CHAPTER 30

Concepts and Theory of Normalization

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PHILOSOPHY AND BACKGROUND

The Essence of Dehumanization

To respond
To a significant degree . . .
To a human being
As if he were not what he is ...
Or could never be . . .
What he might be

I am very deeply honored and feel privileged to be here to share this historic occasion with you. When the Down's Syndrome Congress was born last year, I had the very special sense, having attended that meeting, that you really represented the rebirth of something that happened in the 50's when the then National Association for Retarded Children was established. Then, people arose out of common need to defend their rights and the rights of their sons and daughter's who had special needs. There was an inspiration, an enthusiasm, a militance in the 50's as a new social force came into being in this country—a force to oppose dehumanization, to oppose human abuse, to oppose second-class citizenship. As the years have rolled on, two decades and a half since the founding of the National Association, there has been a quieting, a placidity, a loss of some of the inspiration in that movement at a time when we need that inspiration and militance more than ever. I believe that you represent a resurgence of that, conviction and devotion and sacrifice

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This chapter was presented to the Down's Syndrome Congress, Milwaukee. Wisconsin, September 30, 1974. It presents a valuable philosophical base for all services.

to the common good based on very moral, deeply felt beliefs in the interests of your sons and daughters who have Down's Syndrome.

You are not alone. Naturally, the question of the rights of preschool age children is a binning issue. The preschool community represents a minority group in this country, demanding special and decent quality services for their special needs. The Black, Chicano, and native American communities are asserting their needs. The same is true of the elderly, a national minority that is beginning to realize, little by little, that on a strategic level, they are destined to be institutionalized, and die in loneliness, abandonment, misery, and dehumanization in the vast institutional program that is being erected for all citizens in their advanced years. Ladies and gentlemen, one out of three of you sitting in this room will die in an institution for the elderly if the present rate of construction of nursing homes continues and the ideology persists. Women, the largest national minority, have also raised their concerns for a different kind of society. You, as representatives of another national minority, citizens with Down's Syndrome, will and must take your place alongside the other great national and historical movements whose objectives include no less than survival in our culture, a better quality of life, and social justice.

If one group is devalued, all are devalued. If one group is attacked, all groups will be attacked. I would like to bring to your attention a piece of legislation that was passed in Florida last year by the lower house of the State Legislature, entitled "Death with Dignity." This rider was attached to legislation entitled the "Sunshine Bill," a benefit package for the elderly in Florida. The essence of "Death with Dignity" related to a large number of people residing in the state's institutions for the mentally retarded who were not considered citizens because they were labeled severely and profoundly impaired. The bill proposed that all life-supports be cut off from this labeled population. Fifteen hundred people would have been threatened in Florida had that bill passed the State Senate. That bill may pass the Senate within the next few years. After a bill is passed to exterminate those whom the bureaucracy labels profoundly retarded, who will be the next group that will be selected to be exterminated because they arc a burden, not worth the expense, or lack advocates? In "Death with Dignity" regulations, the priorities for extermination fell upon those people who did not have a parent, guardian, or advocate, and were in the institution.

Therefore, it is not elective that you are here concerned with your rights, though you may feel that you have freely chosen to come. It is imperative that you are here! For as one group struggles for what is just and human, all groups who live at high risk outside the mainstream will gain.

It is in this context that normalization has to be studied and shared. Normalization has four basic thrusts today:

1. The first is for *consciousness-raising.* Normalization will help us dislodge some of the prejudices and biases that both we and the general society at large hold against people who are different. Unless we surface these massive, deeply held, often unconscious beliefs about differentness, as they are directed towards those labeled retarded in our society, we will make very slow headway in transforming social institutions.

2. Normalization is one of the most powerful *organizing tools* that has developed in the human services scene for consumers and advocates to marshall their strength and have a clear vision of where they are going and where human services ought to be going.

3. Normalization is a fundamental tool to *initially indoctrinate and train* all potential human service workers . . . physicians, nurses, therapists, teachers, administrators, anybody in the human services embarking on their educational course. Technology must derive from the normalization concerns, and not vice versa. Sadly, technology today, as we know it, is so entrenched in attitudes and practices which dehumanize and devalue people served that normalization, taught apart from the core curriculum, becomes rhetoric to cloak business as usual.

4. Finally, normalization, or the socio-developmental model of growth, *provides one of the most coherent and systematic ideologies to light the road for all human services:* a guide, a direction in an era of turmoil, arbitrary scientific innovation, grass roots disenfranchisement and moral bankruptcy of so many of our professions.

Normalization is a value-based set of principles. Whether or not we can say scientifically or empirically that normalization works better than other service approaches is a consequence of how we look at things through what we hold to be important, not, as some try to hold, objective "value-free" evidence or data. What arc the values that underlie normalization? All human beings are special and precious. All human beings, like all living things, change constantly and grow. Everyone has the right and need to be loved, have a family, have intimates; each person has the right to be productive, have an education, to have a comfortable dwelling and quality life-supports. These are values. We cannot prove that these work better than pitching people into institutions. That is a matter of value-based attitudes in ourselves and our culture. Normalization is therefore deeply rooted in culture and values.

Three basic rationales for normalizing services are that devalued people will be perceived and treated as: human beings, citizens, and developing, adaptive and responsive organisms.

I would like to share with you some of the historical background of normalization. Some key dates and highlights should suffice for our overview. In 1959, Denmark was the first nation which passed legislation that established a unified agency concerned with the health, education, and welfare of people with special needs, specifically based on helping them experience life as normally as possible. This attitude was explicit in the legislation which confronted basic approaches. Where there had been a permissiveness toward institutions, there would now be a policy of providing home-like living arrangements for all persons needing residential services. Where there had been a domination of the "medical model" based on seeing people as sick or diseased, dependent on health technicians for assistance, the "educational-developmental model" became the dominant approach. Where people had been perceived as subhuman they would be emulated as citizens with rights. Where segregation pervaded the public educational scene discriminating against and separating children with special needs from the mainstream, integration would be a guiding principle and objective goal of the school system in Denmark.

