PTEC 155 – DEVELOPMENTAL DISABILITIES

MODULE 44

NORMALIZATION
Module 44 – Normalization

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NORMALIZATION

Introduction

Normalization is a process of helping individuals with special needs – those with mental/developmental disabilities – to live as “normal” a life as possible for that individual. Living a normal life includes opportunities to make choices, to move about in the community, to earn money, to spend money, to visit friends, to marry, to attend school, to go on vacations, to vote, etc.

An important part of the normalization process is mastering and self-help skills necessary for acceptance into society. Teaching self-help skills to individuals with special needs requires infinite patience and time. The rewards are varied and many. On one end of the teaching–learning continuum, we see in an institution the profoundly retarded resident who may require several years to master just a part of the self-help skill; on the other end of the continuum, we see the individual who has become an adult and has mastered self-help skills sufficiently enough to live in the community either independently or with some help and supervision.

The responsibility and goal of the health care worker are to assist each client to achieve as nearly “normal” a life as he or she is capable of achieving.

“Each person, regardless of severity of handicap, had the potential to grow and develop…. This growth and this development occur across the person’s lifetime….each person grows at his own rate….people with handicaps need certain extra support in order to facilitate this growth and development.”

By Goethe: “If you treat an individual as he is, he will stay as he is; but if you treat him as if he were what he ought to be and could be, he will become what he ought to be and could be.”
OBJECTIVES

THEORY: The successful student will achieve a passing score on a written comprehensive examination based on materials dealing with techniques used to teach and train clients with developmental disabilities in the areas of feeding, positioning, and using orthotic equipment.

ASSESSMENT: There will be a written comprehensive objective type tests; multiple choice, true/false, and matching questions.

MAKE UP TESTS MAY BE AN ESSAY TEST!!

INSTRUCTIONAL MEDIA:

Study Guides:
1. Background Information on Normalization
2. Normalization Defined
3. Power of Expectations
4. Handicappism
5. Clangers
6. Labeling
7. Appropriateness
8. Social Integration
9. Programs
10. Special Olympic Games
11. Teaching Self-Help Skills
12. The Pre-Vocational Program
13. Regional Centers in California
14. Principles of Normalization

Text: Beirne-Smith; Chapter 1: pgs 24-30
       Chapter 5: pgs 174-179
The successful student will be able to:

1. Identify the following aspects of normalization:
   
a. Identify the following related background information:
      
      (1) N.E. Bank-Mikkelson's contribution
      
      (2) B. Nirje’s contribution
      
      (3) W. Wolfensberger’s contribution
   
b. Identify the components of the phrase "developmental special needs."

c. Identify the three ways to change stigma-producing conditions as explained in the included study guides.

d. Identify Wolfensberger's definition of or phrase-by-phrase explanation of the definition of "normalization" and how normality relates to individuals who are mentally and/or developmentally disabled.

e. Identify the practical applications and examples of the normalization principles:
      
      (1) Rhythm of the day
      
      (2) Rhythm of the year
      
      (3) Routine of life
      
      (4) Developmental experience
      
      (5) Choices, wishes, and desires
      
      (6) Bisexual world
      
      (7) Economic standards
      
      (8) Society's standards
   
   f. Match vocabulary with appropriate definitions/descriptions.

2. Identify how expectations affect normalization.

   a. Identify the following aspects of handicappism:
      
      (1) Appropriate description
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(2) Effect on interpersonal relationships
(3) Responsibility of health care professionals

b. Identify the following aspects of clangers:
   (1) Appropriate description/examples
   (2) Effects of clangers
   (3) Responsibility of health care professionals

c. Identify the following aspects of labeling:
   (1) Appropriate description/examples
   (2) Health and Welfare Agency of the State of California’s policy statement
      (a) Purpose
      (b) Summary
      (c) Excuses and abuses
      (d) Responsibility of health care professionals

3. Identify how the status of individuals with special needs can be improved.
   a. Identify the role in relation to the following:
      (1) Individual with special needs
      (2) Health care worker
      (3) Expectations
      (4) Programs
   b. Select in a given list those factors that foster social integration.
   c. Identify the following aspects of program planning:
      (1) The two simultaneous goals
      (2) Elements of a good program
      (3) Development of program for each individual
      (4) Dr. Gold’s “competency deviancy hypothesis”
(5) Demands and risks
(6) Effectiveness and responsibilities of the program staff

d. Identify the origin and purpose of the "Special Olympics."

4. Identify the effect of normalization on the family of the individual who is mentally/developmentally disabled.
   
a. Identify the significance of the family relationships in obtaining maximum development.
   
b. Identify the effect on the normal siblings.

5. Identify the following aspects of education in sexuality for individuals who are retarded.
   
a. Assess the value of sex education as an integral component of the normalization process.
   
b. Identify the need for individualized education in sexuality for the adolescent and adult who are retarded.
   
c. Identify the parental need for early education in the sexuality of their child who is retarded.
   
d. Identify the importance of knowledge of the sexuality of individuals with special needs for all persons responsible for providing care and guidance to these individuals.

6. Identify techniques in teaching self-help skills.
   
a. Identify steps and techniques in teaching self-feeding to the client who is mentally/developmentally disabled.
   
b. Identify steps and techniques in teaching self-dressing to the client who is mentally/developmentally disabled.
   
c. Identify steps and techniques in teaching self-toileting to the client who is mentally/developmentally disabled.
   
d. Identify steps and techniques in teaching self-grooming and personal hygiene to the client who is mentally/developmentally disabled.
   
e. Identify steps and techniques in teaching socializing to the client who is mentally/developmentally disabled.
7. Identify goals and benefits related to occupational preparation for the adult with mental/developmental disabilities.
   a. Identify pre-academic skills helpful in facilitating pre-vocational training.
   b. Identify the goals and benefits of pre-vocational training for the mentally/developmentally disabled client.
   c. Compare the vocational aspirations of the person who is retarded to that of a person who is not retarded.
   d. Select in a given list the characteristics that relate to pre-vocational success or failure for the individual who is retarded.
   e. Identify the role of the health care worker in assessing, planning, implementing, and evaluating a pre-vocational program.

8. Identify the purposes of the sheltered workshops and the effects on the individual with mental/developmental disabilities.
   a. Select in a given list the two basic purposes of the sheltered workshop.
   b. Identify the value of the sheltered workshop to the individual with mental/developmental disabilities.

9. Identify the resources available in the community for individuals with mental/developmental disabilities.
   a. Identify the functions and locations of the "regional centers" in California.
PRINCIPLES

1. Every individual with mental/developmental disabilities or special needs has the right to live as normally as possible at his or her developmental level of functioning.

2. When given the help of caring persons with an infinite amount of patience and time, each person who is mentally/developmentally disabled can develop to his or her highest level of functioning.

3. Acceptance of the client by society is enhanced when the client appears and acts “normal” as defined by that cultural group.

4. The client’s self-concept is enhanced by the acceptance of those around him or her.
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STUDY GUIDE 1
BACKGROUND INFORMATION ON NORMALIZATION

How Normalization Began

There’s a new way to go for people who have developmental special needs.* It has at its heart the principle of normalization.

The roots of this principle lie deep in the long effort to remove the senseless burdens society tends to place on disadvantaged people. A landmark in that effort occurred in the 1950s, when N. E. Bank-Mikkelsen, head of the Danish Mental Retardation Service, began to compare what he saw in the lives of residents of institutions with what he saw in his own life. He thought of the comforts he enjoyed, such as sofas and stuffed chairs, spacious and colorful rooms, a private bedroom and bath. He thought of his stylish clothes and his television set. He could find no justifiable reason for the disparity and began a search for a better alternative.

The result of his search was the concept of normalized settings, which he described as “letting the mentally retarded obtain an existence as close as possible to that of everyone else.” These new insights led to a radical shift in the way services were provided in Scandinavia. A growing social effort began to establish a new standard for the care, treatment, and education of people labeled mentally retarded. That standard was the lifestyle that most people took for granted for themselves. This was the first historical step away from second-class citizenship for persons with developmental special needs.

Bengt Nirje, then the Secretary General of the Swedish Association for Retarded Children, elaborated on the Bank-Mikkelsen definition and said normalization meant “making available to the mentally subnormal patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.”

The normalization principles have been greatly expanded by many people all over the world. The classic example is Wolf Wolfensberger’s basic book titled *Normalization*. Why, he asked, were people collected, segregated, and isolated in such large numbers? Why were they routinely abused and dehumanized? Why were basic human rights ignored and denied? What were the conditions and attitudes that could allow society to offer care to people in a way that treated them as nonhuman?

Wolfensberger concluded that throughout history people who were held in low esteem had often been discriminated against or brutalized. Throughout history some differences have been seen as negative and considered significantly inferior. They have generated uneasiness, fear, guilt, misunderstanding, hate, or alienation. Examples include difference; in race, religion, nationality, and language; physical deformities and disabilities; criminal behavior; mental disability; radical political beliefs; certain social behaviors; and drug and alcohol addiction.

Another critical observation Wolfensberger made was that many negative differences, or stigmas, could be overcome by changing the circumstances that attract negative attention to a person. Conditions could be changed or eliminated so the stigma would be reduced or even no longer exist. The person begins to seem like, rather than unlike, the rest of us. This makes it much more likely that a better life will result for all of us.

* Developmental special needs: learning, coping and growth needs that go beyond what would be considered typical and that require extra services on the part of the service and social systems. This term is used to identify persons who were previously labeled mentally retarded or developmentally disabled.
Normalization – How?

There are several ways to change conditions in order to reduce stigmas. First, by increased exposure to a significant difference, negative attitudes toward this difference can change. Remember when women would never wear long pants to work and how people talked about women who did? Look around you – how many women wear dresses to work. Time aided by the exposure to objectionable things helps shape our old attitudes into new ones.

A second way to change a negative condition is to reduce or eliminate it. An adult who is toothless attracts unfavorable attention. A set of dentures can eliminate the stigma. Inappropriate or out-of-style clothes can be changed. Elimination of odd habits that are caused by odd training and not by a person’s handicap can completely change the way the rest of us think.

A third way to change conditions is informing people and then educating them about unreasonable feelings and attitudes about other people they look upon as inferior or possessing inferior characteristics. Exposing these ideas will often lead to a greater acceptance of differences and the reduction of stigmatizing attitudes. The women’s rights movement in the past decade has certainly sharpened the focus on the discriminatory practices and public attitudes that produced the so-called female role. This continuing discussion has led to changes in law and public policy and in the basic relationships between men and woman.
Wolfensberger, author of Normalization, matched the concept of stigma and its dehumanizing implications with the Scandinavian idea of using normal settings, routines, clothing, and environments. He has given us a definition of normalization, which we will examine more closely:

“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, experiences, status, and reputation....

To the greatest degree possible ....At any given time....

For each individual according to his or her developmental needs.”

The definition is clearer when considered phrase by phrase.

“The use of means....”

The ways in which people are helped are just as important as the help itself. For instance, there are many ways to teach skills. One skill that we might want to teach a child or adult is pouring. One way to teach children is in a sandbox with pails and shovels; but adults should be taught the same skill through cooking lessons or potting plants.

“....which are culturally normative....”

The principle of normalization applies to all societies, but what is “normative” or “typical” in one society may not be “normal” or "typical" in another.

“....to offer a person life conditions that at least as good as the average citizen's....”

This refers to income, housing, health care, social resources, and opportunities – the material basis of everyday life. Anything we would not accept, we would reject at the outset for people with special needs.

“....as possible....”

