IMPROVING THE QUALITY OF LIFE:

A SYMPOSIUM ON NORMALIZATION AND INTEGRATION

IMPROVING THE QUALITY OF LIFE

Hosted by the
NARC Research
and Demonstration Institute on
behalf of the International
League of Societies for the
Mentally Handicapped

The National Association for Retarded Citizens wishes to express its deep appreciation to the Special Center. Rehabilitation Services Administration, U.S. Department of Health. Education, and Welfare which, in cooperation with the Research and Training Center in Mental Retardation of Texas Tech University, provided funding for the Symposium and this publication.

The document contains the collective views of an international group of experts, and represents the policies and philosophies of the International League of Societies for the Mentally Handicapped.

Symposium on Normalization
and Integration:
Improving the Quality of Life
Airlie House, Airlie, Virginia,
USA
August 17-20, 1976

1977

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AN OVERVIEW

Twenty-five years ago, few would have dreamed that leaders from across the world would meet to assess the *quality of life* of mentally retarded persons. Fewer still would have seen any connection between this subject and the word, "normalization." Almost none would have possessed even a glimmer of an idea that such living might depend on a handicapped person's degree of "integration" in his or her own culture and society.

Airlie House was a perfect setting for such a symposium. The meeting room with its large rectangular configuration of tables made it possible to face and address any one of the thirty-four participants* at any moment. The remarkably beautiful hills, woodlands, meadows and lakes — compressed into walking distance — provided an excellent atmosphere for being alone to ponder the issues or reflect about them with another participant. Airlie's isolation (45 miles west of Washington, D.C.) made it possible to tend full-time to the business of the conference. Even the quiet rural nights (the grounds were patrolled by a flock of geese) allowed one to rest well and prepare for the next day's discussions.

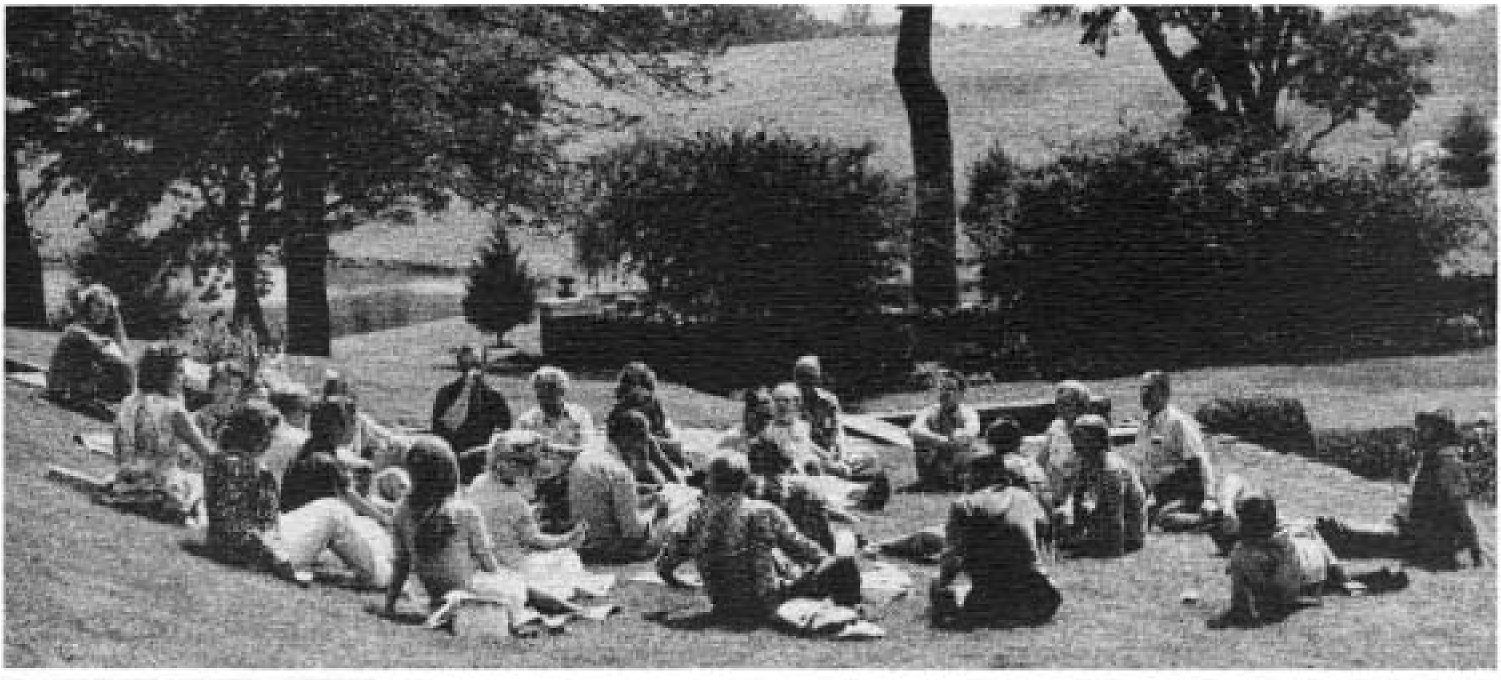
The symposium was divided into seven distinct sessions, each based on a paper written by a selected international expert** (see table of contents).

