

Training Module

**Principles
of Normalization**

Presented by

Kaleidoscope Family Solutions, Inc

Principles of Normalization

The idea of "Normalization" is essentially a philosophy which promotes that all individuals with mental retardation, have the inherent right and should be provided the provisions, to live a life as close as possible to the patterns of mainstream society. These individuals deserve our help to look and behave in a way that is appropriate for one's culture, of similar characteristic such as age and sex.

A Historical Understanding of Normalization

In Sweden, in the middle of the 19th century, the understanding of those with mental retardation changed. Up to the turn of the century, the services for these individuals were primarily concentrated on the use of institutions. There was a very negative understanding of these individuals. They were dehumanized in many capacities, including being essentially jailed, being involuntarily sterilized, and being refused the opportunity to develop personal, meaningful relationships with others. There was no meaning in a day that was only monotonous and quite rigid. There were not choices for these individuals from the clothes worn, to the meals eaten. And, finally it was felt that society had to be protected from these individuals.

Slowly, through the compassionate work of Scandinavian countries, things began to change. The start of the "normalization" process began in 1943. That year, a government committee in Sweden was appointed to investigate ways of making available means of employment and self-support for handicapped persons or "partially able bodied" as they were referred to. "The Normalization Principle" was derived as the result of their work. The suggestions of the committee included means to facilitate these individuals receive employment, thus making it possible to provide for themselves.

Further conversation determined that these handicapped persons should have the right to available services for the non-handicapped population which already existed in society. The implication was that this living, working, and engaging in services among the non- disabilities population was meant to be a positive development for both the handicapped individual and for society at large.

And so the development of "normalization" has continued to expand to the United States. The principle of normalization holds that persons with mental retardation should be supported in leading lives which by daily routine, opportunities, expectations, and treatment are as much like other people in their community and of their age as possible. Wolf Wolfensburger, an early advocate for community services for persons with disabilities, recognized that people with mental retardation are not all alike. They have needs, interests, and abilities that are more like those of people without disabilities than different. An individual's life experience is strongly affected by how others see him or her. Adults with mental retardation who are supported in doing regular and valued things that other people their age do in the community in which they live are viewed in a positive manner.

In other words, the Normalization principle means the right thing to do is to make available to all persons with intellectual or other impairments or disabilities, those patterns of life and conditions of

everyday living that are the same, or as close to possible to, the regular circumstances and ways of life. The facets or elements of the normal patterns or conditions of life that the principle refers to are the following:

Normalization means... A normal rhythm of the day.

You get out of bed in the morning, even if you are profoundly retarded and physically handicapped; You get dressed, and leave the house for school or work, you don't stay home. In the morning you anticipate events, in the evening you think back on what you have accomplished; The day is not a monotonous 24 hours with every minute endless. You eat at normal times of the day and in a normal fashion; Not just with a spoon, unless you are an infant; Not in bed, but at a table; Not early in the afternoon for the convenience of the staff.

Normalization means... A normal rhythm of the week.

You live in one place, go to work in another, and participate in leisure activities in yet another, You anticipate leisure activities on weekends, and look forward to getting back to school or work on Monday.

Normalization means... A normal rhythm of the year.

A vacation is had to break routines of the year. Seasonal changes bring with them a variety of types of food, work, cultural events, sports, and leisure activities. Just think. ... We thrive on seasonal changes.

Normalization means... Normal developmental experiences

Of the life cycle: In childhood, children, but not adults, go to summer camps. In adolescence one is interested in grooming, hairstyles, music, boyfriends and girlfriends. In adulthood, life is filled with work and responsibilities. In old age, one has memories to look back on, and can enjoy the wisdom of experience.

Normalization means... Having a range of choices, wishes, and desires respected and considered.

Adults have the freedom to decide where they would like to live, what kind of job they would like to have, and can best perform; whether they would prefer to go bowling with a group, instead of staying home to watch television.

Normalization means... Living in a world made of two sexes.

Children and adults both develop relationships with members of the opposite sex. Teenagers become interested in having boyfriends and girlfriends. Adults may fall in love, and decide to marry.

Normalization means... The right to normal economic standards.

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

Normalization means... Living in normal housing.

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

This list is based on an easy reading list by Bengt Nitje, taken from an appendix to Wolfensberger 1999 paper.

Below is a basic understanding of what "Normalization" will mean for individuals with mental retardation.

Consider these ideas as you think about how to "normalize" the lives of those individuals with mental retardation.

Choice: All people have the right to choose how they will live their lives, where and with whom. When people need help, it is friends and family closest to them who assist them in broadening their experiences and exercising their right to choose. It is essential that each person have a network or circle of support chosen by them. It is our duty to help facilitate this.

Relationships: The relationships a person has with others are precious and should be treated in that way. All relationships should be nurtured and protected. Those with whom the individual has real relationships with provide the strength, assistance, and security which ensure each person's well being.