These words are important. There are limits to what is possible, and normalization does not demand the impossible. It does, however, demand that we test the bounds of the possible.

“....enhance or support personal behaviors, appearances, experiences, status, and reputation....”

We are working toward enabling people with developmental special needs to learn to appear, to behave, and to act in ways which our society would consider typical or desirable. For instance, only a few people in our society live in large communal groups —learning, working, sleeping, and eating in the same building.

Most people dress and groom themselves with a sense of style. Adults and many children learn to use public transportation and to shop in the community. Yet many people who have special needs have never had these opportunities.

“....to the greatest degree possible....at any given time....according to his or her developmental needs....”

Each person is constantly growing and changing. In order to help in the future progress or development of a person, we need to understand what that person can do now. If the help is below or too far beyond the actual place where the person is, miseducation and injury may result. But for everyone there is a place to start and a lifelong capacity to continue to learn.
In a practical way normalization includes the following:

1. **Rhythm of the Day**: Normalization means a normal rhythm of the day for the individuals who are mentally and/or physically disabled. It means getting out of bed and getting dressed even when you are profoundly retarded and physically disabled. It means eating under normal circumstances: during the span of the day, you may sometimes eat in large groups, but most of the time, eating is a family situation, which implies rest, harmony, and satisfaction. A normal daily rhythm also means not having to go to bed earlier than your peers because you are mentally retarded; not earlier than your younger sister and brothers or not too early because of lack of personnel. Facilities must also give consideration to the individual’s need for a personal rhythm, allowing this individual to break away occasionally from the routine of the group.

2. **Normal Routine of Life**: The normalization principle also implies a normal routine of life. Most people live in one place, work or attend school somewhere else, and have leisure – time activities in a variety of places. Consequently, it is wrong when a person who is retarded, for example, has training classes, structured therapies, and recreating activities in the same building that serves also as his “home.” Of course, even when vocational activities are conducted in a special building, it is not satisfactory if this consists only of a few hours of low-motivated activities for a few days a week.

   Activation of the individual who is mentally retarded, which is all important, must convey the experience that the daily work routine has vigor and meaning and, fills a proper part of the day. The after – work satisfactions of leisure – time activities, whether they are for pure relaxation and fun or have more personal, educational implications, may sometimes take place in institutional or special settings. But for habilitation purposes, use of the facilities of the regular society should be included to lend realism to these activities.

   With wider experiences and proper social training, these individuals with special needs will be able to use the normal leisure – time facilities of their society on their own and also learn to cope with unprepared, unstructured situations without panicking (Avedon, 1967; Chigier, 1967; Nirje, 1967).

3. **Normal Rhythm of the Year**: Normalization means to experience the normal rhythm of the year with holidays and family days of personal significance. Most people change their life situations and refresh their bodies and minds at least once a year by going on vacation. In Scandinavia, travel, including travel abroad, has proved to be meaningful and valuable even for the severely and profoundly retarded.

4. **Normal Developmental Experiences**: Normalization also means an opportunity to undergo normal developmental experiences of the life cycle:
   a. Children should have available warmth of atmosphere, rich sensory stimulation and surroundings, and settings of proper proportions. Handicapped individuals especially need to be fed with stimuli, which will nourish knowledge and abilities. In cases where a child who is retarded cannot live with his own family, this aspect is of special importance.

   In normal society, small children live in a world especially structured for them, guided and taught by a few significant adults. In child-care homes, turnover of personnel should be minimal, thus offering the children basic security and opportunities for identification of the stand-in parents. These essential demands have proved almost impossible to realize in large heterogeneous institutions, where one is confronted with
the specific attitudes of the personnel and the adults who are mentally retarded. It is therefore completely wrong to let children with mental retardation live in the same institutions with these adults who have special needs.

b. Youths of school age in normal society also live in a world specifically structured for them. Childhood is a highly developmental period of great importance for learning about one's own personal abilities and potentialities, for obtaining understanding of oneself, and for building self-confidence that can serve as a sound basis for life after the school years. This is also a period during which social experiences outside the classroom are very important for personal stimulation and development. Youngsters and adolescents of school age who are retarded should therefore never live in a confined setting together with adults who are mentally retarded. The rationale is the young people's socialization and impressions of life should be gained as much as possible through contacts with normal society.

c. For the individual who is mentally retarded, growing from adolescence into adulthood is often a longer, more painful, and more uncertain process than for others. They are not always accepted, treated, and respected as adults. Their self-image often becomes warped and confused. Therefore, the attitudes expressed toward them by others – parents, relatives, or institutional personnel – are of utmost importance.

Like everybody else, the individual with special needs should experience the coming of adulthood through marked changes in the settings and circumstances of their lives. Just as it is normal for children to live with their parents, it is also normal for adults to move away from home and start a life of their own as independently as possible. It is wrong for adults who are mentally retarded to live on the premises that they are different from other adults and that they are as dependent as children. Training programs for young adults with special needs should assist them to become as competent and independent in their personal daily routine as possible and to develop social skills which will enable them to take part in the regular community life as much as they can.

d. The period of old age, when work is no longer possible or feasible, should consist of familiar settings and acquaintances which give each aged individual meaning and security. Therefore, if the aged individual who is retarded cannot remain in the very same place, the alternate living facility should be arranged close to the place where this individual spent his or her adult years.

5. Making Choices, Wishes, and Desires: The normalization principle also means that the choices, wishes, and desires of the individuals who are mentally retarded have to be taken into consideration, complied with if possible, and respected. In May 1968 a conference was arranged for young adults who were mentally retarded, IQs about 35 – 70, from eight cities in Sweden. In this conference, these young men and women, 18 – 30 years old, discussed vocational training and their leisure – time and vacation problems. They wanted stronger voices in there own leisure – time programs, student clubs, and labor union participation. They objected to being included in activities with children below the age of 156 or 16 and to being in too large and too heterogeneous groups. In discussing group study tours and group vacation trips, they stressed their demand to be only in small homogeneous groups. They found communication in large groups unsuitable because it was more difficult to hear and understand what was being communicated. Obviously, they had too often had the normal tourist experience of moving in herds.
6. **Living in Bisexual World**: Normalization also means living in a bisexual world. Accordingly, facilities should provide for male and female staff members. When it comes to the integration of boys and girls or men and women with special needs, the 1967 Stockholm Symposium on "Legislative Aspects of Mental Retardation" of the International League of Societies for the Mentally Handicapped came to the following conclusion: "Being fully mindful of the need to preserve the necessary safeguards in the relations between mentally retarded men and women, the members of the Symposium are of the opinion that the dangers involved have been greatly exaggerated in the past. This has often resulted in the unfortunate segregation of the sexes in an unnatural way and has militated against their interests and proper development.

"Accordingly, the Symposium strongly advocates the mixing of the sexes in a manner as free as is commensurate with normal restraints, not only in day centers and workshops but also in leisure – time activities."

"Experience in some countries indicates the advantage of mixing men and women in hostels and other residential facilities in such a way as is approximate to normal life."

Mixing of the sexes according to the normal patterns of everyday society serves as a strong motivator which often results in better behaviors and atmosphere.

7. **Applying Normal Economic Standards**: A prerequisite to letting these individuals with special needs obtain an existence as close to normal as possible is to apply normal economic standards. This implies giving them those basic financial privileges available to others through common social legislation as well as any other compensating economic security measures that may be applicable. This includes child allowances, personal pensions, old-age allowances, or minimum wages. Of these allowances, the larger part may be used for board and lodging, but a normal amount of pocket money for the individual’s private use should be given regularly to assist in realistic social training and to help foster independent choices. Work done in competitive employment, in sheltered workshops, or within institutions should be paid for according to its relative worth.

8. **Standard Physical Facilities**: An important part of the normalization principle implies that the standards of the physical facilities, e.g., hospitals, schools, group homes and hostels, and boarding homes, should be the same as those regularly applied to the same kind of facilities for ordinary citizens. Application of these standards to facilities of various types imply a number of important specifics:

a. It means that the size of facilities should conform to what is normal in society. The facility for these individuals should never be intended for a larger number of persons than the surrounding neighborhood readily assimilates in its regular everyday community life.

b. It further implies that in planning the location of these facilities, they should never be placed in isolated settings merely because they are intended for the people who are mentally retarded.

With normal locations and normal sizes, facilities for people with special needs will give their residents better opportunities for successful integration.

The League is an international federation of associations of parents of the children who are mentally retarded. The Symposium, published by the League, summarizes basic principles upon which practices in the field of mental retardation should be based. These principles were derived from a definition of the rights of the individuals who are mentally retarded.
All of the facets of the normalization principle make normalization of the life situation of individuals with special needs quite feasible: the normalization process can aid many in achieving complete independence and social integration; a great number will be helped in developing relative independence though they may always need various kinds of assistance to various degrees; even the relatively few who are severely or profoundly retarded or who are afflicted with complicating medical, psychological, or social handicaps will, no matter how depended they may be, have life conditions, facilities, and services that follow the normal patterns of society.

For the child, adolescent, and young adult who are retarded, almost every situation has pedagogical implications, possibilities, and values. Just as the right of education is important for every citizen, so is it important for the individual who is mentally retarded to have a right to equal opportunities for education, training, and development.

Development of various abilities always has bearings on the development of the whole person. Development of the individual who is retarded, therefore, places particularly heavy responsibilities on person in charge of the life conditions of these individuals. Mental retardation as a handicap creates especially high frustrations and hurdles for the individual, thereby making it even more urgent to assist and stimulate them in the building up of self-confidence.

Through stimulation and rich experiences, he can experience himself as an active agent even while sensory deprivation imposes a further handicap. To develop a feeling of personal identity is an essential growth factor, and thus the experience of being nameless and anonymous is dangerous and damaging. The self-image of the retarded must be built on letting him experience his personal abilities and even experience rejection and disregard in order to cope with confusion stress, and unhappiness.

To develop self-regard, these individuals must learn how to succeed through his efforts to cope and thereby to obtain experiences of responsibility. Thus, a too sheltered and barren environment, which does not allow for personal activities too often, leads to experiences of failure and of being without status and value. The development of a feeling of personal dignity can determine the degree of self-control established, while the experience of lack of regard from others is threatening and corroding.

The development of these individuals includes acceptance of the self as an adult who is responsible and self-confident; awareness and acceptance of the self as an adult who is retarded.

As almost every situation for these individuals with special needs have pedagogical significance and often is related to his slow building up of a self-concept, it is essential that they be offered appropriate facilities which assist his educational processes and development and which make it possible for him to experience himself as becoming adult in his own eyes and in the eyes of others. This is a basic requirement for helping his life development come as close to the normal as possible.

Large institutions and the conditions we can observe can never offer facilities of the kind and quality that are essential. In the large wards, the rhythm of the day reduces the retarded to an object in an empty, machine-like atmosphere. The normal rhythm of daily routines of occupation, leisure and personal life is emasculated to surrogate activities and not integrated with a meaningful personal existence. The normal rhythm of the year is mostly dwarfed through the experience of monotonous confinement. The development of individuality is helplessly mutilated and crushed in a life in herds.
Application of normalization principles has profound implications not only to the individuals with special needs, but also to the public, to those who work with them, and to the parents of these individuals. When residential facilities for children who are mentally retarded are constructed, located, operated, and interpreted as homes for children; when special schools for these children are integrated into regular schools or are looked upon as no more than schools for children and youth; when group homes and hostels for the adult who is retarded are looked upon mainly as homes for adults; then such direct and normal experiences will result in a normalization of society’s attitudes toward these individuals. Isolation and segregation foster ignorance and prejudice, whereas integration and normalization of smaller groups of mentally retarded improve regular human relations and understanding, and generally are a prerequisite for the social integration of the individual.