Each subject was dealt with according to the following plan:

- The working papers were distributed in advance to give the participants an opportunity to read them prior to the sessions.
- Ten minutes were allotted to the presenter at the beginning of a session to summarize or add information.
- One discussion leader and two recorders were appointed for each session from among the participants.
- During the evening hours, the discussion leader, recorders and presenter met and drafted a report of the session discussion.
- This report was then distributed the following day and reviewed and discussed by the larger assembly.
- On several evenings, films related to the symposium theme were shown.

The discussion periods were spirited. People spoke from a remarkably wide range of backgrounds. Industrialized nations communicated with developing and beginning countries. Those with different political views often found common agreements when they focused on a specific human situation of a handicapped person. To be sure, opposing views were expressed. Those moments often provided the richest opportunities for learning. It has been said that the greatest advances take place not from contemplating our likenesses, but from the respectful handling of our differences. This symposium tended to validate that belief.

Robert Perske
Symposium Editor



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*See Appendix A for participants' roster.

**The working papers can be obtained by writing the National Association for Retarded Citizens, P. O. Box 6109, Arlington, Texas 76011, USA.

NORMALIZATION AND INTEGRATION: BASIC CONCEPTS*

The remarkable thing about the normalization principle is that it can benefit both the retarded person and society: *First, normalization means making available to all mentally-retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of their society.*

Second, normalization means giving society a chance to know and respect mentally retarded persons in everyday life and to diminish the fears and myths that once caused society to segregate them.

In one case, a retarded person has a chance to be more fully human. In the other, society has a chance to be more fully humane. In both cases it's easy to see how the principle of normalization will inevitably lead to the principle of integration.

Normalization

During its development, the normalization principle has given rise to perspectives which focus new light on the human situations of mentally retarded persons. These fresh viewpoints have energized new efforts on the retarded person's behalf, diminished destructive myths about them, and have begun to enhance their quality of life. The following are a few of the elements of normalization:

- *A normal rhythm of the day.* Retarded persons get out of bed and get dressed when others ordinarily do. They eat their meals at normal times, in a family-like atmosphere which contains the usual relaxation, harmony, satisfaction, communion and commotion. Normalization means that these people experience all that people experience through the course of a day.
- *A normal rhythm of the week.* All the activities of living in a home, attending a school or going to work, having days off and leisure time, follow a normal weekly pattern. These activities also take place at a variety of locations throughout a community.
- *A normal rhythm of the year.* Disabled people, like anyone else, break away from the regular routines to observe holidays, seasonal activities, vacations, and special family celebrations. Normalization should also include involvement in life's normal events such as visiting a sick friend or relative, or attending a funeral.
- *Normal experiences of the life cycle.* Each of the various stages of life calls for specific atmospheres, supports and opportunities. *Infanthood* calls for a security and nurturing that can only be carried out in small, personal, family-like settings. The *school age* should be filled with opportunities for handicapped persons to explore and gain mastery of themselves and their living, and to develop specific skills. This stage should include a quality public school education, regardless of the degree of handicap. The *adolescent stage* should be marked by generous opportunities for the individual to prepare for adult life and all its options. *Adulthood* should allow a handicapped person as much independence, mature productivity and opportunity to make decisions as possible. *Old age* should not represent a break from all familiar things. It should be possible for elderly people to continue living in the places they know. If this is not feasible, alternate living facilities should be close to where one's adult life was spent.
- *Normal respect.* The choices, wishes and desires of a retarded person should not only be considered, but respected. Normalization means paying attention to those who do not speak or who have difficulty expressing themselves. It means allowing them due consideration for their personal belongings, and the right to make their own purchases as they are able. Above all, it means giving retarded individuals the respect of others in their attempts to achieve self-determination.
- *Normal life in a heterosexual world.* The normal everyday society where boys, girls, men and women interact makes for a richer atmosphere and results in increased social learning. The days when retarded people were expected to associate with only the members of their own sex have begun to fade away. Normalization means that every individual is able to pursue and to maintain various degrees of emotional partnerships.
- *Normal economic standards.* The same economic resources we all use are necessary to enable mentally retarded persons to live as normally as possible. This includes support through social security legislation, personal pensions and child and old age allowances. In no case should financial support be seen as a reward for a handicapping condition.
- *Normal environmental standards.* If a mentally retarded person cannot or should not live any longer in his or her family home, the homes provided should be of normal size and situated in normal areas — neither more isolated nor larger than other homes in the area.