Nearly a decade went by before Sweden passed a similar law in 1967-68, creating an agency to unite service resources for retarded persons based on the normalization principle. Then things began to move. Wolf Wolfensberger, Frank Menolascino and a small circle of co-workers mobilized a campaign in Nebraska, spreading over 2 or 3 years to focus efforts of the movement upon establishing a sweeping law that would bring all the elements of normalization into a service system for persons labelled retarded. The upshot was the creation of an agency in 1969 called the Eastern Nebraska Community Office of Retardation (ENCOR), the first model system of regional proportions to completely embrace ideology and goals to enhance people who need help and totally reject the institution as a legitimate way to serve people with developmental handicaps in the United States. In 1972, Dr. Wolfensberger summarized the historical experience and formulated, in depth, the philosophical and practical aspects of normalization in his now renowned book (1). It is to him that we all owe a profound debt. The same year, monumental Federal law suits, class actions, were filed against human abuse in the institutions for retarded persons in Alabama (the Partlow State School) and in the Commonwealth of Massachusetts (Belohertown State-School), both for violating human and constitutional rights of residents in the institutions. The Pennsylvania ARC; then filed its landmark Federal suit against the Commonwealth of Pennsylvania for excluding children from their rightful place in public education.

In 1972, the parent-created National Institute on Mental Retardation in Toronto, the research, development and manpower training center of the Canadian Association for Mental Retardation, made a commitment to establishing a demonstration region-wide comprehensive normalizing service system in each of the provinces of Canada. The project has come to be known as ComServ: That same year, class action law suits were filed in New York State against Willowbrook State School, and in Tennessee against the use of peonage in all, institutions for mental retardation. Ten other such human rights federal-level challenges were filed. In 1973, the demand for preparing more and more people to take leadership in community-based systems brought large scale training in normalization and comprehensive services to California and Pennsylvania as a new popular hope for change evolved. Now, in 1974, you arc the first massive public organization that has stepped forward to do more than pay simple lip service to the principles of human dignity and growth and to devote major time and policy to understanding the developmental growth model as the cornerstone for your parent training and public service role.

At the heart of these events is a philosophy, an ideology which provides a clearer vision of the future. Individual growth is the first benefactor of normalization. The natural strengthening of the parent and voluntary advocacy organizations flows from our personal transformation. The impact of the voluntary associations must affect societal attitudes and values which in turn must precede the movement for more progressive laws by which our relations and services are governed. Value-based services with human rights safeguards against abuses can flourish given the social and legal nourishment and will lead to the enhancement of all generic human services upon which everyone relies. Ignoring the central role of ideology, a minority such as those affected by Down's Syndrome is placed in great danger and at the mercy of the present community of professionals and their traditional ways of "helping." Clearly, we have a great challenge to lake up over the next four or five years if we are to even begin to set a new direction.

I would like to share with you the normalization principle in simplified form. The essence of that principle requires the use of *culturally normative means and methods . . . to offer a person life conditions at least as good as the average citizen . . . and to as much as possible enhance or support his/her behavior experiences, status and reputation.* By *culturally normative means,* we speak about using those techniques, tools, media and methods that are most familiar and valued in our culture. *Life conditions* refer to global considerations including housing, income, health care, and all social resources which we have come to link with quality of life. *Behavior* means skills and competencies; *appearance* relates to clothing, grooming, demeanor, and mannerisms; *experiences* are those feelings of well-being and social adjustment of the growing person. Status and reputation, which flow from the labels,, images, interpretations and attitudes of others toward the person with special needs, are by far the most powerful and decisive factors in determining the fate of any individual in our society. How many human services take these considerations as the starting point for planning? How many professionals use the expectations and characteristics of their own values and respected lives as a starting point in establishing programs and services for others, especially when the people they are supposed to serve are held in such little esteem by tradition and culture?

Does this mean that we treat everyone the same? What of those persons whose special needs are so significant?

The guiding principle, one that requires the greatest good faith and openness, is to employ normalization *to the greatest possible degree . . . at any given time . . . for each individual according to his/her developmental needs.* We cannot make the crude generalization: Everyone who has been segregated must be thrown into open society to fend for himself. That is not normalization! Normalization is profoundly anchored in individualization. Each and every person must be treated and served as special. All services and all relations for people who are devalued must be aimed at upgrading that person's status in the society. This consideration, universally ignored in deference to clinical considerations, is the single most important, basis for the provision of caregiving, beyond any benefit of a clinical nature.

The retort—"Who wants to be normal?"—reflects how easily normalization can be misconstrued today. *Normalization does not mean being normal! It docs not mean good or bad. moral or immoral. It does not mean being or doing like everybody else. It does not mean being deprived of all choices!* If you examine each of these distortions of the normalization principle you will readily sec how widespread the misinterpretation of normalization really is for each of us. It is common for us to bring one or more of these misinterpretations unconsciously to the philosophy, and, based on this distortion, correctly reject the logic. Therefore, we must be impeccable in clarifying not only the affirmative definition, but in exposing the misinterpretation. When it is said that to "normalize," a person is to make that person "average," we must explain that normalization as a methodology says *"at least as good* as the average citizen." This means that we have a reasonably common statistically occurring *floor* below which no human being can be allowed to slip. Furthermore, we have a range of options in relation to any given situation that falls within a normative spectrum from which to choose an appropriate course. Though normalization has its roots in moral considerations and rationales, its application is empirical and statistical. Is it more normative to use a classroom setting with teachers and precision teaching to educate children with special needs or to use a cattle prod in an institutional ward? Is the correlation of physical stigmata —crossed eyes, obesity, and other deformities—more culturally normative among persons of value?

Normalization is not a concept or an approach that will be evident in all its complex manifestations, especially in the face of the tradition of rejection of differentness that grips our culture. I hope to but open the door to you where further thought and study will inevitably be needed for each of you to internalize the principles. The implications and subtleties do not allow for simplification. Ultimately, to grasp normalization, you will need to feel and live the principles, or you will be an outsider to the personal revelations that will come from the surfacing of the deeply held prejudices we each harbor—parent or not. Until we can reflectively and instinctively startle when we see breaches of normalization, we will be unable to overcome our own under development. I have been struggling with normalization for almost two years now. The more I understand the ideas and their implications, the more self-conscious I become about my own life and relations, and how profoundly crippled I am inside in my instinctive responses to people who are different and devalued.