Normalizing a mental retardation setting also normalizes the working conditions of the personnel. Workers perceive the individual with special needs and this individual’s role and their own roles in entirely different ways. In turn, the workers themselves are perceived differently by society. They enjoy a higher status and gain in self-respect. Almost always, an increase in work efficiency and effectiveness is one of the results.

Application of normalization principles also can serve to normalize the parent’s situation. When residential centers, group homes, and schools of normal standards, sizes, and locations are available, as well as day centers and workshops, the parents of these individuals can choose placements according to the needs of the family. Their choice of placement can be accomplished freely and rationally rather than the result of anguish and the choice between the horrible and the impossible.

The closer the persons in the decision-making bodies of society come to the individuals who are mentally retarded, the more likely they are to render decisions which foster the principles of normalization.
STUDY GUIDE 3
POWER OF EXPECTATIONS

“If you treat an individual s he is, he will stay as he is; but if you treat him as if were what he ought to be and could be, He will become what he ought to be and could be.”
By Goethe

Too often we take for granted the things we value most. As long as things go reasonably well, we hardly think twice about what our forefathers risked their lives for – “We hold these truths to be self-evident, that all men are created equal....”

Many of us accept the following facts without giving them much thought:

- We have a name and a recognized identity.
- We are accepted by friends, neighbors, and merchants, as worthwhile.
- We live with people we love, in a comfortable home, with good neighbors.
- We have the opportunity to make choices and not be limited to one job, one style of dress, or one television show.
- We can do things for ourselves.
- We can make our own decisions and know the confidence of being right—or even of being allowed to be wrong.
- We can be respected for doing a job well; we can be considered competent.
- We can have friends who enjoy our company and will include us in their social affairs.
- We have a future in which to do and be something else if we wish.

We expect these things, and we do not dream that they exist only because we expect them.

Once, in a while something happens to remind us with a jolt how weak our hold is upon these precious things. Many of us can think of a time when we were laid up from an injury. We remember how hard it was to get around the house, let alone to public places. We remember how people started. It was not a good time to be invited to a party, certainly not a good time to apply for a job. People we met for the first time did not think of “John Jones, who teaches at a school around the corner and sings in the choir on Sunday,” but thought of him as “that cripple.” Fortunately, the injury or effects of the injury did not last long.

A prominent doctor in Sweden, Dr. Sven-Olof Brattgard, who has completed much research about disabilities, says, “Sixty percent of all healthy twenty-year-olds will have special needs (be handicapped) and require assistance in mobility before they die.” This is a large part of the population, and the assistance may not be needed for more than a year, but it is a vital fact in the effort to develop better public services.
But what about the many people who year in and year out are in the position we were in when we were injured. They rarely shop beside us in the stores, we rarely meet them at amusement parks or picnics or parties, we do not often hire them to work for us or beside us. They are rarely seen in the choir on Sunday. Instead of knowing them personally as Juanita Smith or Bradford Delaney or the daughter of the dentist down the street, they are hidden from us and we apply strange “sick” names to them --- “retarded,” “epileptic,” “schizophrenic,” “autistic.” And we accept these facts without much thought. It is not important to us that they have any of those things we accept so easily for ourselves.

Worse, we may even assume it is “best for them” not to share these privileges we take for granted. They have “special needs,” so we help them by providing “special” services for them in “special” places. And since we do not hear them complain, so we assume they are content. And we certainly do not feel deprived of their company and their help.

One of the first lessons of normalization is that all of this is wrong.

We talk about these people by attaching strange labels to them instead of names; we talk about these who are shut up in institutions or restricted neighborhoods, who go to special schools and work in special workshops —these “strange” people are strange basically because we expect them to be strange and treat them in such a way that they have no real choice to behave normally. They suffer from our negative or low expectations, and we who impose those expectations are impoverished along with them.

Normalization proposes a different set of expectations from which all of us can gain rather than suffer.

Basically. Normalization proposes services that tend to fulfill expectations. If you know and believe that people with developmental special needs can and will learn and grow, then your program will usually help them learn and grow. If you think or hope people can learn and grow, then your program might help them. If you believe that growth is unlikely or impossible, then you will never help growth or learning occur. For example, let’s say that a caregiver does not believe a person with special needs can ever learn to travel on public transportation. The caregiver therefore does not attempt to teach the person how to travel independently. The person does not learn how to use public transportation. The caregiver’s expectation is fulfilled; the person does not travel independently. That does not mean the person cannot learn to travel. It simply means that no one ever had the necessary expectation and, therefore, no one ever taught the skill.

Whole sets of expectations can become part of a stereotype. For example, with the labels “developmentally disabled” and “mentally retarded,” we frequently find the following images associated with them: slow, sorrowful, homely, childlike, unpredictable, helpless, suffering, unfeeling, passive, good-natured, sexually irresponsible, menacing. We can easily fail to notice that an individual could not have all these qualities at once. If we think of a person as inferior, we have little difficulty giving this person whatever inferior qualities we happen to dislike.

Dr. Marc Gold, a noted leader in the field of developmental services, uses a familiar example about how powerful our expectations can be. Dr. Gold describes what is likely to happen when we feel we are dealing with a basically intact system with some non-working parts, as opposed to a non-working system with some intact parts.
Let us take a brand new car that does not start. The owner does not hesitate to call the garage and make arrangements for the repair of the car. The news that the electrical system is out may “hurt” but there is no hesitation to fix it, almost regardless of the cost.

On the other hand, if someone tries to sell you an old rusted junker which is up on blocks and raves about what a perfect transmission is has, you are not likely to invest. This junker is a non-working system with a few working parts.

When you see a person with severe difficulty in controlling his or her muscles, drooling now and then, and being pushed in a wheelchair, how do you view that individual? Do you see an intact system with a number of non-working parts or a non-working system with a few working parts? What you are willing to invest depends on this basic expectation. IF you think the person is basically capable of growing in ability to live a full life, there may be no limit to what you can do to help.

The great breakthrough of normalization is just this: we are seeing people as intact systems that can be helped rather than as condemned institutional “junk-heaps.” We know they are learning, growing, and producing instead of merely existing.

Our society’s history of setting groups of people off to one side and explaining this act as being “in their best interest” has been terribly costly in many ways. Few of us have had the privilege of growing up or going to school with a friend who has a physical disability, who learned very differently, or who had no hearing or sight. Our television programs still avoid showing persons with disabilities because it is presumably “in poor taste.” At best we may learn of the courage, skill, and enterprise of “handicapped” people from a book or a rare television program. Our stores, theaters, apartment buildings, and museums, for the most part, present barriers to people who cannot climb stairs or walk through doorways.

Deprivation and lost opportunity to grow are common to people with developmental special needs. Their lost opportunity to grow is ours as well. When society segregates and excludes the unusual person, we, the members of society, are robbed of the benefits that would be available to all in a fully integrated society.

Apply the principles of normalization can break this cycle and ensure that we integrate people with developmental special needs into everyday community life. We will be in a position to protect their rights to enjoy all the things that we value for ourselves and to establish a deeper sense of identity and common cause among all people.

*Normalization is doing and saying everything we can wherever Possible to integrate people who have developmental special Needs into everyday community life, to enjoy all that we value for ourselves*

In summary, we cannot enjoy the things we hold as precious as life itself – freedom to associate with anyone we wish, to live, work and play where we wish, and, above all, to test how much we can learn and grow together –if there is a wall between us and the associate we need to know. If anyone is the prisoner of our poor expectations, then we all are. Normalization is the freedom we all seek.
Definition

“Handicappism” like “racism” sums up a set of negative expectations and degrading practices. “Handicappism” can be defined as a set of expectations and practices that promote unequal and unjust treatment of people because those people appear to have, or are assumed to have, a physical or mental disability.

Often, the ones who provide services to the people with developmental special needs perpetuate attitudes, which hurt these people. We see its presence in the form of labels, myths, stigmas, derogatory language, and crude characterizations. For example, in a public service advertisement, a young boy was pictured sitting in front of his birthday cake with eight candles. The caption read: We’ll be eight years old for the rest of his life.”

“Handicappism” pervades our lives. It creeps into almost everyone’s attitudes and behaviors toward disabilities. The following sections illustrate how its presence can be seen in interpersonal relations, in public policy and practices and in the professions as well.

“Handicappism” is basically a term for the power of low expectations. It is an assumption that a person with a handicap is fundamentally a non-working system. It prevents us from applying the full resources of modern science to assist people with developmental special needs.

Normalization as a public policy turns this attitude around – the real handicap is the low expectation that wastes people’s lives, needlessly forces them to rely on public support and charity, and deprives us all of their services, friendship, and wisdom.

Interpersonal Relationships

Most of us frequently do not know how to act around people with developmental special needs. “What should I do?” “How can I know if I’m doing the right thing?” Here are a few of the more common wrong things:

♦ Assume that the person with a disability is sad.
♦ Pity the person who has a disability.
♦ Focus on the disability so that the person’s other qualities is overlooked.
♦ Treat the person like a child, use a juvenile form of the person’s name –“Joey, “Janey, “Junior.”
♦ Avoid people with disabilities.

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Interpersonal Relationships (continued):

- Speak for people with handicaps instead of letting them speak for themselves. “He’s trying to tell you he likes you.”
- Use derogatory humor.
- Describe someone by a label. “He’s a typical example of environmental deprivation.”

The Professions That Serve People Who Have Handicaps

We would not expect the professions that serve people with developmental special needs to be caught up in Handicappism. We expect them to be involved in promoting equal and just treatment of people. But this is not always the case.

Much of the research in the field of developmental services has been colored by pre-established acceptance of handicappist attitudes that led to the preference for segregated services, schools, residences, and work places. It goes back to self-fulfilling expectations.

Once people were labeled “mentally retarded,” they lost their individuality. Often they were placed in institutions, “homes (or hospitals) for the mentally retarded.” The expectations and practices that followed denied these mislabeled and stigmatized people the opportunity to grow and adapt to the outside world. And the industry on “permanent disability” and “incurability” thrived.

“Handicappism” is as much a real part of our culture as “racism” and “sexism.” The more we recognize this phenomenon, the sooner we will free ourselves of the weight of its injustices. By consciously asking ourselves, and others to be open and curious about how Handicappism works in our lives, we can help ourselves and others overcome our prejudices. In this way we free ourselves of our most serious handicap.
What are Clangers?

It is important to be alert to signals that say “label,” “stigmas,” or “misfit.” These signals may be called clangers. A clanger produces instant recognition of oddity. It is a realization that something does not fit. It might stick out like a sore thumb, it might be very subtle.

We do not usually pay very much attention to things that appear to be in harmony. However, we zero in quickly on things that see odd or out of context. We do not consciously make a mental list of the unusual, but as soon as we see or hear something odd – CLANG!!!

Besides recognizing that we have our own clangers, we also need to recognize that everyone else has them too. Some clangers occur when you see something odd or mismatched. Examples would be a very official-looking sign or institutional fire bell on the front of a suburban home, someone wearing outrageously mismatched clothes, a barbed-wire fence around a front yard, or a childish dress on an adult woman. Other clangers start ringing when you hear something strange or upsetting. More clangers are:

♦ Labels such as “crippler,” “mongoloid,” “TMR,” “moron,” “DD,” or “vegetable.”

♦ An everyday phrase like “Anyone who voted for X is a complete idiot.”

♦ Hearing someone talk baby talk to an adult.

♦ A loud dinner bell in a “home.”