Integration

It is essential to understand the vital needs of retarded persons that can be satisfied through *integration* in the society. Integration is by no means a one-dimensional concept. At least six basic levels can be cited:

- *Physical Integration* has to do with the basic security needs which are drawn from physical settings — living in a ordinary house, attending classes in a regular school building, working in industrial or business areas, and taking an active part in regular leisure-time activities in ordinary leisure-time environments.
- *Functional Integration* means using the necessary and ordinary segments of the environment such as gyms, school yards, restaurants and public transportation along with the rest of the population.

**Based on a working paper by Bengt Nirje (Canada).*

- *Personal Integration* pertains to meeting the retarded person's need to be loved through personal interaction with parents, brothers and sisters, friends and marriage partners.
- *Social Integration* deals with the respect and esteem that the retarded person experiences in the community.
- *Societal Integration* provides the opportunities for self-fulfillment, growth and achievement as a responsible and contributing citizen.
- *Organizational Integration* focuses on the proper balance between generic* and specialized services.

Views From Participants

- There is no place in the world where mentally retarded citizens do not need the rights and rhythms as they are stated in the normalization principle.
- Integration is truly integration when detailed planning takes place and there are built-in safeguards which can structure and enhance the integration process.
- The normalization principle is a tool which came into being as a reaction to the *denormalization* that has been going on with handicapped persons.
- We are dealing with the public at large and with government officials. They, too, need to understand the simple rhythms and rights of the normalization principle.
- We do *not* normalize people. We normalize environments. Many misunderstandings stem from this single misconception.

**Generic services are the regular services that already exist in the community and are in everyday use by the general population.*

NORMALIZATION AND INTEGRATION: BEGIN AT THE BEGINNING*

Two separate discussions developed from this session title. One dealt with how developing countries *begin* services for mentally handicapped persons. The other was concerned with a mentally retarded person at the *beginning* of life.

Developing Countries Beginning Their Services

The presenter who came from a land she preferred to call "a newly starting country," began with an interesting observation. She stated that in her country integrated programs were all they had.

Here it dawned on many in the symposium that *normalization means different things to different countries.* To industrialized nations, normalization is a vehicle for counteracting the horrible denormalization of the past. Quite often in developing countries, normalization has been practiced naturally, yet now those countries face the problem of keeping it that way! Industrialization and the greater emphasis on production and speed frequently lead to discrimination and separation for retarded citizens. Some of the issues the presenter raised included: *New Beginnings* "We are beginning many things all at once. We are planning, but we are being careful. We are looking at the models from many countries, but we are selective. We are now setting the direction for our country for many years." *Community Facilities* "We must use the community facilities. We don't have our own buses. We don't have our own clinics. We must use what is already there." *Top Priority: Prenatal Care* "It should be a concern to everyone, not just public health officials, to see that:

- Prenatal services are made more useful and available to all groups, especially those in impoverished areas.
- Special attention is given to high-risk mothers.