Let us look at the roots of such response to deviancy. "Deviancy" is a social science term. Deviancy does not mean "deviateness." (Deviate relates to a person's essence, their being.) Deviancy is a concept that relates to how a person is *perceived by others.* The social science definition of deviancy is that a person becomes deviant by being different from others in one or more dimensions which arc perceived as significant by others who value this difference negatively. In our American society, many groups are considered or perceived as deviant. The mentally retarded, visually limited, physically handicapped, mentally disordered, aurally limited, sexually unorthodox, epileptics, addicts, alcoholics, the aged, the unemployed, dissidents, criminals, the delinquent and unassimilated racial, religious, or ethnic groups are among the prominent categories. Lots and lots of people in our society are negatively valued because of some significant aspect that is different from the mainstream's.

Dr. Wolfensberger (2) has put forward 10 role perceptions that come from our social history in relation to deviant individuals, especially common to the community labelled mentally retarded. Be aware of these roles, for you will see how they are mediated in our society and reflected in our service system. First and foremost, the retarded are perceived as subhuman, as animals, objects, or vegetables. Second, as unspeakable objects of "dread." Third, the retarded are seen as menaces; fourth, they are seen as objects of ridicule; fifth, as objects of pity; sixth, burdens of charity. The seventh historical role is that of eternal children. The eighth as diseased organisms, sick things, or sick persons. The ninth perception is that of the holy innocent, the opposite extreme of the "subhuman" role—the suprahuman role—nevertheless dehumanizing. What we can expect from "angels" in the factories and schools? Finally, the tenth and least common role perception is that of human being, developing person and citizen. Historically, I suggest that if we trace the advent of democracy and its progressive exercise to include not just the privileged few, but all peoples, we will find the growing expression of the last role perception at the forefront, only recently.

Three themes have been voiced by those who have traditionally been the arbiters of morality in relation to the devalued person. These entrepreneurs have touted deviants as injuring themselves in this life or the next. Deviancy is described as "catchy." If you sit close to someone that is different, you may get it. Sexual contact, a sneeze, and the like make deviancy contagious. Thirdly, deviancy is described as predatory. Deviancy will cat us up; it will eat our society up. Thus, in the service system, when a person is identified as deviant, he is put into a group of other people who are perceived as deviant. That person will imitate others who are different and will then be expected to act deviantly. This role expectation from those about us is the single most powerful determiner of behavior that we know. To break out of the role of father, brother, wife, sister, boss, joker, and the like is almost impossible when it is reinforced by those around us. Thus, the person complies with the expectations to act deviantly and is kept in the devalued group. All social ties and relationships are confined to devalued ones which entrench more and more the differentness and, naturally, how that person is perceived. The vicious cycle is in motion. It is no wonder that among the community that has been so ruthlessly segregated, those persons labelled and perceived as retarded have been locked into roles which could lead nowhere but down. Whether the segregation was warranted is not here at issue. What I want to underscore is the insight that for good or evil such role models and consequent practices result in predictable social attitudes which happen. If we are not sensitive to this phenomenon, if we do not respect this occurrence, then we are doomed to repeat service approaches that in the short and long run destroy the very people we aspire to help.

Another phenomenon has occurred because of our blindness to the dynamics of devaluing people. We have taken service workers who have tended to drift into those places where devalued people are served, who themselves may be perceived deviantly. They have often identified with devalued professional models, learned to act differently with the people they serve, have been kept in image-degrading jobs and service settings, established all their social ties with others in similar status and the result has been the creation of a massive subculture of differentness and dehumanization.

Institutions have been the most classic example of these subcultures of deviancy that have been perpetuated over the centuries. Virtually, to the present day, we have had but one solution. Due to mysticism, prejudices, underdevelopment, the lack of resources, we have incurred a heritage of systemic human abuse that is unparalleled. Children who have been perceived as different in our society have been offered *no care* or total care. The form of total care in our culture has been the large, overcrowded, dehumanizing, isolated institution. These have been separated from modern science and technology, separated from our populous communities. Within these institutions, all seven major functions in our society have been clustered: domicile, school or place of employment, recreation, place of worship, hospital, and place of detention. These spheres, if you examine your own lives, are normally highly differentiated and physically dispersed in everyday life. You do not work where you sleep. You do not receive an education where you worship, you do not recreate where you eat. Yet the institution has created a culture that has congregated all these activities under one roof, in one place. More than the cultural aspects that determine expectations of persons traditionally served in this way, there is another group of reasons why institutions are so prevalent. These reasons may upset you. They are certainly presented much too superficially in this overview. There are very concrete and material reasons why institutions thrive.

Institutions cost from $80,000 to $100,000 per bed to construct and range in size from 100 to 3,000 beds, thus providing an enormous building contract and benefits derived to the contractor therefrom. In those states where construction is financed by bonds, the large financial houses own the mortgages until they are paid off with debt service which, at a minimum, doubles the cost in every instance. Because of the natural concern for "fiscal responsibility" enforced by these banks and their representatives in government, questions of public policy regarding the abuses inherent in institutions are not central considerations as the public is locked into decades of dehumanization in keeping with the 20 to 30 years mortgages for construction. Over and above the profits and patronage within the construction contracts go the massive maintenance contracts to supply food, drugs, bedding, furniture, and the like to the institutions. The use of low paid and undertrained staff which is virtually universal in institutions results in high turnover which keeps salaries low, but more importantly, enforces an impersonality on the part of the workers who resist identification with their dependent clients who are everywhere victimized. Finally, the institutions employ highly paid bureaucrats who are usually only loyal to the bureaucracy and see community-based services as competitive to their empires. In short, the political and economic realities of institutions have had as much to do with their longevity as has the cultural heritage of dehumanization which encumbers us all. These realities make public hostages of persons who become institutionalized and the payment of public ransom for their release axiomatic, philosophy notwithstanding. Once built, if we cannot turn the institutions' mortgage-encumbered physical plants into something else to pay off the banks, as we provide enhancing, developmentally-based and normalizing service forms, then we will be exhorted to surrender a better future so the state will not lose its low-risk credit status and low-interest, tax-exempt borrowing capacity in the private money market.