♦ A crowd of adult men idly sitting around on a porch on a normal work day.

♦ Toys on the shelves of an adult’s room.

♦ A “bowl” haircut.

Not everyone is going to react in exactly the same way to oddity. What strikes one person as being odd may not trigger a “clang” in another. However, every society has generally accepted norms, and the violation of these norms will cause uneasiness in most people. Those generally accepted attention-getters must be the focus of our concern.
Clangers are created by people who usually are not aware of how their actions are perceived by others. Even when they are aware of it, they are usually not concerned about the consequences. People often suspend their everyday good sense and courtesy when working with dependent people.

Normalization provides the means to turn this habit around. We can weed out the clangers we can control. We can help others see the clangers they are creating and get rid of them.

**Identifying Clangers**

Here are some questions to ask ourselves:

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?
STUDY GUIDE 6
LABELING

One of the easiest but most humiliating ways to subject human beings to injustice is through the use of belittling words. This is true whether the phrase is intended to offend or is merely used without thought to identify a service or a special need.

While some labeling practices do serve a functional need, most do not. A service system must constantly strive to avoid the use of unnecessary negative references to people regardless of their problem or disability. All human beings should be treated with dignity, and this especially includes the words chosen to describe or address them.

The purpose of the following policy statement from the Heath and Welfare Agency of the State of California is to make people aware that humane treatment of all persons involves words as well as deeds.

**Policy Statement Regarding Stigmatizing and Excessive Labeling of Persons with Developmental Special Needs**

The field of developmental services has grown progressively more sensitive and responsive to the unnecessary, excessive, and stigmatizing use of diagnostic and descriptive labels associated with its clients.

Such labeling practices have a long tradition with roots coming from both the evolving sciences of human development and perpetuated prejudices. Historically held against people who are significantly different.

Labeling has limited helpful uses. Ideally, it must assist in preventing, treating, and overcoming various human debilitating conditions and situations. Labeling has also focused the channeling of resources and organizations to improve the conditions of minority groups of all kinds. It has served to aid in setting priorities in the face of finite resources given our wide social needs.

Nevertheless, labeling invariably draws negative attention and stigma upon the individual or group concerned. It gradually supplants the unique identity and totality of a person with a stereotype that emphasizes the need, problem, or liability of an individual as the main aspects of that person or group. It does injury to a person’s social value, status, societal mobility, and freedom.

Labeling carries with it a constant danger of being abused for professional and bureaucratic convenience to the detriment of people with special needs.

California has adopted the principles of normalization in human services, which underscores the rigorous approach of serving people in such a way as to avoid stigma and establish program quality criteria as a minimum above which services must be aimed. Eliminating unnecessary and injurious labeling is basic to normalization.
It is therefore the policy of this administration to clear away all archaic, stigmatizing, dehumanizing and syntactically incorrect usage of labels and replace these with appropriate socially valued references that emphasize the humanity and individuality of our consumer constituency whenever possible.

**Excesses and Abuses**

The following are typical frequent instances of such excesses and abuses:

1. Equating a person with his/her deviancy so that the deviancy becomes the person.

   Examples: An “MR,” a “retard,” an “autistic,” “epileptic,” “schizophrenics,” a “spastic,” “CPs” (cerebral palsies), etc., instead of “persons who have mental retardation” or “who are labeled mentally retarded,” or “persons with developmental social needs.”

2. Depersonalization or literally dehumanizing an individual via a label to a status equivalent to an animal, vegetable, or object.

   Examples: Referral to persons by number, as objects, items, clinical material, low-grades, vegetables, etc.

3. Application of any diagnostic, descriptive, or classification term that is archaic or racist.

   Examples: “Mongoloid idiot,” “mongoloid,” “imbecile,” “moron,” “lunatic,” “borderline,” “higher functioning,” “lower functioning,” etc.

   a. Unnecessary application of labels that denote:

   b. A devalued status.

      Example: Using last names without titles —“jones” rather than “Mr. Jones.”

   c. Age-inappropriate and degrading labels and titles.

      Examples: “Adult child; “Johnny” instead of John or “Mr. Smith.”

4. Repeated unnecessary use of a label when initial identification or the context makes such repetition necessary.
Our Responsibilities

Any labeling that must be used should immediately lend itself to identifying rational, particular, helping services interventions, modern treatment modalities, or needs.

The archaic equation still heard that “a Mongoloid baby should be put away and forgotten” represents a compound insult that must be exposed and ended once and for all. The equation that a person with a low IQ score “is beyond help, will never go to school, be employable, or go to college” denies the flexibility, breadth of options, power of educational technology, and normalization principles that have evolved in our serve system design today and its continued improvement tomorrow.

Such equations blunt our thinking, confuse our technology, and humiliate all of us.

In sum, to establish positive and socially valued images and identities for people with special needs, every effort must be explored and exhausted to clear up our example, practices, and literature regarding such stigmatizing labeling. Given the deeply ingrained tradition of substituting labels and diagnoses for people’s identity, effecting change will require considerable effort, sensitivity, and affirmative spirit to redo and undo what has become secondhand and unconscious for most of society.

In the spirit of this policy, we are involved in developmental services. In principle we wish to stop referring to “people with disabilities.” The term “developmental special needs” is not offered to substitute one label for another but to move the emphasis away from the negative. It aims to affirm that there is a common bond. We can all be special and have special needs without calling each other names.
STUDY GUIDE 7
APPROPRIATENESS

Appropriateness in human services is anchored in two basic frames of social reference that all of us notice: (1) a person’s chronological age and (2) a person’s normal environment and place in the community.

We experience the keenest discomfort—a clanger—when a person’s clothes, possessions, activities, and/or attitudes are not appropriate to that individual’s apparent chronological age. And we note appearances or relations between things that are at odds with our culture. Both clangers and oddities reduce a person’s dignity.

For example, most people associate places, things, situations, and some objects in common ways. To most people a cemetery connotes death; a sanitation plant—garbage and refuse; a charity plague—pity.

If a person or a group of people who already suffers from Low status is made to live or work in a place labeled With negative symbols, each individual’s status is Further lowered. In order to improve the Status of people who tend to be labeled With low expectations, appropriateness is necessary.

People who are helping individuals with special needs Counteract historic associations with low expectations must be Exceptionally conscious of what draws negative attention. Some typical examples are:

♦ A group of adults of the same sex do not hold hands while walking down the street.
♦ Middle-aged women do not openly play with dolls in their spare time.
♦ Children of widely different ages are not normally mixed in the same classroom.

It is often argue that controlling these aspects of people’s lives robs them of individuality and freedom of choice. The argument is: “Who are we, parent or professional, to stop a grown woman from carrying a doll in public? Society should adjust to individual tastes and not homogenize us into the gray middle. Who wants to be ‘average’ or ‘normal’ anyway?”

There are two aspects to consider here. First, adults who retain children’s toys as essential sources of security and interest need opportunities to learn to deal with appropriate possessions. Care giving and training obligations include freedom and opportunities to make realistic and appropriate choices.
The second point is familiar to every parent. The toll taken by society in shunning or disenfranchising a person because of lowered expectations usually results in loss of opportunity far more serious than the loss of inappropriate behavior. A person exchanges eccentric ways for access to the total range of acceptable human behavior. What is usually needed is expanded expectations from all of us, who can then open doors to new experiences.

In order to improve society’s view of these individuals, we can promote a “normal” look. The client’s clothing can promote this “normal” look; that is, properly fitted and currently fashionable—not necessarily “designer’s delight” —but apparel suitable to and currently being worn in the environment. Often the garments worn by clients are baggy and ill-fitting, probably because the clothing was not purchased specifically for that client. No one wants to wear ill-fitted garments and/or look out of place. Apparel, which includes a broad range of colors, should be selected. It is important that the client makes as many personal choices in the selection of clothing. It is clear why mental health units and other facilities encourage clients to wear their own clothing (not patient gowns and robes)—the goal is normalization.

Since an important responsibility of the staff is to role model normal behaviors to the client, the staff in many facilities wear street clothing rather than uniforms —this looks more “normal.”

The same is true of the client’s grooming. If hair styles and makeup are contemporary-looking, then the client will feel and appear more “normal.” Again, personal selection is an ego-satisfying task. As often as possible, allow the client to make decisions. For these reasons clients are encouraged to care for themselves, and again the health care worker can serve as a role model.

Here are some things we can do.

♦ We can disperse programs that have been gathered together in one place for the sake of convenience. Treating people who have different kinds of special needs under one roof or in one place creates a pressure cooker of negative images and lowest-common-denominator practices, which spread to everyone there.

♦ We can refuse to allow secondhand clothes and products, which lack dignified images to be associated with people who easily take on undignified images.

♦ We can refuse to use as service facilities places that have histories of being asylums, condemned properties, neighborhood problems, and white elephants.

♦ We can put a stop to the practice of treating people according to their supposed “mental age,” indifferent to the expectations raised by the person’s chronological age. A 25-year-old person is just that, despite a “mental age of 8 years.”

If a person’s activities, appearances, and living conditions are to be as much as possible like those of other people of the same age in the same community, there must be appropriate services, facilities and activities available for them at different stages of life.

People undergo continuous change —developmental and environmental. As we observe people progressing from childhood through adulthood, requirements for change become clearer. Responsibilities are slowly expanded from early childhood to adulthood.
The child first learns to deal with immediate family and relatives, later trusted friends, then strangers.

Play gives way to school, then to productive work.

Hobbies and leisure activities are separated from work as maturity unfolds.

Appearance, clothes, and grooming change as a person passes through different ages. Hairdos, jewelry, and makeup usually proclaim both age and degree of sophistication.

When people with developmental special needs are deprived of opportunities to pass through these stages of change, they cannot grow, develop, or change. In programs where the expectation is reversed, everyone grows. The following statement summarizes the resulting developmental model:

Each person, regardless of severity of handicap, has the potential to grow and develop....this growth and development occur across the person’s lifetime;....each person grows at his own rate;....people with handicaps need certain support in order to facilitate this growth and development. (Source Unknown)

As a service system, our major task is to create programs that support the growing person’s progress toward more productive and more independent living. To ensure growth in and through each stage in living, we need a variety of programs matched to various age groups, to various stages of maturity in behavior in each age group, and to as many variations as possible.

NOTE: It is usually a mistake to combine adults and children with special needs in the same program. The usual reasons for such combining are: convenience, “They have a lot in common,” “they help each other,” “it is more normal for children and adults to be together.” When “housed” with adults, who appear as eternal children, the expectations of children will be “to grow to be only that kind of adult.” Staff members also tend unconsciously to favor one age group over another. Separation of adults and children who are receiving developmental services encourages the appropriate treatment for each. This encourages staff treatment and physical décor appropriate to the age group. This sort of harmony encourages expectations of achievement and growth and greatly reduces inappropriate changes.

Remember that expectations are more important in determining growth than any other single factor. Growth will match the expectations of staff and everyone involved as each person moves along his or her own developmental path.
Most of us know what to do in our daily contacts with other people because we were naturally and carefully taught while growing up. Our first shopping trip to the corner store with a note from mother was an important lesson. So was our excitement in deciding what to buy with our 25-cent allowance. The environment around us provided opportunities to learn and Grow and to acquire social skills that we still use every day.

Persons with developmental special needs who have been removed from their families or from normal school and work environments are nevertheless expected to have the same knowledge of what to do in many kinds of situations. But their environment did not provide normal learning opportunities. They learned how to live in institutions—they learned to stand in lines, to wait for someone to tell them what to do next, and did not need to make personal decisions about their lives. They learned to be dependent and just a member of the group with little or no personal identity. They did not learn to cook because there were no pots and pans—or even a stove. They did not learn to use and value money because money was not needed or used. A segregated environment does not give people the chance to learn the independent living skills that others take for granted.