- Genetic counseling is provided for, especially in communities with a high ratio of consanguinity, or where there is a known history of prevalent inborn defect.
- A minimum education in health nutrition and infant care can be given to women at the same time as the antenatal examinations. Incorporated into this education should be some basic facts on patterns of early infant development and signs of any differences, or delayed development . . ."

Vulnerable Children "In a study done on various systems for delivering health care, it was suggested that children most in need may be the last to receive it. The reasons could vary from physical or economic barriers to social or cultural factors, or simply poor motivation."

Recommendations From Participants

As a response to the stated issues, the following statements were made:

- ► "Newly beginning countries seeking structures for their system on a national level should be careful to involve from the very start all governmental departments to ensure that all needs of the various aspects of life of the retarded individual are met."
- "Specialization and overstructuring of services may lead to a repetition of past errors and result in segregation of the individual from the main stream of society. This arrangement is the antithesis of the principle of normalization upon which services should be built."
- "Beginning on a wider scope, as is the case in newly starting countries, means adapting a fresh outlook, avoiding preconceived ideas taken from outdated models and being careful to continue to develop and evolve."

That Precious Beginning of Life

It can now be shown that the time from the middle of gestation until beyond the second birthday is the most formative period in a human being's development. In short, a lot is happening that will never happen as readily and as rapidly as it does in this period. This single vivid fact inspired a common purpose and direction in the participants. In some sessions there may have been the usual disagreements and healthy debates, but when it came to early intervention, it was agreed that:

- Adequate prenatal care is an urgent need for every child.
- There should be a concerted, all-out attempt to support the family above everything else, and to do it as early as possible. More often than not, it is most economical and efficient to bring services into a home rather than to serve a child elsewhere.
- Waiting to intervene until the third birthday is much too late.
- There must be a *coordination of all agencies* in this early intervention period. It was further agreed that every child should have an assigned "client program coordinator,"** as well as a tailormade individual program plan.
- There should be parents of mentally retarded children who, after having coped successfully with their own child and family, are "on call" for parent-to-parent relationships with newly identified parents.

**Based on a working paper by Lena Saleh (Lebanon).*

***A single person or combination of persons coordinating the effective development and implementation of an individual program plan.*

NORMALIZATION AND INTEGRATION: SPECIAL SERVICES FOR SPECIAL NEEDS*

One theme was raised daily in the symposium sessions. It had to do with a realistic balance between *special* and *generic* services. When should special services be turned over to the regular agencies of the community? Are there some services that will always need to be specialized? No easy solution was reached. Different national situations tended to call for different balances. Nevertheless, some important ideas came forward:

- Normalization and integration must continually influence a movement from specialization *toward* generic services.
- Some representatives felt professionals in generic agencies were not as well trained and often had less commitment than their specialized colleagues.
- Others felt generic professionals needed programs to give them healthy attitudes toward retarded citizens.
- Representatives from developing countries, who utilize generic services for the most part, felt there is a very real danger in instituting too many specialized programs because they may lead to labeling and segregation.
- The public school systems in many nations have begun to develop special and integrated classes for retarded students in regular school buildings. This usually happened because of pressure from voluntary agencies. Some representatives felt that public school officials would eventually see this movement as healthy, and they would continue on their own.
- It was agreed that well-coordinated individual program planning, utilizing both specialized and generic services, is a step in the proper direction.
- One leader suggested that vocational training of handicapped persons should be controlled by ministries or departments of labor instead of by vocational rehabilitation agencies, as has happened in some countries.
- Some reported that relationships with labor unions had already been initiated. A few representatives were fearful of such relationships.

Views From Participants

- Most of our first specialized educational approaches began in small, out-of-the-way places. They took place in church buildings and small houses. Then, we often built large special buildings. Now, public schools are welcoming us, but we don't want to leave the security of the buildings we've built. When we build such fortresses we need to watch out, for they begin to control us.
- Sometimes an oversimplification of the interpretations of the normalization principle has led to the misconception that extensive use of the generic services would offer a cure for all social and political problems.
- The shift to generic services has to be gradual until each generic service has developed sufficient understanding, experience and commitment to serve mentally retarded persons.
- A child is a child first, and handicapped second. Therefore, a handicapped *child* should be included in regular *children's* services as far as possible.

