the least restrictive alternative as options available, possible, and/or economically feasible. For example, if options that are available within a community are only considered, the range would be extremely limited for communities with few resources. A small town of 12,000 may presently not have a group home and, therefore, suggest placement in a regional residential center as an available option for a severely handicapped person. However, if that same town had a planning agency whose members chose to interpret the concept as the least restrictive alternative possible, they would encourage the development of residential options within the community that would provide a living environ-

ment for all handicapped residents based on their current functioning level. There are also planning agencies whose members will weigh the pros and cons of residential placement by using a financial yard stick for determining the least restrictive alternative. Often these agency members are swayed by cost-benefit information that is not derived from a common denominator and thus provides an inaccurate comparison.

Dignity of Risk

Perske (1972) expressed the essence of a dignity of risk orientation in his article in *Mental Retardation:*

> You are a human being and so you have the right to live as other humans live, even to the point where we will not take all dangers of human life from you.
>
> [There is a] human dignity in risk and there can be a dehumanizing indignity in safety.

In his definition of a dignity of risk, Perske is not advocating a reckless abandon approach in our interactions with persons who have severe handicaps. Instead, he is recommending that we challenge these residents and give them skills to become adaptable and autonomous when they enter adult service options. Risks are a normal daily occurrence in crossing streets at busy intersections, playing on the public park's recreation equipment, learning a skilled vocational occupation, camping and outdoor leisure pursuits.

In relation to the previously enumerated activities, individuals with severe handicaps must be adequately prepared and demonstrate relevant safety behaviors. For example, if a resident does not respond to the verbal cue "stop" in a training setting, it would be foolish to immediately allow him/her to walk unassisted in a busy parking lot where a car might unexpectantly cross the student's path while the teacher is giving a cue "stop." There is a definite line that needs to be distinguished between acceptable risk and foolhèartiness. Of specific concern is the student's mobility, physical stature, response to verbal safety cues, auditory and visual acuity, and tolerance level under multiple stimulus conditions.

ECOLOGICAL ORIENTATION

Russell (1976) in his book *Health Education,* strongly advocates for an ecological orientation to a decision-making process. "Relationships

to understand" should replace a "problem to solve" attitude by persons responsible for decisions that affect another's present and future activities. This "relationship to understand" orientation contains four major interconnected elements: the individual, significant others, the physical environments, and culture. Pertinent information that should be included in these elements follow.

Individual

Medical Information
Psychological Reports
General likes and dislikes
Role expectations: student, worker, son/daughter, friend
Aptitudes, strengths
Primary and secondary Reinforcers

Significant Others

Primary home care giver(s)
Trainers, aides, schoolmates, therapists
Friends, peers, and siblings
Community Service Personnel

Physical Environment

School setting: classroom and grounds
Community Activity Sites
Classroom Materials
Home environment and neighborhood

Culture

Operationalized philosophic orientation of the school/community
Portrayal of handicapped persons by community news media
General attitude of nonhandicapped members toward persons with handicaps
Outcome of judicial and legislative decisions
Orientation of helping professionals