The worst thing that happens with any segregated setting is that it reinforces the false notion that those who are segregated need to be segregated. It causes the average person in the community to believe that there must be something wrong with the person so that segregation is required.

More and more facilities, with the goal of normalization in mind, group their clients into “family” clusters. Obviously, this is to give the group members a sense of closeness—one of the benefits of being in a family. It also serves as a testing ground for interactions, competitions, and cooperation. The process of role definition and reality testing can more safely occur in this supportive milieu. Social integration offers opportunities for persons with special needs to learn along with the rest of us.

- More learning opportunities exist through more variety of experiences, more kinds of people to imitate more normal expectations.
- It is more likely that service will be of good quality. “Separate-but-equal” does not happen with any kind of disadvantaged people.
- There are more opportunities to exercise choices and citizenship privileges.
- There are more opportunities to meet a wide range of people and form mutually satisfying relationships.
- One can develop a better opinion of himself or herself, and one has a greater likelihood of contributing to society.
What can we do to foster full social integration?

- Encourage the mixing of people who have developmental special needs with ordinary people their own age in all areas of life, in every setting and program.

- Serve people in the smallest possible numbers. This includes eating, traveling, shopping, playing, living, and loving.

- Carry on training programs where people will ultimately use their skills. Teach shopping in real stores, teach how to live in an apartment, and other skills. Ignoring this makes transitions much tougher.

- Insist that different groups with different special needs be served in different places with normal people. Do not lump programs together for many kinds of people who tend to be labeled with low expectations.

Buildings—homes, schools, work places, and entertainment centers—must be accessible. They should also fit their surroundings in ways that will raise the community’s opinion of people who use them. Buildings tell us something about the people who live or work in them. They send out positive or negative images depending on how they look, what they are used for, and where they are located. For example, a house next door to that of a famous person would probably take on added social value, while the same house next to an adult theater might be viewed negatively. The house would be the same, but its surroundings would change the value and image of the house immensely.

In locating homes and services for people in danger of being stigmatized, we need to strive to eliminate clangers all the time and to become sensitive to the fact that a building can be a clanger if it is not in harmony with its environment. Some examples of building clangers are:

- A factory or workshop in a residential neighborhood
- A home in an industrial neighborhood.
- A sign on the front door giving a home an official name instead of the house number.
- An abandoned school building used as a special education center.

We cannot underestimate the importance of harmony. When things fit together smoothly, when they are graceful, people value them highly. And they tend to impart those values to the people who use them. That kind of transfer is very important to people who have traditionally not been seen as valuable.
These are some tips to keep in mind when thinking about building projects:

- A home should be in a residential neighborhood and have easy access to shopping, recreation, and public transportation.

- Segregated facilities to live or work in often reinforce the false notion that the people there need to be segregated.

- Living arrangements for people who have special needs should be highly dispersed and not "clanged" into zoning ghettos.

- Places to live in should be small. If 15 adults live together in a neighborhood of single-family dwellings, people will wonder if something strange or undesirable is happening there.

- A home should feel and look warm; it should be decorated thoughtfully and appropriately for the age of people who live there.

- Buildings should be in harmony with their surroundings. When harmony is missing, clangers arise.

The courts have stated that programs and living arrangements should always be provided in the least restrictive setting.

Consider the factors listed below when thinking about the least restrictive setting for residences. Each of the following options should be explored before moving on to the next more restrictive and less flexible option:

1. Support, do not supplant, the natural home.

2. Use foster placement or family-like settings, especially for children.

3. If a non family setting must be used, lease, do not buy.
   
   d. Buy existing, do not build.
   
   e. Build typical, not special.
   
   f. Build special, in the middle of things, not isolated.

First determine the appropriate program objective for the person who has a special need. It might be more appropriate for a 7-year-old child to remain at home or in a family setting and be inappropriate to consider the same residential option for a 28-year-old man or woman.
A program is any service intentionally planned and put into action, which serves to teach or help another person to grow and gain skills. Programs have two simultaneous goals: (1) to help the individual in everyday life, and (2) to improve the way that person sees himself or herself as well as the way others see and experience the individual.

Programs should emphasize the opportunity for each individual to make his/her own life decisions and to shape his/her own life at every decision point. This tells both others and the individual—whether child or adult—that this is a person who can learn to be self-reliant.

Programs are most effective when the learner practices what most of us have to learn---shopping with credit, living in an apartment, eating out in restaurants, joining church or social groups, attending events, and wearing tasteful, age-appropriate clothes. If the person has a physical handicap, the most innovative wheelchair system should be used both to give maximum access to places and to make favorable impressions on others. In short, make every effort to get persons who have developmental special needs to the point at which the action is positive and enhances both their expectations and the expectations of others.

♦ The elements of a good program include:

♦ Need assessment and program planning.

♦ Acquiring competencies needed by others.

♦ Training and practice in making demands and taking risks.

♦ Good program staff.

**Need Assessment and Program Planning**

In order to design a program of services pertinent to the individual’s developmental needs, an assessment of the person’s abilities and evolving needs is essential. It is also important to select behavioral goals that build on current skills. The program begins with each person’s strengths.

An assessment of an individual should be complete. It must show facts and evidence to understand the person’s cognitive, social, communicative, emotional, sensorimotor, medical, nutritional, dental, and vocational capacities and needs.

A program must set up objectives in such a way that anyone could correctly judge whether they had been accomplished. The person responsible for such goals and objectives must be identified.

Coordination of the person’s program among the various service agencies that provide the program should be well thought out to ensure that all the objectives are met. But unnecessary regimentation must be avoided. People should be expected to express and assert themselves in assessing their own needs and planning their own objectives and in determining how these objectives will be accomplished.
Measuring results is also of vital importance. Personal growth occurs daily and, ideally, should be summed up frequently, at least every two weeks. An assessment every six months, or yearly, may be relevant for “report purposes” on gross advances, but it is unsatisfactory to guide daily programming. It can lead to the sacrifice of a year of someone’s life because no one paid attention to whether something really worked.

**Acquiring Competencies**

Above all, everyone who is able must gain some competency that makes it possible to do something for someone else. It is enough to have merely the self-care and social skills that eliminate stigma. One must be capable of accomplishments that bring tangible responses of gratitude or payment, which in our society makes one a “useful citizen.”

Dr. Mar Gold has developed an idea that is very helpful in getting a better feeling for this aspect of a program. He has coined the term “competency-deviancy hypothesis.” This means that the more competence an individual has, the more his or her deviance will be tolerated by others. Deviance, in Dr. Gold’s definition, is all those things that bring negative attention. If a person has to live with behavior or appearance that calls up negative feelings, then it is a program responsibility to teach competencies that will shift the balance of how society sees that individual—toward higher expectations.

**Training and Practice in Making Demands and Taking Risks**

The program should be real work. It should be carried on during an eight-hour day or longer. People with developmental special needs have for too long been seen as fragile and only capable of low output. Why else do children with special needs have shorter school days than typical children? Why do vocational service centers close at 3:00 p.m.?

When the program is in operation, it should communicate a sense of expectation. If you know and believe that people with developmental special needs can and will learn and grow, then your program should signal this attitude to both clients and others. The tempo, energy, naturalness, and social comfort can be felt if things are going right.

Maximum challenge to and maximum demand on the growing individual are important. Being “on the move” should be the spirit of the program—movement from more to less supervision, from more to less support, from dependence to independence, etc. There is never an end to better ways of doing things.

Risk taking should be encouraged because risk is the heart of growth. It is the ground for discovering and cultivating the power necessary to control our own lives. If we deprive a person of everyday risks, we deny the core of that person’s humanity. Unnecessary or probable dangers can be avoided, but the line between this and overprotection must be kept in focus. Respecting and encouraging human development requires making risk a partner in life. Overprotecting a person powerfully lowers everybody’s expectations about that person.
Good Program Staff

The effectiveness of any program rests in the hands of the staff. Good programs come from a good staff. Good staff members require good training and orientation. There must be continuous training for all staff members.

The program staff should find it appropriate to express their high regard for each other and for clients, visitors, and the public in all possible ways. The staff should be sensitive to symbols or signs that differentiate themselves from clients, such as separate areas of shared space, uniforms, tags, separate bathrooms. Separate areas may be necessary for live-in staff in a home, but otherwise they label clients as second-class people.

Appropriate people should be working with the right clients, doing what their training and background have best prepared them to do. For instance, a setting in which people are learning lifestyle skills in a living arrangement should be staffed with teachers of practical living skills, not by nurses or nurses’ aides. Staff members whose competencies are in industrial skills and production should be the primary staff in industrial services, not psychologists and social workers. A person engaged in two programs aimed at achieving two entirely different goals should be served by two different staffs, unless real crossover skills and training exists.

Human service workers should be sensitive about how much their background, their expectations, and the service model they learned liberates or constrains clients. They should seek the least restrictive and most appropriate techniques.

Finally, when we look at programs, we must be ready to say, “It is we who are the learners.” In this way we can take responsibility for the knowledge we have yet to gain, the skills we have yet to learn, and the patience to try another way. We have to accept the challenge and responsibility for any lack of progress rather than blame the person we are supposed to help by labeling him or her incompetent.
From Backyard Camp to Global Movement:
The Beginnings of Special Olympics

The global Special Olympics movement got its start on 20 July 1968, when the First International Special Olympics Games were held at Soldier Field, Chicago, Illinois, USA. But the concept of Special Olympics was born much earlier, when Eunice Kennedy Shriver started a day camp for people with intellectual disabilities at her home in 1962.

Welcome to Camp Shriver

Shriver believed that people with intellectual disabilities were far more capable than commonly believed and deserving of the same opportunities and experiences as others. So, in June 1962, she invited 35 boys and girls with intellectual disabilities to Camp Shriver, a day camp at Timberlawn, her home in Rockville, Maryland, to explore their capabilities in a variety of sports and physical activities.

Even before Camp Shriver, Eunice Kennedy Shriver already had a long-standing commitment to people with intellectual disabilities. She was instrumental in focusing the Joseph P. Kennedy, Jr. Foundation on improving the way society deals with its citizens with intellectual disabilities, and helping identify and disseminate ways to prevent the causes of intellectual disabilities. Shriver is Executive Vice President of the Foundation, which was established in 1946 by her father and mother, Ambassador and Mrs. Joseph P. Kennedy, to honor their eldest son who was killed in World War II.
Using Camp Shriver as an example, Shriver promoted the concept of involvement in physical activity and competition opportunities for people with intellectual disabilities. Camp Shriver became an annual event, and the Kennedy Foundation gave grants to universities, recreation departments and community centers. In 1963, the Foundation supported 11 similar camps around the United States. By 1969, the Foundation supported 32 camps across the country that served 10,000 children with intellectual disabilities. The movement grew beyond the Kennedy Foundation, and between 1963 and 1968, more than 300 camps similar to Camp Shriver were started.

**Let the Games Begin**

In the early 1960s, Dr. William Freeberg, then Chairman of the Recreation and Outdoor Education Department at Southern Illinois University at Carbondale, Illinois, USA, worked with the Kennedy Foundation to develop one-week workshops for recreation directors across the country. The workshops focused on the principles that everyone, including people with disabilities, benefits from recreation, and everyone has talents and gifts to share with others. In 1965, 10 recreation teachers from the Chicago (Illinois) Park District attended one of Freeberg’s workshops on a grant from the Foundation. One of those teachers was Anne Burke.
By 1967, the Chicago Park District wanted to do more for people with intellectual disabilities and Burke joined a team to assess the needs and how to address them. She proposed holding a citywide track meet modeled after the Olympics to raise awareness of the program. Freeberg, who had joined the team as a consultant, suggested they develop a proposal to submit to Shriver at the Kennedy Foundation.