**Based on a working paper by Ingeborg Thomae (West Germany).*

NORMALIZATION AND INTEGRATION: FOR THE WHOLE FAMILY*

A new type of family is emerging across the world. These items from the recorder's report say it succinctly and clearly:

Consensus: Today there seems to be less parental guilt upon discovering that their child is retarded.

Consensus: Parents are now more accepting of their child's handicap.

Consensus: The presence of a mentally retarded child does not necessarily bring harm to brothers and sisters. Siblings tend to reflect the attitude of the parents.

Consensus: Parents still experience grief upon learning their child is mentally retarded, and the intensity is the same as it always was. But now, there seems to be more understanding of the problem — perhaps through public education and parent modeling. Consequently, the duration of the intense grief seems shorter. *Consensus:* Selected parents must be trained and used to help counsel other parents.

Consensus: The first information given to parents must focus on more than the disability. The baby is a human being with positive characteristics.

Consensus: All families have problems which cause stress and may result in family disorganization.

Consensus: Strengthening parent associations is vitally important if quantity and quality of services are to be improved.

Many countries are working on viable, detailed, parent-to-parent systems.

They may be called by many different names, but they all have much in common. Parent-to-parent systems are a form of peer group education. One successful parent provides a model for another. There is an exchange of knowledge between one who has had the experience and one who has a hunger to know what lies ahead. They advocate — even become angry — when other parents and their children have been victimized or ignored.

Here are brief glimpses of parent-to-parent models that are emerging all over the world:

- One country officially recognizes special parent counselors and contact persons as paid members of each community comprehensive care system. These parents are trained and recognized as valuable team members in the existing community-based service systems.
- In other countries, hospitals or physicians select parents of mentally retarded children to join a medical team on which the parent assumes the role of a social worker or counselor with the newly identified parents.
- A formal organization of "Pilot Parents" operates in one town. The parents are selected for training sessions which include: "The Principles of Normalization," "An Orientation of Community Services," "Hints for Healthy Relationships," and "The Assignment and Reporting Process." to name a few. There is a central core of persons who receive requests for pilot parents. They make formal assignments, provide assistance and conduct a formalized continuing education program. All this is done by a volunteer organization.
- In another country, parent counselors are trained at a state-run center. Successfully trained parents are assigned to catchment areas (approximately 3,000 population each). The state pays for these services through the local parent association.
- Fathers are trying some new things. In one country, a group of fathers invites other newly identified fathers to a beer party. "We begin with each fellow telling a little about himself and his handicapped son or daughter, and we go on with our party. You can do a lot of sharing over a glass of beer."
- Fathers in another country have formed a "crisis team" which is on call for emergency assistance.

Views From Participants

- **It** was proposed that parents change more easily than anyone in their attitude toward a mentally retarded child. The hardest attitudes to change are those of the professionals. A parent from an industrial country addressing a class in the medical school (she was also a professional) found the students utterly disinterested in mental retardation. One student stated, "I'm more interested in renal tubing." A professor added, "Our students aren't interested in mental retardation." The parent-professional responded, "You mean you won't teach about a malignancy if they're not interested?"
- It was reported by at least two countries that they now pay parents — who need it — the transportation expenses incurred in visiting their child at an institution. Reaction to this practice was mixed. Some wondered if this might violate the principle of normalization, while others saw it as a fresh step toward rebuilding parent-child relationships.
- Some parents need emotional support, but some don't. All they need are straight answers.

**Based on a working paper by Victor Wahlstrom (Sweden).*


PERSKE

NORMALIZATION AND INTEGRATION: THE COMMUNITY*

A Rich Quality of Life Gets Started in a Community Integrated Preschool.

One evening, a participant showed an audio-visual production on integrated preschools located throughout a particular town.** In it, normal children were talking about relationships with their handicapped friends. One young child was asked about her friendship with a severely retarded and multiple handicapped girl.

"What's that thing behind Carrie's head? "
"That's the thing that holds her head."
"Why does she have to have that?"
"Because then her head won't do anything, but it helps her to lean back a lot."
"How would you feel if Carrie couldn't come here to school? "
"Well, then I'd go to her house."