Those who have instinctively understood the risks of institutionalizing their sons and daughters, those who have rejected this public "solution," have generally sought a private answer, a parallel answer for services in the community which coexisted with the institutional system. Thus, the Associations for Retarded Children opted for this coexistence. They lacked the power and the ideology of normalization to demand that the staggering public resources poured into institutions be rerouted *in toto,* and failed to call for the end to institutions. A tragic example in my own state of New York shows how parallel services were mounted by the state ARC over the years, building to a budget just under $10 million. Meanwhile, the state's mental retardation budget soared to $351 million. Simultaneously with the growth of the ARC, the state built 25 warehouses for the retarded where 25,000 persons languish. In fact, the entire department's budget for mental hygiene, for the most part used in institutional settings, has reached the billion dollar mark, while the voluntary associations are preoccupied with their less than token pay-off from the state. They have cashed in their independence and morality and forsaken organizing people in meaningful ways or even demanding accountability from the monolithic public bureaucracy.

The institutional system has therefore become the single most important contradiction in forestalling the change in public attitudes and practices in providing developmental services to people. The institutions are grave obstacles materially and ideologically, incompatible with everything we have learned scientifically, educationally, socially, economically, and morally.

Another example should suffice to make the point indelible. In Nebraska, there is a single state institution for persons labelled retarded, Beatrice State Home. Beatrice serves 1,200 citizens. The budget for Beatrice is $15 million dollars. In addition, a satellite building program is slated over the next seven years to erect bungalows around the remote institution to "normalize" living there. The cost: $7 million. The total: $22 million. ENCOR, the community-based, comprehensive service system has an annual budget of $4 million serving 2,700 people, including persons of all ages, whose disabilities are as complex and significant as any person's left in the institution. It we look at the rate of growth of the institutional budget as compared to the community services budget, we can predict a public backlash against such expenditures, as the institution gobbles up, like a wild cancer, the vital, limited resources of the state.

New York and Nebraska, poles apart in size, poles apart in coming to grips with normalization, arc both usurped by institutions. For institutions, like every other approach to human service, owe their existence to ideology, social values, and beliefs. Their origins lie among the beliefs that the retarded needed to be put away, far away. They could not be "cured." They could not learn. They menaced society. And science obliged by producing the necessary evidence to corroborate the prevailing social values and beliefs. All this by virtue of a label.

We know that this institutional system violates families, clients, and workers alike. It undermines all other human services and diminishes society. As long as we have a place for the child or adult whose special needs challenge the school system, or the paucity of dignified jobs for people who are dependent in some area of their functioning, institutions will be an easy out.

Therefore, unless we are able to combat the old myths, we will be stuck with out-modcd models of the past. We need a modern, intelligible, publicly acceptable and moral ideology. *No clinical solutions will work, no new technology, no new method will do the job for us!* It will require an approach to human services that people on the street will be able to understand, identify with and internalize to make our clinical advances workable.

By clinical solutions, I would pose such questions as: Will an operation or particular medicine change the situation for a devalued person? Will either segregated or integrated schools as such alter how people are seen? Will group homes or foster homes or community-based services, behavior modification, special education alter society's treatment of differentness? No, these arc all tactical questions. Yet, they are posed for us time and time again as the "answer" to our search. I am saying emphatically that if *the ideology behind the technology is unworkable, the technology will not work!*

The best teachers fail. The best doctors and health workers fail. The best therapists fail. The best administrators fail. The best plans and programs fail. Many of you have seen that. One of the best opthalmologists in Montreal was presented with an 18-month-old youngster with Down's Syndrome because the child had crossed eyes. The surgeon refused to operate! One of my dearest friends in Staten Island where I have recently been living had a three-year-old boy with Down's Syndrome who since birth had been unable to defecate independently. During the week, the infant would become more and more distended, and remained nutritionally underdeveloped. The outstanding pediatrician whom the family relied upon and who had been caring for the family's three other children told the mother "You will just have to evacuate this child every week with your finger." After two years of this regular, painful and demoralizing procedure, the mother again confronted the doctor who all this time had never looked at the child, but always at the mother. The doctor said to the mother "You are just complaining too much," and implied that Marie was not a good mother. This man was a fine physician, highly respected in the medical community.

When I first saw this boy, I recognized the classical manifestations of a condition that a second-year medical student would have identified as easily—Hirshsprungs Disease, a condition where the lower bowel lacks nerve endings in the muscle wall of the colon and cannot squeeze the digested waste along and out. The solution was simply to surgically remove the short part of the bowel that, was defective and -the child was as good as new. Yet, for three years, both the mother and child had lived in misery because of this physician's ideology, not his technology!

These are questions of method or technology:

What program do we develop for kids with low IQs?
Can we help children with Down's Syndrome?
Are community-based services better than institutions?
How do we train teachers to work with the disabled?
What curriculum is best?

These arc questions of value:

What quality of life can we build?
How can we enhance a person in every way?
What is full citizenship?
How can we insure each person democratic power?
How can human services normalize and enrich life?
How can we integrate and nourish all citizens with special needs in our society?

We have to be able to tell the difference. We must make the value-based questions the foundation of our organizations. For if we do not have the values and goals, then we will heroine the slaves of technology and of the technicians, who arc for the most part paid by the old way, through the institutional system and the bureaucracy.

Only you, as an organization and as individuals, in this entire nation stand between the abuses and insensitivities heaped upon citizens with Down's Syndrome and the advent of social progress.

In closing this first part of the presentation, let me say that normalization, though I am fervent about the concept, is not a panacea to solve all of our problems. I'm sure all of you sense that. But it does carry a profound power to bring about change. We have but to look carefully at those persons who scoff at normalization, who distort it, who are all too ready to oversimplify, to deny its practicality, to deny its applications.