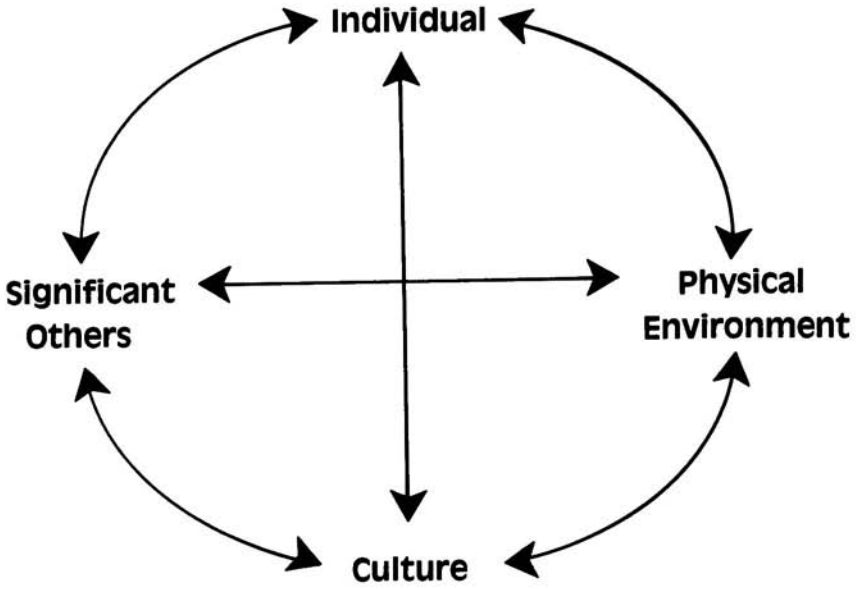


Fig. 1.2 Ecological Analysis of Decision Making

The major concept of the ecological analysis toward decision making is the impact that a change in one element has on the entire system of elements. Every element is intrinsically related to all the others. To operationalize this orientation, we would suggest that each resident have an outline of the ecological model at the front of his/her Individualized Habilitation Plan (IHP) folder. Within each model, all the pertinent information would be listed beneath each element and updated as changes occur in each element. The decision-making process must be concerned with the overall change that can be anticipated when altering one of the element's components. For example, the decision of when to initiate a toileting program for a resident cannot be made in isolation. Knowledge of the support in the home environment and of the specific individuals who can be targeted to implement the regimen must exist. More specifically, it is highly recommended that detailed inventories of skills be recorded in physical environments frequented by the resident's peers. The trainer can then assess the resident on his/her ability to independently perform as many of these skills as possible and target areas for individualized goals and objectives.

In summary, consider the effects a decision to implement a

program will have on each of the elements within the ecological model. Residential trainers must be proactive and not reactive to crises that often occur through lack of careful planning and foresight.

SUMMARY

Included in the previous sections were six guiding principles or philosophy statements with some explanatory information for each principle. How a group of community service providers operationalize these principles can be diverse. For example, two operation statements originate from The Association for Persons with Severe Handicaps (TASH—formerly, The Association for the Severely Handicapped) and the Center for Human Policy at Syracuse University.

The TASH Board of Directors passed the following resolution at its 1980 national conference:

> To realize the goals and objectives of The Association for the Severely Handicapped, the following resolution is adopted: In order to develop, learn, grow and live as fully as possible, persons with handicapping conditions require access to services which allow for longitudinal, comprehensive, systematic and chronological age appropriate interactions with persons without identified handicaps. Such interactions must occur in domestic living, educational, vocational and recreational/leisure environments. Specifically, handicapped individuals should: 1) participate in family-like and/or normalized community-based domestic living environments; 2) receive educational services in chronological age appropriate regular educational environments; 3) receive training in and access to a wide variety of vocational environments and opportunities, regardless of functioning level; and 4) participate in a wide range of normalized recreational/leisure environments and activities that involve persons without identified handicaps. The Association for the Severely Handicapped believes that the above conditions must be met in order to provide quality service and that these conditions can only be met by community-based services. Therefore, The Association for the Severely Handicapped resolves that it will work toward the rapid termination of living environments and educational/vocational/recreational services that segregate, regiment and isolate persons from the individualized attention and sustained normalized community interactions necessary for maximal growth, development and the enjoyment of life.

Similarly, Bogdan (1979) issued the following statement in a widely disseminated manuscript:

In the domain of Human Rights:

All people have fundamental moral and constitutional rights.
These rights must not be abrogated merely because a person has a mental or physical disability.
Among these fundamental rights is the right to community living.

In the domain of Educational Programming and Human Service:

All people, as human beings are inherently valuable.
All people can grow and develop.
All people are entitled to conditions which foster their development.
Such conditions are optimally provided in community settings.

Therefore:

In fulfillment of fundamental human rights and
In securing optimum developmental opportunities,
all people, regardless of the severity of their disabilities, are entitled to community living.

There are many approaches available for changing the life options of severely handicapped individuals. An organization may not feel that the strongly worded statements from TASH or Bogdan (1979) best personify the intent of its charter and may present their own statement of operation. An organization functions at a higher level of efficiency when its members know the underlying philosophic principles for its day-to-day actions. Six guiding principles have been detailed in this chapter. Without a personal commitment that is based on one or more of these principles, the following chapters will not assist individuals to facilitate the entry of persons with severe handicaps into the community.