This presentation illustrated something important: that these small children have no prejudice. The following conditions were present:

- Adult attitudes toward handicapped children were warm and respectful.
- Questions raised by normal children about their handicapped friends received straight answers (e.g., why a child can't walk, or talk, or move his arms well, or why his head has a "funny shape").
- A natural peer group education was provided for both the handicapped and the normal child.
- A resource person on the preschool staff worked with other teachers until they felt confident to carry out group and individual programs on their own.

Some persons, of course, may die still holding on to their prejudices about retarded people. But it was clear to all that prejudice is a *learned* behavior. Furthermore, if prejudice can be learned, then tolerance can be learned as well. Herein may lie one of the keys to improving the quality of life for retarded persons in the community.

Mentally Retarded Persons Face the Law

The normalization and integration principles can lead to painful human situations. This was apparent when the symposium members entered into an intense discussion about the law and the handicapped. The recorder's summarization statement speaks clearly about this hard side of things:

The consensus was that it was *not desirable to keep mentally retarded persons outside the due process of law.* However, there was a general agreement that much more should be done with regard to the following areas:

- More information about mental retardation should be given to law officers.***
- Better orientation of judges would assure a more equitable application of the legal process.
- Mentally retarded citizens should have more education regarding their legal responsibilities.
- There should be judicious allowance for different degrees of responsibility according to the capacity of the individual.
- Mental retardation should not be a basis for avoidance of the due process of law. nor for indefinite commitment to an institution.
- Often a prison sentence is preferable to indefinite commitment to an institution.

Discussions on Sex Were Brief

It is interesting to note how certain subjects which once consumed long hours of discussion time in other symposia were handled with quick dispatch. Sex was one of them. After an extremely brief discussion, the recorder's report was succinct and to the point:

"A mentally retarded person has the same right to and need for sexual relationships as has any other person.

"There was general consensus on the need for age-appropriate sex education, including birth control techniques and parenthood information.

"With regard to voluntary sterilization and abortion, the same rights apply to a mentally retarded person as to any other citizen."

Comprehensive Community Service Systems

Several participants charted the system of services that seemed to be working best in their country. These flow charts and diagrams of inter-agency relationships dramatized the fact that the time is coming for all services for mentally retarded persons to be brought together into a single system including both specialized and generic efforts. The institution should be considered as part of that larger community network as well. These comprehensive community service systems should have such characteristics as:

- Sound planning
- Regional organization
- Cost/benefit evaluation
- Preventive orientation
- Responsiveness to community changes
- An equitable distribution of services
- A full continuum of services
- Normalization as a basic principle

**Based on a working paper by Donald Crawford (South Australia).*

***" Why Be Friends. " Produced by the Eastern Nebraska Community Office of Retardation (ENCOR), Omaha, Nebraska, USA.*

****At least two countries (Canada and USA) have produced curricula for training*

Individualized Program Planning Schemes

Leaders across the world report another hopeful trend. Various types of individualized plans an beginning to emerge. It appears that — to an increasing degree — those who work with mentally retarded persons have begun to be less defensive about their own exclusive professional roles. Most remarkable of all, they are beginning to communicate with one another in simple, ordinary, understandable words! They feel less need to speak the special language of their own profession. There's a new willingness to listen to each other. The following is a description of only one of many such plans: *"The individual program plan is a written plan of intervention and action that is developed, and modified at frequent intervals, with the participation of all concerned. It specifies objectives and goals and identifies a continuum of development, outlining projected progressive steps and the developmental consequences of services. "**

Its vital components are:

- Central focus on the individual's optimal development
- A program coordinator for each individual
- Client and family input as plan base
- Specific and separate long-term and short-term goals
- Time-framed, sequential and measurable objectives
- Understandable language in behavioral terms
- Specific modes of intervention
- Specific responsibility assignment
- Evaluation of the effectiveness of interventions
- Serious consideration of barriers to achievement
- Quarterly review and revision

The Right to Give of One's Self

One representative reported a program where college students form strong small group relationships with mentally retarded persons. Together they plan and carry out volunteer service programs with persons living in homes for the elderly. The retarded person is given a chance to utilize a most important human right that has often been ignored: to give of himself or herself and to be of service to others. This is integration in the community at its richest.