Shriver immediately saw the potential of the idea and asked Burke to expand its scope to include more sports and athletes from across the United States. Shriver sent Kennedy Foundation staff to Chicago to work with Burke and the Chicago Park District to start planning, and announced that the Kennedy Foundation would provide a grant to underwrite the event. On 20 July 1968, Shriver opened the Chicago Special Olympics (the First International Special Olympics Games), which were held in Chicago’s Soldier Field, with 1,000 athletes with intellectual disabilities from 26 U.S. states and Canada competing in athletics, floor hockey and aquatics.

“The Chicago Special Olympics prove a very fundamental fact,” Shriver said in her Opening Ceremonies address, “the fact that exceptional children — children with mental retardation — can be exceptional athletes, the fact that through sports they can realize their potential for growth.” Shriver also announced a new national program — Special Olympics — to offer people with intellectual disabilities everywhere “the chance to play, the chance to compete and the chance to grow.”

Chicago Mayor Richard Daley, who attended the First International Special Olympics Games that day, said to Shriver, “You know, Eunice, the world will never be the same after this.”

Special Olympics today is a global movement with 2.5 million athletes in 165 countries around the world. Follow its growth from 1962 to today in Special Olympics Milestones.
ONE PERSON MAKES A DIFFERENCE

THE MOST LASTING KENNEDY LEGACY
How Eunice Shriver and her family changed the world for the mentally retarded

Not long after John Kennedy entered the White House in 1961, his sister Eunice Kennedy Shriver began one of the most heartfelt campaigns any Kennedy ever undertook. She argued to family members that it would be immensely helpful if they revealed one of their most closely guarded secrets: that one of their own, the president's sister Rosemary, was mentally retarded. It took more than a year to bring the idea to fruition, and it finally won sanction after the clan's two central figures blessed it: Patriarch Joseph Kennedy made clear he could live with the disclosure as long as President Kennedy supported it. In the spring of 1962, Eunice told JFK she wanted to write a piece for the Saturday Evening Post about Rosemary, and he responded: "That's fine. Let me see it first." The article appeared in the September 22 issue, and it was one of the biggest moments in perhaps the most important contribution the Kennedys made to the nation.

What is stunning about the Kennedys' -- and most particularly Eunice Shriver's -- role in changing the way the world treated mentally retarded people is how little noticed it has been. It is difficult to recall today the life such people faced in the generation before Kennedy's administration. Scores of thousands were warehoused in institutions located in the most remote sites available. That was especially true of women because it was thought to be important to keep them from getting pregnant and creating another generation of "idiots, morons, imbeciles" -- all terms of scientific precision used to classify different levels of retardation. One surgery textbook recommended that "mongols" (those with Down's syndrome) not be given life-saving procedures because, the text implied, they were subhuman, and some were allowed to die.

Families like the Kennedys that kept retarded family members at home as they grew up were the objects of considerable scorn. Rosemary was born at the height of the worldwide flu epidemic in 1918 and, though no one was ever sure what caused her relatively mild retardation, it became a difficult fact of life by the time she reached school age. Though the family tried to make things as normal as possible for her, she fell far behind in the hypercompetitive environment as she got older. As she became a young woman, her problems grew and she began to lash out violently on occasion.

The lobotomy.

Joseph Kennedy was told that there was a "miracle" surgical procedure called a prefrontal lobotomy that could help Rosemary. Without consulting anyone else in the family, he ordered the operation in 1941 and it was botched. The surgery was supposed to leave her mental functions relatively intact while eliminating her aggressive behavior. Instead, it rendered her zombielike and she was moved to St. Coletta's in Jefferson, Wis., where she still resides. Until Eunice's magazine article, the family told inquiring reporters that she was in a convent. Joseph Kennedy was tormented by the fate of his daughter. In 1946, he created the Joseph P. Kennedy Jr. Foundation (named after his deceased war-hero son) to help retarded people, and in the mid-1950s, he asked Eunice to determine how the foundation's grants could best be used. She traveled the nation talking to the small number of experts willing to buck the forget-'em philosophy and visiting the notorious "snake pits" that housed most retarded Americans. "There was a complete lack of interest in them and lack of knowledge about their capacities," she says. "They were isolated because their families were embarrassed and the public was prejudiced."
Not surprisingly, Eunice Shriver -- the one family member who continued to call her big brother "Jack" after his election -- hammered at the issue as JFK entered the presidency. He responded by setting up a task force headed by eminent educator Leonard Mayo to devise a legislative program to attack mental retardation. The president named White House deputy special counsel Myer Feldman to work with Eunice and the panel.

Eunice Shriver was clearly the commander of the administration effort. When her friend and panel member Robert E. Cooke suggested the creation of new university-affiliated research centers, she stuck it in the final plan. She and Feldman helped broker disputes on the panel between the "hard" scientists, who thought retardation was best addressed as a genetic and prenatal problem, and their "soft" colleagues, who favored an emphasis on education to help improve the lives of retarded people. She also helped arrange the necessary support from congressional leaders, although that task was not very difficult: Most knew that the president cared deeply about the issue. JFK even broke away from one of the emergency meetings on the Cuban missile crisis on Oct. 15, 1962, to receive the panel's report. (More than 70 percent of its 112 recommendations were eventually implemented.)

As political leaders began to change their thinking, Eunice felt the public still lagged behind. She and her husband, Sargent Shriver, persuaded the Advertising Council to devise newspaper and magazine ads in early 1962. But she thought the single most powerful act to capture public attention was the revelation about Rosemary.

Journalist David Gelman was asked to work on the fateful article through the summer. "Eunice ran it like a campaign," he says. "There was a brain trust of experts at the ready, and she kept piling boxes near me of material to cram into the piece. Everybody was really nervous about the piece. But she was determined to knock down all the competitor afflictions when it came to getting government funding." In August, Gelman watched as President Kennedy speed-read through his copy, offered a few suggestions and gave his blessing.

**A goal realized.** As Eunice Shriver predicted, the change in public and scientific attitudes prompted by the article and the work of the presidential panel was striking. Over the next generation, the Kennedys' goal -- to bring the retarded into the mainstream of American life -- has been largely realized. Research breakthroughs on the causes of retardation and beneficial educational programs have proliferated, thanks to the funding launched in the Kennedy administration. American life and the lives of the retarded have been incalculably enriched by the drive to bring the retarded into full participation in communities, schools and workplaces.

The spinoffs from these first efforts are equally impressive. The family campaign to bring the retarded out of the closet, including the Shivers' creation of the widely hailed Special Olympics, was a precursor of the larger disability rights movement. And Sargent Shriver says his inspiration to create the much admired Head Start program for disadvantaged children came from his familiarity with research that early-intervention educational efforts could raise the IQs of the retarded.

When the full judgment of the Kennedy legacy is made -- including JFK's Peace Corps and Alliance for Progress, Robert Kennedy's passion for civil rights and Ted Kennedy's efforts on health care, workplace reform and refugees -- the changes wrought by Eunice Shriver may well be seen as the most consequential. With a lot of help from her very powerful brother Jack and inspiration from her powerless sister Rosemary, Eunice Shriver helped move the nation for good and for all.
STUDY GUIDE 11

TEACHING SELF-HELP SKILLS

Goals: To assist the student with some steps and techniques in teaching self-help skills to persons who are mentally/developmentally disabled.

To provide samples of forms that can be used to evaluate the progress of the client.

The younger and the more severely retarded the client, the longer the period of time needed to teach self-help skills. Since each person is unique with individual capacity for learning, a timetable cannot be set. The child with physical, as well as mental disabilities, will probably require more time and special techniques. When readiness is determined, the interdisciplinary team will set up the objectives for each client’s program.

TEACHING SELF-FEEDING

Introduction

It is generally considered necessary for the child to sit up and to hold the head up before the child can learn to feed himself or herself. To have reached this stage of development certainly makes the task easier; however, some children have learned to feed themselves while propped up in wheelchairs. Some hydrocephalic children with moderately enlarged heads who are unable to hold up their heads can be positioned in a wheelchair with a head support and learn self-feeding.

In self-feeding, positioning is important in promoting safety in swallowing and in promoting relaxation. The resident/client should be in an upright position with feet supported. This means the table and chair should fit the individual, and the wheelchair must have footrests for support. The health care worker assisting the resident/client should also be seated in a relaxed position beside the resident/client. A health care worker who is relaxed will help the resident/client to relax and thus help make the meal the happy time it should be.

A. Bringing Hand-to-Mouth

1. The child may help to develop this hand-to-mouth motion. A bit of syrup, jelly, or peanut butter dabbed on the child’s fingers can be used to encourage the child to develop this motion.

B. Eating Finger Foods

1. For the severely and profoundly retarded, this may be the next step. If the child is able to chew and to grasp, the health care worker could start by offering a small crust of bread or a cookie. A finger food diet tray would offer bread or toast, bananas, fruit cocktail, sausages in small pieces, etc. Cornflakes or other dry cereals are good finger foods.

C. Feeding Self with Spoon

1. The next step is teaching the child to use a spoon. For the child who has difficulty grasping or holding on to the spoon, a number of specially designed spoons are available.
Module 44 – Normalization

a. Short, fat-handled spoon……..for the small child

b. Swivel spoon (the bowl of the spoon is not firmly fixed to the handle)…………….to aid the child who lacks wrist movement

c. Large-handled spoon………….for child with poor grasp

d. Large-handled spoon with Velcro strap attached to handle…………….for child who has difficulty holding on to the spoon

e. Handles bent into various shapes…………….for specific individual problems

2. Training program for the moderately retarded child, one could start the training program with spoon-feeding.

a. The first step in spoon-feeding would be to get the child’s attention telling the individual that the meal is beginning and telling the child to look at the spoon or to look at the food

b. Instructions should be simple and short and repeated over and over. Steps will usually have to be broken down into small parts. Techniques may vary according to the individuality of the child. A simple breakdown of steps would be to encourage the resident/client to:

(1) Pick up the spoon

(2) Scoop up the food

(3) Bring spoon to mouth

(4) Remove food from spoon

(5) Place spoon back in food

Note: Always reward the resident/client for each success—small or great

c. Phasing out: These phasing-out techniques may be used:

(1) Step 1: HCW places own hand over the resident’s /client’s hand while the resident/client is holding the spoon. The HCW:

(a) Guides hand to bowl or tray

(b) Scoops up food

(c) Carries food to mouth

(d) Returns spoon to place
Module 44 – Normalization

(2) Step 2: HCW lets go of the resident’s/client’s hand just before the spoon is put into the mouth

(a) After this step is mastered, the HCW lets go of the resident's/client’s hand two or three inches from the mouth, then six inches from the mouth, etc.

(b) The HCW gradually phases out his or her participation

Note: After the resident/client is able to use a spoon, the client should not be allowed to use fingers except for foods normally eaten with the fingers.

Socialization Skills Learned in the Dining Room

Moderately and severely retarded residents in institutions using the normalization-treatment approach are being trained to eat their meals family-style. Residents/clients are seated at small tables for four. The food is served in bowls, and the resident’s learn to pass the food and to share; therefore, they become more aware of their peers. A health care working sitting at the table and eating with the residents/clients can serve as a good role model in teaching table manners. Residents/clients who are retarded learn faster by imitating than by being told what to do.