Contribution and Community: Everyone has the ability to contribute to their community in a meaningful way. Giving of ourselves helps us establish a sense of belonging and identity. Community membership means having the opportunity to be employed, to have your own home, to be truly involved in the routines of the community, and to make a difference in the lives of others.

Roles and Responsibilities: Individuals, as they take greater control and authority over their lives and resources, assume greater responsibility for their decisions and actions. They are also responsible to contribute to their supports if resources exist to do so. They will find their power, become self advocates, and communicate their needs.

Professionals and staff assist people to create more meaningful relationships, link them with needed supports, remove barriers, develop safety networks, and help make dreams come true.

Control: People have the power to make decisions and truly control their lives. This includes authority over financial resources, as well as authority to determine what supports are needed, how they will be implemented and by whom. People also have control of hiring those who will provide support.

Dreaming: All people have hopes and dreams which guide the actions they take and are most meaningful to them. A commitment to helping people determine their dreams, respecting those dreams, and helping make dreams come true is crucial.

Dignity and Respect: All people have an inherent right to be treated with dignity and to be respected as a whole person. Most of life's greatest lessons are learned when we make choices that we later realize were mistakes. All people have the right to the dignity of risk. The network of support makes risk possible by weaving a safety net which provides safety and supports growth.

Fiscal Conservatism: Making things happen does not always require money. It is imperative that alternatives to paid supports be found. When supports must be purchased, people will get what they need, pay only for what they get, make real investments, spend money more efficiently, and make adjustments when they are needed. To find the best quality for the most reasonable price, people are free to purchase in and out of the system.

Whatever It Takes: An attitude that nothing is impossible, as long as it is legal and causes no harm, is required. "No we can't" as an answer is replaced by "How can we make this happen?" Those who work in the system become barrier removers.

What does this look like for you?

As we talk about working to normalize the lives of these special individuals, it starts with the idea that living in an institution is simply not appropriate. This does not, in any way, shape or form, support the inherent rights in all individuals to live a full, rich, self-directed life. But, it is significant to note that providing services and supports to persons with mental retardation in their own homes and communities is still fairly new ideal, and we are continually learning about better ways of helping these individuals live regular "normal" lives. In the twenty-five years or so since deinstitutionalization began in earnest, a great deal has been learned about the best ways of teaching and supporting persons with mental retardation. In the last two decades, our society has changed significantly in the way we view persons with disabilities. Though our knowledge continues to evolve, we have a much better understanding of what works and what doesn't work in supporting persons with disabilities in leading active and fulfilled lives in the community.

The intent of this training module is to introduce you to the values that should guide you in your work with persons who have mental retardation. The following set of Principles will guide you to an understanding of a consumer driven system of supports and services for individuals with mental retardation. Understanding of and commitment to the following principles are essential to ensure that this basic human right is respected and ensured. Each action and decision made within the system should be weighed against these principles.

The concepts that help promote normalization are really some simple, common sense ideas:

Dignity of Risk

Community Presence and Participation Personal Choice

Respect Individual Rights Zero Reject

Promoting Normalization

Dignity of Risk: Dignity of Risk means giving people chances to take the risks that go along with ordinary life. These risks are necessary for personal growth and development for you, me, and the people we serve. Dignity of Risk is a principle that must be applied with care and support, based on each person's needs, interests and abilities. It is your responsibility to help the individual develop informed decision-making skills and to provide opportunities and supports that allow individuals to take certain risks and make their own decisions. You could support the principle of dignity of risk by the following activities:

- Support an individual's desire to get a job at a local restaurant, grocery store, or day care center
- Teach an individual to ride the bus
- Assist a person in planning a special date
- Demonstrate to a concerned parent that his adult child really can walk to the corner store independently and safely for a soda. Select a site for your group home in a neighborhood and in a house you would be comfortable living in!
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Community Presence and Participation: This principle should guide the selection of sites for homes, the placement into jobs, and the development of our consumer's Service Plans. All people with mental retardation and other developmental disabilities belong in the community, in the same schools, neighborhoods, stores, and jobs where other people spend their time. Community presence is the experience of sharing the ordinary places that define community life. Without focused effort, people with handicaps will be separated from everyday settings by segregated facilities, activities, and schedules. Taking people out to ordinary places is the first step, but unless you make the effort, it is possible for the people you support to be present but not actively involved. You must take steps to help each individual get involved in activities he/she wants to do. Partial participation is better than sitting on the sidelines watching others. Your role may include breaking a task into manageable steps that the person can complete. An example of partial participation in helping to make breakfast might be pushing the handle down on the toaster or holding the glass while someone else pours the juice. Both persons with disabilities and their peers without disabilities are more enriched by the challenge and opportunities of living, working and playing side-by-side. You can help an individual experience full participation in the community by:

- Convincing your minister or rabbi that adults with mental retardation should attend regular church or temple services and adult classes, not "special classes" for the disabled
- Find out what a person likes to do and make arrangements for him to participate with your support
- Avoid taking people out in large groups because this is not how most people participate in the community.