**This individual plan reflects the standards of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MR-DD); 875 North Michigan Avenue; Suite 2201; Chicago, Illinois 60611, USA.*

The Residential Assumption

The presenter offered the following provocative statement in his working paper:

"Somewhere, on the path to developing our current alternatives in residential services, I stumbled upon the realization that we were approaching a 20th century concept — normalization — with a 19th century mind-set — the residential assumption.

"The residential assumption means a person is assumed to need residential services just because he or she is retarded. For years that assumption was never questioned. We grew up hearing things like, 'That Scott girl is going to be put in an institution.' 'Why?' Oh, she's retarded, you know.' It seemed like a reasonable answer. This assumption persists in spite of statistics showing that the vast majority of mentally retarded persons are not in residential systems .. .

"Another characteristic of the assumption is that having entered a residential continuum, a mentally retarded person must often remain there indefinitely. This is the basis for a number of legal actions . . . which allege that some residential systems are engaging in extra-legal incarceration with no assurance the 'prisoners' will ever get out. Unfortunately, the prevalent view in the minds of many, many parents, private citizens and fellow professionals is that mental retardation alone is sufficient justification to remove people from a most normalizing environment into an artificial one. In ten years, 1 have never been challenged by anyone wanting to know, 'Why do mentally retarded people need residential services.

Thus began a presentation describing a change in thinking about mental retardation that is taking place in some parts of the world:

Once, when a person was found to be mentally retarded, the automatic thought was, "To the institution."

Now, when a person is mentally retarded, there is an increasing tendency to think, "Support that family as much as possible, and do it early.

This is not to say that some mentally retarded persons will not have to leave their home. But more often, they will leave home for the right reasons, not merely because they have been diagnosed as mentally retarded. And when they must live elsewhere, they should stay as close to their home as possible, and for the shortest possible period of time.

There are three basic situations in which stress can be so overwhelming that a person may need to live elsewhere for a time:

- The person has a problem.
- The family has a problem.
- The community has a problem.

When that happens, it is good practice to know which problem it is that is causing the stress, and to work for a specific solution.

Without a clearly identified *raison d'etre*, a predictable cycle of conflicts develops between the service system and the family. The family is displaced. Previously agreed upon arrangements become blurred by time. Roles are confused. The family wonders why their suggestions are ignored and they become more insistent. The staff feel resentment since they cannot understand the causes of the friction; they feel like martyrs because they are performing surrogate family functions. Hence, accusations and counter-accusations:

"I *always put Jimmy to bed at 9 o'clock."*

"Why don't they take him home if they think they can do better."

"But how could you possibly lose three pairs of socks? I just bought them last month. "

Why don't they carry on with the training over the weekend when he goes home? We spend Monday and Tuesday undoing the damage they've done. " **"What do you need in order that your child can grow and develop in her or his own home?"** This is by far the most important question a helping professional can ask parents of a mentally retarded child. Parents should be encouraged to express what they really need, no more and no less. Some responses might be:

- A request for periods of relief. Some parents need to get away for a weekend to relax. All they need is a skilled baby sitter.
- A request for counseling or support. The family may be struggling with a specific weakness or misunderstanding. All they really need help for is a single problem.
- A request for in-home training. There may be the need for a teacher or therapist to come into the home and aid the parents with a special need.
- A request for short-term crisis assistance. Death, hospitalization or marriage separations may be occasions for assistance until the crisis has passed.
- A request that the child be taken out of the home due to overwhelming stress.
- A request for financial assistance if the mother would otherwise have to seek work outside the home.

Alternative Residences: Some New Directions

The participants agreed that there is a growing number of options for retarded persons who must live away from home. Although the development of alternative residential services has been healthy but slow, the following components were seen as hopeful signs:

- Fewer persons view the institution as the only alternative.
- Community group homes have taken many different shapes, but even they are not seen as the only alternative in the community.
- Service systems in some communities have developed a remarkably wide array of responsible placements in regular families within the community. The family heads are recruited, screened, intensely trained, closely supervised and salaried as they

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**Based on a working paper by Edward Skarnulis (USA).*

care for a retarded person. • Increasingly, retarded persons are not expected to fit into existing residential programs. Instead, a retarded citizen receives a program plan tailormade for his or her specific needs. Then, an alternative residence is sought that provides what the person specifically needs.