If the residents/clients were living at home, they would probably help with setting the table and carrying dishes to the kitchen, hence these tasks should be a part of the normalization process. The residents/clients enjoy having an important task to do, and each small achievement adds to their self-esteem.

Drawings or plastic cutouts of plates, cups, knives, forks, and spoons can be glued to their proper places on the table as aids to teaching the child how to set the table.

A container of flowers on each table, curtains at the windows, hanging plants, and wall-hangings make the room attractive and encourages the residents/clients to help keep their dining room looking nice.

Note: Feeding skills are also included in the modules entitled Teaching/Training Using Developmental Models, Part B, and Nutrition—Assessment and Intervention
TEACHING SELF-TOILETING

**Introduction**

Readiness for a toilet-training program for persons who are disabled mentally/developmentally can be determined by observation on the part of the parents or surrogate parents (HCWs in institutions). If the child shows signs of discomfort when we or soiled, retains urine for about two hours, and usually had only one or two bowel movements at about the same time each day, the child may be considered for a training program.

The single most important part of toilet-training is consistency. If the program is to be successful, the training must be carried out over the 24-hour period. The child (or adult) should wear training pants or shorts—not diapers.

A. **Suggested Routine for Toileting**

   1. Upon arising
   2. After each meal
   3. Mid-morning
   4. Mid-afternoon
   5. Before going to bed
   6. Once during the night

   Rewards for success should be given immediately. Do not scold when accidents occur. (See module entitled Teaching/Training – Using Developmental Models, Part B).

B. **Facilities**

   The toilet must be available (no locked doors to bathroom). The toilet seats should be adjusted to fit. For example, a small seat attached to the top of a regular sized toilet, a potty-chair and footrests and supports. When starting the training program, it is better not to flush the toilet where the child is sitting because the loud noise may be frightening and, therefore, discouraging.

C. **Separate Skills and Rewards Until Each Part is Learned**

   1. Eliminating: Start with this step. Take the child to the bathroom. Later the child could be just reminded to go
   2. Pulling down clothes
   3. Wiping
   4. Washing and drying hands

D. **Record Keeping**
Record keeping is essential. A chart should be placed in the bathroom. A sample chart is attached—Record of Elimination Chart. Adding gold stars may be rewarding to some individuals.

TEACHING SELF-GROOMING AND PERSONAL HYGIENE

Introduction

Individuals with mental/developmental disabilities who are clean, neat, and smell good are more acceptable to others and will more likely be welcomed in their homes or in work situations in the community.

A. Oral Hygiene

1. If a definite time is established for the learning situation, care of the teeth will be more meaningful to the retarded individual; for example, after meals and at bedtime

2. Suggested steps in a training routine:
   a. Locate sink
   b. Get cup for water
   c. Get toothpaste
   d. Get toothbrush
   g. Turn on water tap
   h. Fill cup with water
   i. Turn off water tap
   j. Remove toothpaste cap
   k. Put toothpaste on toothbrush
   l. Re-cover toothpaste container
   m. Brush teeth
   n. Rinse mouth
   o. Turn on water tap
   p. Rinse toothbrush
   q. Turn off water tap
   r. Put toothpaste away
   s. Put toothbrush away
   t. Put away or dispose of cup

B. Washing Hands

1. The best time to teach hand washing is before meals. The hungry child soon learns that hand washing precedes eating, and so the meal becomes the reward

2. Imitating is the best teacher for the retarded person. The HCW can show the child how the hands are washed and perhaps, make a game of it; for example, singing “this is the way we wash our hands; this is the way we dry our hands,” etc.

3. Teach in simple steps and reward (praise) each step
Module 44 – Normalization

a. Locate towel  
b. Turn on faucet  
c. Wet hands  
d. Soap and rub hands  
e. Rinse hands  
f. Use towel  
g. Dry hands  
h. Dispose of towel

4. Record keeping is important because it shows progress and evaluates the training programs for oral hygiene and hand washing.

C. Bathing

1. The same steps in learning to wash hands apply to learning to bathe. The use of bath powder and deodorants would be added

TEACHING SELF-HELP

A. The Clients Who Are Retarded, Who Are Post-Cerebral Vascular Accident (Stroke) Victims, or Who May Be Partially Paralyzed

It is never too late to teach the individual who is mentally/developmentally disabled the task of self-dressing. With much patients and time, persons who are severely retarded and victims of strokes and paralysis can be taught to dress themselves. Many of the profoundly retarded can be taught to at least help with dressing.

1. Undressing
   
a. It is easier to pull off than to put on a sock, shirt, etc., so the first step in teaching self-dressing skills would be to teach undressing.

b. Start with the HCW pulling a sock almost off while saying to the child “pull your sock off.” Gradually phase out your help, remembering to reward each success—small or great

c. Other examples are removing a shirt. The HCW removes the child’s shirt except for one sleeve, then says, “pull off your shirt” while guiding the child’s hand to help finish the task. That’s a good boy, “the child hears too many words at one time and may be confused as to what you want him/her to do. It would be better to say simply, “put your shirt on,” and repeat the same phrase several times if necessary.
2. **Instructing Verbally**

   a. Keep verbal instructions simple and short. If you say to the child, “Johnny, I want you to be a good boy today and put on your shirt and then I’ll be so pleased. That’s a good boy,” the child hears too many words at one time and may be confused as to what you want him/her to do. It would be better to say simply, “Put your shirt on,” and repeat the same phrase several times if necessary.

3. **Learning Success**

   a. As making the task easy will help the child learn because each small success is rewarding to the child, success builds on itself and helps the child feel good about himself/herself. As he/she finds he/she can do something for himself/herself and is rewarded for doing so, he/she will want to do more.

   b. Retarded children want attention and approval as much as or even more than two children with normal abilities.

4. **Selecting Clothing for Training Program**

   a. Start with knit shorts that stretch and so are easier to pull off and put on. Do not start with shirts having buttons; fastening button is too difficult at the beginning. Skills like this can be taught later.

   Start with trousers with elastic waist bands, then progress to Velcro

5. **Dressing**

   a. Teaching self-dressing is a slow process and needs to be broken down into small steps with rewards given for each small accomplishment, it'll be easier for the retarded child to start learning by completing an almost finished task rather than starting at the beginning of a task that has little meaning. For example, to hold out a shirt and say, “Put your shirt on,” even while helping the retarded child with the shirt is a more difficult task for the retarded child than a normal child. A retarded child cannot visualize the results. But if the shirt is almost on, the concept of what is to be done is easier to understand, and the training period will be shorter.

   b. Start with the easiest task and progress to the more complex, one step at a time:

   (1) Undressing skills:

      (a) Socks

      (b) Shirt or dress

      (c) Trousers

   (2) Simple dressing skills:
Module 44 – Normalization

(a) Socks
(b) Shirt or dress
(c) Trousers
(d) Sweaters
(e) Shoes
(f) Coats

(3) More complex skills:
(a) Tying shoe laces
(b) Fastening with Velcro, buttons, zippers, etc

6. More Complex Skills
   a. Special training tools have been devised to aid in teaching the more complex skills. For example, large shoes for the child to practice tying shoelaces, colored marks on the bottom of shoes to teach and designate left and right shoes, and material with large buttons and button holes to practice buttoning and unbuttoning.

B. The Client Who is Moderately Retarded

The individual who is moderately retarded will learn self-dressing skills at an earlier age and more easily than the individual who is severely retarded. Because the moderately retarded will have some opportunities for placement in the community, the needs in relation to self-dressing will also include:

- Independent care of clothing including laundering
- Learning to purchase clothing
- Learning to dress appropriately for a work situation, parties, recreational activities, etc

1. Selecting Suitable Environment for Teaching
   a. A crowded day room, where the child would be easily distracted, would not be suitable. A good area would be at the bedside near the clothing locker. If not too crowded, the bathroom would be suitable before and after bathing. The experience should be pleasant and rewarding for the child.
2. Teaching Safety Factors

   a. Consideration for the safety of the individual being taught self-help skills should always be a part of the training program. Some general safety rules:

      (1) Be observant of and clean up water spills in bathrooms
      (2) Teach residents not to splash water unnecessarily
      (3) Check water temperature
      (4) Teach residents to check water temperature if they are being considered for independent living arrangements
      (5) Be aware of rules for leaving children alone in bathrooms. For example, a profoundly or severely retarded child should never be left unsupervised in the bathroom
      (6) Glass bottles and other glass objects should not be used in the bathroom area where they can be broken and stepped on or fallen on

3. Caring for the Hair

   a. A good time to start teaching the person who is mentally/developmentally disabled to comb hair is before breakfast. The child learns the routine of getting up, going to the toilet, washing, dressing, and combing the hair before going to breakfast.

   b. Hair ribbons and berets help stimulate an interest in pretty hairstyles for girls. If girls can go to the beauty shop for haircuts or permanents, they will take better care of their hair because they like to look pretty

   c. When boys start combing their hair, they too will be proud of their haircuts because they like approval for their neat appearance

   d. Teaching hair combing includes locating the comb and returning the comb to the same place, for example, a shelf in the child’s personal clothing locker.

4. Teaching More Complex Grooming and Personal Hygiene Skills

   a. Other areas of grooming and personal hygiene to be taught are shaving self, care of nails, use of deodorants, and shampooing hair. Moderately and some severely retarded adolescent girls can be taught self-care during menstrual periods.

5. Selecting Suitable Bathroom Environment for Teaching

   a. Try to choose a time when the bathroom is not too crowded for teaching oral hygiene and handwashing. So the child will not be confused, these skills should be taught in the same area of the bathroom. For example, a child would not
be taught to brush his/her teeth at the bedside if later this child is expected to go
to the bathroom to brush his/her teeth.

b. Hair combing should be taught where there is a conveniently located mirror so
the child can see the results

SOCIALIZATION SKILLS

A. Socialization can be defined as making one socially adjusted to, or fit for, cooperative group
living.

1. How does the individual who is mentally/developmentally disabled adapt to the
regulations imposed by society? For example:

   a. Does the dressing appearance compare with the average person?
   b. Does the person look clean?
   c. Is the person toilet trained?
   d. Does the person feed self?
   e. Does the person fit into a group as does the average of his/her peers in the
      community?
   f. Does the person get along reasonably well with others, take his/her turn, share?

2. Socialization skills can be taught as a part of daily living.

   a. Self-help skills including toileting, feeding, dressing, grooming, and personal
      hygiene.
   b. Good manners will best be learned by imitation.
   c. Taking turns can be learned when washing, going to the store or canteen,
      setting the table, at picnics, and other activities; like playing games.
   d. Sharing is learned by eating family-style, playing games, sharing treats by
      passing treats around to peers, parties, etc.
   e. Attending church, movies, parades, dances, and parties.
3. Activities in the community to enhance socialization skills include:
   a. Attendance at parades.
   b. Trips to local restaurants.
   c. Trips to the zoo, the beach, the snow, etc.
   d. Trips to Disneyland, Sea World, Magic Mountain, etc.

CONCLUSION

Potential for Learning Self Help Skills

The younger and the more severely retarded the child, the longer the period of time needed to teach self-help skills.

The children who are severely retarded are difficult to teach, but they can learn to feed, dress, and toilet themselves. They can learn to brush their teeth, wash their face and hands, comb their hair, and help with bathing. Months and even years may be needed to learn these skills. These children will need a lot of help with socialization. Interacting with peers may be difficult for them, but they usually respond happily to activities with the staff and their peers, such as picnics, train rides, pony rides, simple musical games, playing on swings and slides, and trips to an animal farm.