If we look at those persons who resist to the end, we either will find persons who have endured and .suffered too long and can no longer adapt to change, or persons with material conflict of interest. It is from the detractors that we best can sense the power of normalization. True change never comes without true sacrifice and often great pain.

THEORY INTO PRACTICE

In the first part of this presentation of normalization, we took a look at its theoretical or philosophical underpinnings. The emphasis was on appreciating how profoundly important ideology and values are in determining the implementation of human services. Traditional human service models have invariably interpreted the people served as less than human. This image has both grown from expectations of citizens labelled retarded and other devalued people who have had to "fit in" to dehumanizing services.

In this second part of the presentation, let us review how services and society see, interpret, and care for devalued citizens and how the application of normalization can affect this. Unfortunately, we must cover much too much in too short a time. I urge you all to take responsibility for continuing to study on your own. Understanding normalization is a continuous process, and like ridding oneself of intolerance, it must be refreshed continuously to prevent old attitudes and unconscious prejudices from creeping back in to obscure our aspirations for the present and the future. Certainly the most elegant and thorough analysis of the application of normalization to practice is to be found in Program Analysis of Service Systems by Wolfensberger and Glenn (3), which is a systematic evaluation scheme that breaks services down into 48 areas that relate to quality of care.

If we were to boil down the highlights of implementing a developmental social model of services—a normalizing model—it would have at least seven major areas:

A. Aspects of the physical settings or place
B. Image, interpretations, labels (devaluing vs. enhancing)
C. Age appropriate continuum
D. Integration
E. Dignity of risk and program intensity
F. Future systems—comprehensive, continuous, normalizing services
G. Voluntary associations and their role

A. Aspects of Physical Setting

Where have we located our human services for people who by society's standards have little or negative value? Far away. Away from our community, away from family, away from resources, away from sight and mind. Institution after institution has been built in a former corn field. Where we place a service tells a lot about how we value the people served.

What considerations have been made for ease of access to and from our services? Have we considered bus routes, freeways, auto convenience, parking, in relation to speed and comfort? All too often access is a barrier to client, family, workers and/or ordinary citizens coming and going.

How large is a service, how many people are congregated in one place? We have traditionally piled up our devalued citizens in numbers, a system which in and of itself stigmatizes in our culture. Our state residential and treatment institutions have ranged between 100 and 6000 people. People have been lumped together because they shared a common label: the retarded, aged, mentally ill. Even now, we congregate 12-30 people in group homes, knowing full well there is no normative models in our culture where that many *valued* people share a dwelling. Over and above just the image barrier of putting a lot of people in one place, a strain is usually put on local resources called on to absorb unnaturally congregated children or adults. Can the restaurants, movies, stores, recreation settings absorb a large population of people who may look or act different? Thus, normalization mandates bringing the size of services down and dispersing services—especially residences—to reduce and eliminate the stigma that excess congregation brings.

How harmonious is a service setting with its surroundings? Is the service—whether it is residential, school, work, play, coordinative—plated where such settings are usually found? Are homes where people live, work places in industrial or business areas where people work and the like? By ignoring the inappropriatcness of placing a dwelling or school in an industrial park, or a workshop in a school building or church, one denies the dissonance that people experience faced with such incongruities. Expectations differ from type of setting to type of setting. Human relations and functional community resources vary in residential, or business, or industrial areas. All too often, experience, a donation, cheapness, community rejection, conflict of interest have been decisive in determining where we have established our services for devalued citizens. It is time that we recognize how such shortsightedness has cruelly undone our service efforts.

What range of resources exists immediately about a service? Arc there banks, libraries, parks, theaters, stores, restaurants, laundries, barber or beauty shops, markets, bars, post offices in the vicinity? Are these not basic "media" for a program of social integration and habilitation? Traditionally, in keeping with our heritage of segregation, normative resources have been absent. Today, though plans are made to relocate service projects back into society, human service managers are still not locating services in the center of things—undoubtedly an unconscious carry-over from our dark past.

Are settings comfortable by everyday-evcrybody basic standards? Is there good light, sunshine, temperature and noise level control, space, definition in the setting to accommodate different kinds of grouping and activity, furniture which is inviting, food which is nourishing and appetizing in appearance? Are, we thoroughly apt to overlook comfort or provide a low common denominator, considerations based upon the attitude that, "comfort is not important nor appreciated by *them"?* Or, "they" get along quite well with a lot less than we do and don't mind a bit.

What attention has been paid to beauty, environmental decor and aesthetic sensibilities? How do you make a living or working place beautiful? What place do plants, art, arrangement, color, architecture have in the lives of people who are negatively labelled and expected to be impervious to or unaware of their surroundings. It is shameful that questions such as comfort and beauty must be raised, but across the entire human service system, the devalued have been deprived of such elementary conditions and then blamed for tolerating barrenness and monotony.

These aspects of the place are important as ways of communicating how we value people. More than words or plans, the structures we use clearly sum up our expectations toward those who rely on us for help. These arc physical *preconditions* that must be scrupulously designed in our movement to reinterpret the rejected and pitied, the eternal child, and return the victimized to society and real citizenship.

B. Images, Interpretations, Labels

More complex is the second large area of practical concern to normalization. The most abstract, the most elusive, the most entangled of our prejudices focus on image and interpretation of people with special needs. Let one slogan be repeated over and over until it completely guides all our thought and actions. Johnny Mercer said it loud and dear in his old song *Accentuate the. Positive—Eliminate the Negative.* Were we to have the power to measure every service by this guideline, we would demand a total about-face and launch into a new area of care-giving.

How do we employ "accentuate the positive" in our language? Ladies and gentlemen, here is such a transparent window to our own feelings and convictions. For ourselves, for the valued, words are: we, us, our, I, normal, whole, good, majority, parents, professionals, smart, adjusted, peers, friends. Listen to each other carefully, for when we speak of persons who lack value, we say: they, them, their, those, retarded, different, minority, client, patient, bad one, handicapped, my mongoloid, our brain-injured, C.P., L.P., E.D. . . . . son or daughter.