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- Assist an individual in becoming a volunteer at a local SPCA, or other community agency, such as Meals on Wheels or the AIDS Ministry
- Help an individual get a membership to the YMCA where he or she can participate in regular classes for Yoga, swimming, aerobics, or even a spinning class
- Assist people individually in going to a neighborhood beauty salon or barber shop for their haircuts. How about a manicure or pedicure?

Personal Choice: Personal choice defines and expresses individual identity. This includes the small stuff and the big stuff, from what to wear in the morning, what to eat for breakfast, who to live with, or what kind of work one will do. You can help an individual experience personal choice by:

- You accompany the persons individually to the bank to cash their paychecks (as opposed to pulling the van up to the drive through and passing three sets of checks and IDs to the teller)
- You ask the person what they would like for breakfast, such as cereal toast, yogurt, eggs, etc., instead of saying "It's Wednesday today, so we are having cereal."
- You help a young woman find affordable, personal belongings for her bedroom by taking her to shop in several stores in her price range. Talk about personal likes, and dislikes, and the importance of being practical and staying within a budget
- Assist the individuals you support in buying attractive, well-fitting and affordable but fashionable clothing which is appropriate for their age and gender
- You write down daily, weekly, and occasional choices the individual may demonstrate. Count how many of these daily choices are actually made by other people. Consider how and what you can do to increase individual's opportunities and independence in making some decisions

Respect: Just like the rest of us, those with mental retardation deserve the opportunity to earn the respect of others. We earn the respect of others by making contributions to the community, of others. There is a general tendency to underestimate the abilities of people with mental retardation. In fact, it is common for us to focus on our own limitations, rather than our talents. Low expectations will limit the opportunities available to people with mental retardation. Respect requires that we see an individual as a person, first and foremost. It is important to recognize that all people, individual people with disabilities, want and need the same things we do: Love, security, personal satisfaction, communication with others, and the opportunity to exercise some control over the day. You can respect these individuals by:

- Don't call you friends, talk on the phone, or watch your own TV shows while you are on duty. It is not your home; it is the individual's home. It is just where you work!
- If you are staff in a group home, you should join the people you support for meals by sitting with them, eating the same food, and using the same plates they use on a daily basis.
- Don't talk about the individuals you support in their presence or talk to another staff member or person in the community as if they were not present.
- Ask yourself honestly, would you like to live in this home or work in this workplace?

Individual Rights: People with mental retardation and other disabilities have the same rights as non-disabled people. Like us, they are entitled to privacy, to get married, to vote, to live in neighborhoods, and to speak their minds. You can show that these individuals have the same rights as you and me by:

- Periodically, maybe once a year, sit down with the people you support. On an individual basis, explain to them their rights in a way that they will understand.
- You speak up when you sense that another staff member or person is violating a person's right to privacy or other rights.

Zero Reject: Is the concept that all people with disabilities belong in the community. No matter how severe a disability, or how challenging a behavior, it is possible to develop flexible, individualized support to help meet this person's needs. It is your responsibly and the responsibility of the program to devise plans that will meet the person's need, to help them gain skills, or to help them change their behavior. Zero reject recognizes that it is the responsibility of the community provider to develop the support that a person needs to succeed in the community, rather than expect the person to change before they can get those services. You can support this concept of zero reject by:

- The day program you are working at as admitted a young lady who has a "history of aggressive behavior, and of assaulting staff persons." Additional staff has been hired, and training has been provided to implement positive behavior supports. You commit mentally to working with your team in supporting this individual instead of complaining "She doesn't belong here."
- The members of your team adjust your work schedules to offer more staff support to a person who has been aggressive following the death of loved one.

Some Benefits of the Normalization Process

All the above-mentioned facets of the normalization principle make a normalization of the life situation feasible: the normalization process can aid many individuals 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 dependent they may be, have life conditions, facilities, and services that follow the normal patterns of society.

Just as the right of education is important for every citizen, so it is important for the mentally retarded to have a right to equal opportunities for education, training, and development. The personal development of those with mental retardation places particularly heavy responsibilities on persons in charge of the life conditions of these individuals. Through the normalization process, the stimulating, meaningful, and rich experiences will help develop a feeling of personal identity. The self-image of these individuals must be built on letting them experience personal abilities. It is essential that the mentally retarded should be offered appropriate facilities, which assist the educational processes and development and which make it possible for one to experience becoming an adult in one's own eyes and in the eyes of others. This is a basic requirement for helping one's life development come as close to the normal as possible. The lives of the individuals we serve, as well as our lives, will be richer and more profound when we do the right thing, and normalize the lives of individuals with disabilities.