In the past, the profoundly retarded had been considered by many to be untrainable. It may take two years for the child who is profoundly retarded to learn to feed himself/herself; it may take longer, but many can and do learn. With toilet training, it may take two years or four years to be considered successful. Some can learn to help with dressing, toothbrushing, and haircombing. They may never be wholly successful, but even small successes are better than none. Every child has the right as a human being to receive the help necessary to reach his/her fullest potential.
Pre-vocational therapy plays an important part in helping the resident/client who is mentally/developmentally disabled learn good work habits. It helps the resident/client learn skills in interpersonal relationships, which are necessary for satisfactory performance in a work situation.

The Role of the Health Care Worker

1. Observation of the individual who is mentally/developmentally disabled for possible recommendation to an interdisciplinary team for placement in a pre-vocational program.

   a. Does resident/client have satisfactory self-help skills to enable him or her to take part in a work situation?

      (1) Is the resident/client toilet trained? This self-help skill should be necessary for a client to be placed in a work area.

      (2) Is resident/client able to feed self? Resident/client should be able to feed self with a minimal amount of help.

      (3) Is resident/client able to dress self? The individual should be able to with the exception of the individual with physical handicaps requiring assistance.

      (4) Is self-grooming and personal hygiene satisfactory? It is important to be clean and neat when reporting to a work assignment.

   b. Does resident/client have sufficient social skills to work with others?

      (1) Does the individual with special needs usually get along well with peers and staff?

      (2) Can the individual follow simple directions?

   c. Is resident/client oriented to time and place?

      (1) Can the client tell time? In order to get to work on time, the resident/client should be able to tell time.

      (2) Would resident be able to find the way to work area and return to the resident’s home unit without too much delay? Good work habits would include being on time.

2. Supervision of resident assigned to a pre-vocational placement on the HCW’s work unit:

   a. The HCW should be aware of the work assignment.

      (1) The resident/client works only in assigned area.
(2) The resident/client works only specified hours, usually not more than 6 hours a day; not more than 5 days a week.

(3) The resident/client must have specified lunch hours and rest periods, usually one hour for lunch and one hour for rest periods.

b. Through participation in the pre-vocational therapy program, the resident/client should develop the following qualities:

(1) Emotional stability

(2) Dependability

(3) Honesty

(4) Social compatibility with peers and supervisors

(5) Ability to adjust to daily routine

3. Responsibilities of the employee to whom the resident/client is assigned:

a. Work with the resident/client by assigning the same type of work at the same time.

b. Make reports to industrial therapist concerning the resident/client.

c. Notify the home ward if resident/client does not report to work.

d. Notify industrial therapist and resident’s/client’s home ward of emergencies requiring discontinuance of assignment.

e. Prevent other persons from working on the pre-vocational therapy resident’s job.

4. Responsibilities of health care worker on resident’s /client’s home unit:

a. Maintain a time sheet record of resident/client to be sent to coordinator of pre-vocational training.

b. Notify unit or area where resident/client may have been assigned if resident fails to return to home unit within 30 minutes of the expected time.

Placement of Resident/Client in a Pre-Vocational Program

1. Institutions

a. In institutions, the assessment, planning, implementation, and evaluation of a pre-vocational program is carried out by the industrial therapist and/or the rehabilitation department based on recommendations from the interdisciplinary team.
2. Some examples of pre-vocational assignments:
   a. Making beds
   b. Laundry truck
   c. Food truck
   d. Gardening
   e. Janitor work
   f. Escort aides
   g. Kitchen aides
   h. Big sisters, big brothers

Vocational Programs

To broaden the student’s knowledge of the breadth and scope of vocational programs in California, a brief summary of Porterville state Hospital’s program (an example of one such program) follows:

1. Vocational Preparation

   Vocational preparation provides structured, low-level work activity for residents/clients. The tasks are simple, and incentive rewards, such as money or other tangible items, may be given to the resident/client for work efforts. When connected with a meaningful work activity, rewards may stimulate a resident/client to further develop vocational skills and appropriate social behavior. Work activities geared to the functional level of the resident/client helps in teaching the client that success may be achieved through work efforts.

   In the program, an interdisciplinary team assesses the resident’s/client’s participation to meet identified resident’s/client’s needs and establishes objectives for the resident in conjunction with the vocational group leader.

   A rehabilitation therapist or vocational group leader organizes the work-activity groups.

   The unit nursing group leader (may be a HCW) may conduct the work activity of residents in his/her unit’s program with the guidance and assistance of the rehabilitation therapist.

2. Pre-Vocational Training

   This training is a therapeutic placement of residents in work situations within the hospital. Placement is based on the individual needs of the resident and never primarily on the needs of the hospital.

   The expectation of assignments in this program is to teach the resident/client emotional stability, dependability, honest, social compatibility with peers and supervisors and to aid in the
adjustment of the resident to daily routine. Assignments must be meaningful and productive to the resident.

The unit interdisciplinary team assesses the resident’s/client’s needs for this type of activity, and with the coordinator of pre-vocational training, establishes an individualized pre-vocational training program. The coordinator of pre-vocational training makes periodic evaluations and written progress notes on each resident in the program.

3. Work Activity Center (Sheltered Workshop)

The center provides residents an opportunity to receive monetary rewards for their work. The program serves residents who have been selected to participate solely on the basis of their needs.

This assignment is expected to teach that meaningful work and monetary reward are factors in stimulating the individual to achieve a higher level of performance in the vocational area. The work activity center experience serves as a useful measure of a resident’s potential for participation in more sophisticated vocational programs and/or success in a vocational placement in a community setting.

Work activity center projects include making Christmas cards, silk-screening and printing, catering, ceramics, industrial assembly, and horticulture.

4. Hospital Skill Training

The hospital provides skill training for selected resident trainees who have a vocational potential to function in areas such as the laundry, main kitchen, housekeeping, garage, and bakery.

Some residents/clients may assume a relatively independent vocational role in the community if they can master the skills required in the performance of certain occupations. This program will utilize the various occupational skills in the hospital community in training the resident in various occupations in which they appear to have an aptitude and interest.

5. Community Skill Training

Community skill training provides for selected resident trainees believed to possess the vocational potential to function at this level with specific on-the-job training in a community setting. These on-the-job training situations are under the direction of the Department of Rehabilitation, Division of Vocational Rehabilitation, who will furnish the resident with incentive pay, uniforms, tools, etc., during the training process.

This vocational program may be the final step before community placement.

6. Community Placement

The community employment program provides that a resident trainee works in the community and that a plan has been prepared for community living. The program provides for a specific type training of employment in collaboration with the Regional Centers and the resident/client, based on the vocational and social level of the resident.
Residents referred to this program usually have had the benefit of other vocational training programs. They have been evaluated and trained in vocational and social areas. Center residents may assume a relatively independent-living, as well as a vocational role, in the community. Others will require the protection of a sheltered workshop with a foster home or other community placement.
<table>
<thead>
<tr>
<th>Check Appropriate Comment</th>
<th>Elaborate on comments checked in left hand column, and describe duties</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AMOUNT OF WORK PERFORMED:</strong></td>
<td></td>
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<tr>
<td>_____ Exceeds expected amount</td>
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<tr>
<td>_____ Meets expectations</td>
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<tr>
<td>_____ Does not meet expectations</td>
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<tr>
<td><strong>QUALITY OF WORK:</strong></td>
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<tr>
<td>_____ Better than expected</td>
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<td>_____ Meets standard requirements</td>
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<td>_____ Below standard</td>
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<tr>
<td><strong>SOCIAL ADJUSTMENT:</strong></td>
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<td>Relates well to:</td>
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<td>_____ Employees _____ Co-workers</td>
<td></td>
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<tr>
<td>Relates poorly to:</td>
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<td>_____ Employees _____ Co-workers</td>
<td></td>
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<tr>
<td><strong>ATTITUDE:</strong></td>
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<tr>
<td>Does client seem happy with this assignment?</td>
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<td>_____ Yes _____ No</td>
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<tr>
<td>Does client frequently complain about assignment?</td>
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<tr>
<td>_____ Yes _____ No</td>
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<tr>
<td><strong>ATTITUDE OF CO-WORKERS TOWARD THIS CLIENT:</strong></td>
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</tr>
<tr>
<td>_____ More popular than most</td>
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<tr>
<td>_____ Accepted by co-workers</td>
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<td>_____ Disliked by or avoided by co-workers</td>
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<tr>
<td><strong>DEPENDABILITY:</strong></td>
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<tr>
<td>_____ Client reports for assignment on time</td>
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<tr>
<td>_____ Client frequently late</td>
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<tr>
<td>_____ Client frequently fails to report for assignment</td>
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<td><strong>ABILITY TO LEARN:</strong></td>
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<tr>
<td>_____ Learns duties and procedures quicker than expected</td>
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<td>_____ Learns in usual length of time</td>
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<tr>
<td>_____ Slow in learning duties</td>
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<tr>
<td><strong>APPEARANCE:</strong></td>
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<tr>
<td>_____ Overgroomed, fastidiously clean</td>
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<tr>
<td>_____ Shows normal concern for appearance</td>
<td></td>
</tr>
<tr>
<td>_____ Careless with grooming and dress</td>
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</table>
Regional Centers, funded by the State of California, were established in 1965. By 1975, twenty centers were authorized. These centers were developed to facilitate placement of developmentally disabled clients in the community near their home.

The regional centers are referral points in the community where the assessments are made as to the needs of mentally retarded persons and their families. Centers are centrally located to meet the needs of the region each serves. To aid the families, the centers are located within two hours of driving time from the family of a developmentally disabled child.

The regional centers of California provide:

1. Multidisciplinary diagnosis
2. Evaluation
3. Counseling
4. Admissions to and discharge from State Hospitals for the Developmentally Disabled
5. Alternate solutions for parents whose children require institutionalization

For the families unable to afford to carry out the recommendations of the centers, the centers have funds to pay for such things as dental care, physical therapy, a visiting nurse, and participation in activity centers and sheltered workshops. If residential care is needed, the family pays a monthly fee based on its ability to pay. The centers will also pay for respite care. Respite care is usually for a period of one or two weeks and provides care in a residential facility when the family needs temporary help. For example, if the mother is ill or if the family just needs a brief period of relief from the responsibilities of caring for their retarded child.

The regional centers have been an important factor in relocating many developmentally disabled clients away from institutions back into the community, where they are able to live a more normal life,
Fathers of normalization

- Bank-Mikkelsen
- Nirje
- Wolfenberger
Module 44 – Normalization

Slide 4
Paradigm shift - shift in attitudes
- Increase exposure
- Reduce stigmatizing condition
- Education

Slide 5
Applications
- Rhythm of the day
- Normal routine of life
- Rhythm of the year
- Normal developmental experiences
- Making choices, wishes, and desires
- Gender integration
- Normal economic standards
- Standard physical facilities

Slide 6
Social behavior
- Don't assume sadness in disabled person
- Don't pity them
- Focus on their ability, not disability
- Don't overuse cute nicknames
- Don't avoid because of their disability
Slide 7

Social integration
- Foster relationships with all people
- Small group settings in community
- Do training in natural environments
- Integrate home, workshop, school in like surroundings

Slide 8

Institutional behavior
- Would I want my family member treated that way?

Slide 9

Marc Gold
- Competency-deviancy hypothesis
Training principles

- Do real work
- Place a maximum of demand and challenge on individual to achieve maximum growth
- Risk-taking to be encouraged