Ridding ourselves of these tainted, apologetic, dehumanizing, stigmatizing words and the innuendo that goes with them is rough even when you are aware and try. It takes extra words to positively describe a child with special needs. It is awkward and slows down talk, but it is worth every drop of discomfort and conflict to really *identify with* the strengths of people who are different, and whom society has robbed of humanity.

Look at the labels we put on our services: hope workshop, where there is no hope; New Opportunities Center, where people are one step away from the institution; Garden of Optimism; Home of the Angels; Guiding Hands Home; Rescue Mission; Convalescent Hospital—on and on in keeping with historical role perceptions of holy innocents, diseased objects and the like. Spastic Children's Foundations where *adults* are served in equal numbers imposes the eternal child interpretation. Workshop or Occupational Training Center, Goodwill Industry—such titles never applied in a typical industry.

What should be the purpose of names and labels if it is not to enhance, to dignify, to normalize people's images and expectations? How paralyzed are we by pity, charity, apology, defeatism, that we inadvertently advertise *our* attitudes when we name our traditional programs? Even the label *group home* is a signal of deviancy here. How do we label or refer to our own homes?

The elderly suffer grievously by such settings labelled Sunshine Haven, Placid Lakes Home, Golden Hopes, Tranquil Acres, euphemism[illegible]ked with the imminence of death, disability, inactivity—in short,stigma

An image, whether it be good or bad, transfers. This phenomenon, though readily understood, is remarkably denied in actual practice. If a highly valued person associates with one who is devalued, a positive gradient occurs and an aura of the valued person transfers to the less valued. This is the rationale of traditionally associating glamorous people with less than glamorous causes. Likewise, negative images transfer as readily. Placing a symbol, person, or thing that has a strong negative image near a devalued person compounds the image injury. We do this everyday in our human services: funeral flowers donated daily to a senior citizens' residence, children in the institution playing on a coffin box or in a sewer pipe at a segregated playground, street signs by institutions—"Dead End," "Sewerage Process Area," and "Animal Control Center"—are common scenes. Barbed wire or chain link fences around human service settings, garbage and refuse juxtaposed to a facility, all say these low-valued or ominous things and people all naturally belong together.

By far the most damaging deviant image comes from charity. Charity says people do not have rights like everybody else. They do not deserve or cannot get social benefits and privileges of first-class citizenship. It says the dependent must survive on a second tax. Charity has undermined the establishment of a single high quality, rightfully based, human service system. It has divided volunteer associations by competition for monies and cast an image on those who rely on charity as pitiable, helpless, and submissive. Though eliminating charity and pity-image fund raising is a terribly difficult step forward, it must ultimately be taken and be placed on our agenda of critical normalization goals. We can start now to educate ourselves and the public to a different way of thinking once we believe people with mental retardation and all others with devaluating labels are real people, like us!

The history of our service settings often brings indelible insult to the image of those served. When tuberculosis was finally treated and cured, citizens with mental retardation inherited the evacuated sanatoriums. When the drug addiction centers moved from detention to community maintenance, the retarded were again the beneficiaries of the image-tainted buildings. Bankrupt, overbuilt nursing homes and institutions for the mentally disordered have become depositories for the least powerful and most heavily stigmatized social minority. This thoughtless trend to use the cast-off, the evacuated places soaked with a previous misery and dehumanizing history, is to be universally found and represents a public betrayal in human services.

There are other major ways in which we have ignored how people are interpreted and perceived by others. We simply have relied on "clinical" solutions and closed our eyes to social considerations that have determined the clinical outcomes to a large extent. We have consistently clustered devalued groups with different labels in one place or area—erecting pockets of deviancy, ghettos of the disabled, in our communities that degrade everyone within. For example, building settings for the mentally disordered, retarded, delinquent, ill, aged are clustered all in one place. Zoning has been a real factor in this phenomenon, but then our notions of devalued people have been coupled with congregating people in such unnaturally large groups that no typical community in its right mind would want these "institutions" in their midst. *Normalization demands' smallness, dispersal, and high degree of relevance of a service to the special needs for growth and development of persons served in each setting.*

We have consistently placed our services next to cemeteries, mortuaries, places for the sick, dying, and hopeless. The elderly are invariably within eyeshot of where they are destined to die. The expectations are fixed in everyone's mind and services are molded, virtually becoming self-fulfilling prophecies of doom.

The most common breach of our concern for enhancing the image of people with special needs has been the labelling associated with sources of administration, coordination or regulation. When a person receives aid to the totally disabled funds, rather than unemployment compensation, what image and interpretation are raised?

C. *Age Appropriate Continuum*

If there is a single basis upon, which people are identified across culture, it is on their age. Every culture, every society has evolved a whole range of age-specific, age-identifying relations and settings. Almost everything we do considers how old we are. One of the eeriest cultural experiences that we all have is when we encounter a situation where there is a disregard for a person's age that usually denies growth. Horror movies often use this device to heighten ominousness and discomfort. There are at least 6 major areas upon which age continua can be identified. Normalization demands ruthless respect for age appropriateness in each and all of these areas.

1. Is the *decor and appointment* of a setting age-appropriate? Are toys and mural cartoons about where adults reside and work, that create a dissonance? Is an adult service placed in a setting usually reserved for children, propagating the image of "eternal child?"

2. Are *possessions* of a person age-appropriate and age-enhancing?

3. Are the *daily activities* age-appropriate? Are midday naps confined to the below four-year-old age group? Are full school-day or workday schedules operating for the proper age group? Arc the *rhythms of the day week, month, and year* age-appropriate: vacations, holidays, seasonal considerations experienced along an age continuum? Are the *daily and weekly routines,* lunch breaks, learning or working, or recreation operations and the like organized with respect to age?

4. Arc the *rights of each person* based on an age-appropriate continuum: the right to privacy; the right to movement; the right to privileged communication; the right to socializing, drink, smoking; the right to health care; the right to property and possessions which increase with age; the light to education, work, leisure; the right to choose with whom one lives; legal rights—equal protection, due process, etc.; political rights which include more than just voting, but the right to dissent?

We have entered an era of incredible expansion of consciousness of what is rightful, human, dignifying, democratic. This is a new experience for many of us who have never really thought about these things. This new awareness, these discoveries are startling and often painful to come to grips with for ourselves, let alone for those who have been seen as less than citizens, less than human, without rights. Many of our rights exist on an age continuum in our culture.

5. *Sexuality* is probably the most controversial area that has been a stumbling point for all of us who fancy ourselves to know what is right for our children and society. We have feared the myth that the retarded are more promiscuous than everyone else—not true. We have feared *our* own sexuality more than anything. We cannot unravel these very complicated questions here, but the point that must be made is that, in our culture, sexuality exists on a very clear continuum based on a person's age. If we arc to be true to defending the image and enhancing the status of our sons and daughters with special needs, we must struggle to keep the relations between the sexes on the continuum from childhood through the mature years. Normalization is not a call for abandonment to carelessness or a trip to a bordello. Normalization requires the same delicate and loving considerations we expect in our

own lives to be extended to the lives of people who may be more interdependent than is typical. Moreover, we must be on the lookout for dehumanizing sex-tracking for our constituency. Are girls tracked into., limited roles in schools, work, recreation? Arc we continuing traditional sex-role differences among those people whose lives we powerfully dominate and control?

6. Possibly the most obvious area that is *a powerful interpreter of age is appearance.* Clothing, accessories, mannerisms, demeanor are sensitively perceived along age lines. Hairdos, jewelry, cosmetics, colors and complexities of dress are highly associated with age. Nothing is more uncomfortable to our sense of appropriateness than to see an adult decked out as a child. When any of these six considerations is violated, a dehumanizing cycle evolves: A handicapped adult is seen and treated as a child. He/she responds as a child. He/she sees self as a child, and is seen and treated by others as a child which continues the cycle.

Concretely, some examples of the most common violations of normalization principles with regard to respecting a person's age include:*

—the use of the "poster child" to symbolize mental retardation or other disability;

—the use of child-related names of action groups where adults are involved;

—referring to handicapped adults as "boys," "girls," "kids";

—neglecting to call handicapped persons by their full names when appropriate, such as "Mary," when "Mrs. Smith" says a lot about our perception or interpretation;

—taking adults to workshops in vehicles marked "school bus";

—teaching or conducting child-like forms of recreation;

—claiming that handicapped adults prefer to associate with children because they have more in common with them;

—dressing handicapped adults in styles appropriate to a younger age.

These are but a few of the practices that dominate our present service system. Further, in this area of age considerations, there are four

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• Many of these lists were developed from training aids by Dr. Wolf Wolfensberger **at the** Training Institute for Human Service Planning, Leadership and Change Agency, Syracuse University.

major drawbacks in grouping people with special needs of widely differing ages.

1. Handicapped children imitate older handicapped models rather than non-handicapped peers.
2. The image of child or adolescent is transferred to the older handicapped person.
3. Staff, which is oriented to one age group that dominates programming, will never be able to adjust with quality in other age group needs.
4. The public's image of the "helplessness" of the aged is transferred to younger handicapped people.

Thus, unlike any other ideology, normalization concretizes the issue of how important respecting and enhancing a person's age must be in all of our social and service relations and interpretations. This is all the more critical in dealings with people who already experience such status injuries due to their differentness.

D. Integration

Like the issue of age respect, the issue of integration stands at the heart of normalizing our service and community relations.

What is integration? Being a part of things, rather than being exus crystalize the empirical rationales for integrating our dependent citizens.

1. Real integration is invariably associated with a much greater variety of experiences, access to valued peer models, and a greater likelihood of expectations of a normalizing kind. These add up to *more, learning experiences.* This has been documented over and over again in our everyday experience.
2. Integration is linked with a greater likelihood that services will be truly based on human and civil rights and be of good quality.
3. The opportunity to exercise more autonomy, choices, citizenship benefits, and freedoms exists in integrated situations.
4. There arc more opportunities to meet a wide variety of people and form mutually satisfying relationships.
5. There is a clear transfer of image from valued to devalued persons in integrated settings.
6. People respond positively to normative behavior, and this behavior is more likely to occur in integrated settings of a normative kind.
7. One's self-image is greatly strengthened.
8. The likelihood of contributing to society is greater.

These are compelling rationales that no segregationist can compete with. They are founded not only in the values of social justice, but in fact. They apply both to the workers in the field who arc victims of segregation and to the handicapped.

Nevertheless, the resistance is deep and old. It must be made clear that integration *does not* mean:

—being forced into impossible competition;
—being denied special services;
—mixing persons with different types of handicaps;
—merely using services already in existence;
—combining agencies.

Why should we go backward in our approach to providing a decent life for people with special needs? Why should we tolerate the practices of those who would strip us of all the benefit and advances, the support system, and the individualized attention, by equating integration with "dumping" and denying the specialness of every person? Integration is a call to insure each and every person a special, valued place in life and society, not mediocrity and conformity to the present level of bureaucratized schooling, health care and work, known as the mainstream. Yet, as advocates of individualization in all human services, we have been too ready to surrender our progressive role in upgrading all society and accepted an outsider's status, used outside solutions and felt like outsiders. By retiring from alliances with the mainstream families, not asserting *every* child is special, we have remained a special interest minority. The mainstream has suffered by our withdrawal to separate services for our sons and daughters. *Integration must come to grips with quality and safeguards against abuse for everyone or it is not integration!*

E. Dignity of Risk and Program Intensity

The dignity of risk is a concept that comes directly from grasping the fact that human beings constantly grow and constantly change. This implies being continuously at the forefront of new and unknown experiences. The risk of failure is always present, yet if this risk is denied, the reality of how we grow and learn is also denied.

When we arrange a service or program to exclude physical and social risk, it tells how we see a person. We make a compelling judgment about people's humanity and future. It tells others what we expect. It over-emphasizes the traditional concerns to protect, comfort, keep safe, take care of, and watch over people seen as being less than you and I.

Normative protection is one thing—protection that occurs for most of society. *Over-protection* is another matter. We have built walls, fences, doors, used restraints, drugs and rules where they would not be tolerated in open society. We have diminished educational programs, jobs, social and sexual relations to remove most or all of the risk and in so doing, we deny a person's dignity by saying this person cannot be allowed to err or, for that matter, strive. Normalization requires that *risk be programmed in* to insure humanity is preserved and people will be raised to be part of this real world with all its dangers, cruelty, and discovery.

Above and beyond eliminating overprotection, normalization demands *maximal intensity* in human services—maximal challenge in our developmental programs. This is vital for the young age group, such that the consequences of idleness and low expectations which have prevailed in our services do not result in more generations of truly injured people, retarded by our training and service inadequacy. How many people have we inadvertently crippled by setting limits on what we thought they could do? Life is adaptive; it responds to challenges. If these are limited, the outcomes will be limited.

Growth occurs in a rational developmental sequence. Do we destroy our one-year-olds because they are midgets? Yet we will surrender hope of walking or speech or productivity in people when they are just delayed and need more time and support. All too often, I have heard my professional colleagues say a parent "is not facing reality," "is expecting too much," "must accept his or her child's limitations." Well, why not expect everything and work toward that? Let the child set limits—not us! Our job is to throw in everything that we know and constantly dream up new ways to open the doors and windows of development to every child and adult.

F. Future Systems

There remains the issue of the future to touch upon in our swift overview of how the theory and principles of normalization are applied in practice. We live whole lives, complexly textured in a way that has yet not been matched by our human services. We have slowly come to face the awful fragmentation that characterizes these health, education, and welfare services. There is bureaucracy, duplication, with gaps everywhere. We cannot convey a *feeling* of "living unity" and well-being to a person whose life depends on supports and nourishment from outside his/her family, given the nature of our human services. We have anarchy and chaos now. Normalization cannot work as an island refuge where an ocean of dehumanization stretches in every direction. Thus, we must come to grips with the system in its entirety—first on a regional basis, for here there is the building block for the establishment of comprehensive continuous normalizing systems of services. Beginning at the regional level, serving a population between 200,000 and one million, we can truly meet a wide variety of human needs—prevent the experience of fragmentation by people served, respond to needs in ways that enhance human dignity and status, and maximize economy and effective use of resources.

Such systems are only to be found in a scant few places. Nebraska is the only place in the United States that has constructed such a system based on normalization. The people to run them are yet to be trained. The people to monitor them, people like yourselves, self-conscious citizens, have yet to be organized and educated. I am talking about our movement, which will need, to carve out a different future.

Normalization demands comprehensiveness in practice and dimen-
with the family home, foster, adoptive, boarding homes, group homes,
sions—not a residential component, but a system of residences beginning

apartments—in short, an entire spectrum of community living arrangements to serve all ages and age appropriate behavior levels, to address progress, integration and independence appropriate to a person's age and competencies. The components are limited by our imaginations.

We must provide not just a "sheltered" workshop, but the entire spectrum of training settings from segregated, supervised work to independent work to insure *movement* through the system as growth and skills inevitably occur.

Normalization requires not a segregated preschool or regular school setting, but a continuum of highly demanding, progressively integrated developmental settings to individualize each child's needs and emphasize the most powerful teaching-learning relation—peer modeling. I never could understand the logic of working to get a child to talk in a setting where other children didn't talk and relying on a speech technician as opposed to having the child with delayed speech among other childien who talk!

These, what I call *hard services,* services that build and maintain life skills, are needed first; then we should include the "soft services" and support systems: administration, fiscal services, staff development, research, public relations and education, transportation, family guidance and support, counseling, recreation, and citizen advocacy.

We have suffered with a domination of soft services and "soft" professionals that would drive anyone crazy—counseling and referral—until a circular grove, 10 miles deep, has been trudged by most families. Where are the hard services? Where has our emphasis been? The consequence is underdevelopment and defeatism.

If we want normalization, we had better roll up our sleeves and put our heaviest boots on and collectively flex our muscles because we must reach higher than society has ever reached before. We are in a new place in history, science, and technology. With these new conditions, we must have an equally powerful action ideology at the forefront of our movement.

I am convinced, if we are clear about our goals and stick to them, that we will certainly overcome the difficulties ahead. What are the service outcomes toward which we aspire?

1. Prevent institutionalization.
2. Return people from institutions.
3. Prevent emotional breakdowns.
4. Avert family destruction.
5. Dispel loneliness.
6. Preserve health.
7. Insure social participation.

8. Provide proper treatment and helps.
9. Habilitate people.
10. Save money
11. Save and enhance workers in human services.
12. Render justice.

Is this not what our service systems must achieve? This is the direction in which normalization moves.

G. Voluntary Associations

I know many of you harbor great fears and apprehensions. I do. There is good reason, for our historical experience, our political and social experience, has been one of underdevelopment and injury related to people with Down's Syndrome. Yet there are grave dangers in just defending one's self and not taking the offensive toward social change. We live in a dynamic society. The forces for euthanasia, segregation, institutionalization have had great traditional influence. We are still kicked about by the expert who knows best, where bureaucracy is king. If we do not become active, if we just defend what little there is that we hold onto, we will never rise to meet the challenge of social progress and innovation, or know the unlimited potential for solving problems inherent among us as people.

As a voluntary association, beginning on your struggle, learn from the errors of other efforts of the past that have bogged down or sold out.

Our role is not to compete with the public sector but to secure the proper quality of life which is rightfully ours as citizens. Our role is to *organize:* to change public attitudes, monitor human services, take legislative action, litigate against abuse, build liaison with generic services, obtain unmet needs and services, trailblaze, volunteer within services, promote development of workers in human services, engender applied research and those special jobs for task force groups that are always needed In short, we must become a force for social change in harmony with our status as a national minority at high risk.

Normalization provides a line beginning point. Let us get on with it! Together!

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