Views From Participants

- Starting now, the planning for future systems should be for mentally retarded persons to move from the natural home into the community. The system should not begin with the institution.
- Mental retardation should first and foremost be seen as a community problem. More often than not, the best solutions will be found in the community when the people are inspired to work with the problem on the local level.
- There should be no mentally retarded person who cannot live in the community.
- A true residential service system promotes rapid, easy movement toward the least restrictive, most normal setting.
- Private charity may be helpful to mentally retarded persons for a while, but everyone should be wary of depending on them for any great length of time. Often, privately run services tend to excuse the government's responsibility to deliver services which retarded persons should receive as a legal right.

NORMALIZATION AND INTEGRATION: SHIFTING EMPIRES*

Normalization has had a remarkable history as a principle guiding public policy. Its first official mention took place in 1959, when Denmark enacted a law that radically changed its residential system for mentally retarded persons. Since then, a sizable amount of empire shifting has taken place. Although none of these shifts are complete, the following trends were recognized:

- *From a Medical Monopoly to Shared Leadership.* There was a day when physicians dominated the care systems for mentally retarded persons. It first gave way to a broader base of leadership in Denmark's statute of 1959, when medical superintendents of institutions were replaced by a four-person directorate (administrator, physician, educator and social service director). Now, new types of power struggles appear. Today, a function carried out by a health department in one country will be handled by education or social services in another. According to the presenter, "What once was no-man's land has become disputed territory." The consumer advocacy groups are in a strategically favorable position to use the normalization principle to advocate for a healthy distribution of services carried out by a shared leadership.
- *From the Institution as Focal Point to a Network of Community Services.* Here we see the shifting empire in its most dramatic form. For years, industrialized nations tended to segregate mentally retarded persons into large, cumbersome units with thousands of residents and thousands of employees. The sociological principle by which a *system struggles to maintain itself* forces many institutions to attack the normalization principle. The building of comprehensive community systems requires nothing less than an all-out effort on the part of many persons and their governments. Consumer advocacy groups, aided by clear knowledge of the normalization principle, have always been a key force in bringing about this transition.
- *From Centralized Government to Decentralized Decision Making.* Normalization, rightly understood, can help a community to solve a handicapped person's need for growth and support on a local level. According to the presenter, "In this battle of shifting empires, centralized government will always feel more comfortable with large, authoritarian institutions than with decentralized, individualized, dispersed community services."
- *From a Closed, Academic, Exclusive School System to One That is Inclusive and Teaches Basic Values of Life.* Somewhere amid these shifting empires, normalization took on a comrade, "integration." At this point it shows up vividly in public education. In North American public schools, the expression often used is "mainstreaming."** This does not mean the end of special classes. Rather, it means that no one should be in a special class who, with assistance, can manage well in a regular class. It also means that special classes should be as close to regular classes in location, general programming and management as the special educational needs of the pupils will permit. Normalization has widened the breech between two different types of educators: the educational traditionalist who sees his professional responsibility to exclude from education all but those he or she deems worthy, and the educator who welcomes the professional responsibility to serve all children, no matter how handicapped or disadvantaged.
- *From Vocational Rehabilitation to Human Rehabilitation.* Rehabilitation as a structured, governmental activity started as a narrow vocational program for specific groups of "feasible candidates." *The Declaration on the Rights of Disabled Persons,* adopted by the UN General Assembly in December 1975 — which firmly embodies the normalization principle — has opened the door for the rehabilitation of all handicapped persons. The declaration sets forth that "rehabilitation is a right that shall be granted to all disabled persons without any exception whatsoever."
- *From Charity to Rights.* This slogan indicates "the passing of the benevolent despot."

Normalization amid the shifting scene enabled parents to seize power for the sake of their handicapped child. They became aware of their children's entitlements. They no longer had to beg for services. Recently, they've become aware of their right of access to information about their children. Those who safeguard professional empires know that power is built by refusing to share information, or at least by making it difficult to obtain. It has been suggested by many that parents should be given, in writing, a detailed, intelligible summary of their child's assessment. In every state in the USA parents now have the right to inspect their child's school records.

**Based on a working paper by Gunnar Dybwad (USA).*

***Mamstreaming refers to the placement of mentally retarded students with their non-retarded peers in regular public school classes. The mentally retarded students may leave these regular classes during various portions of the school day in order to receive special instruction.*

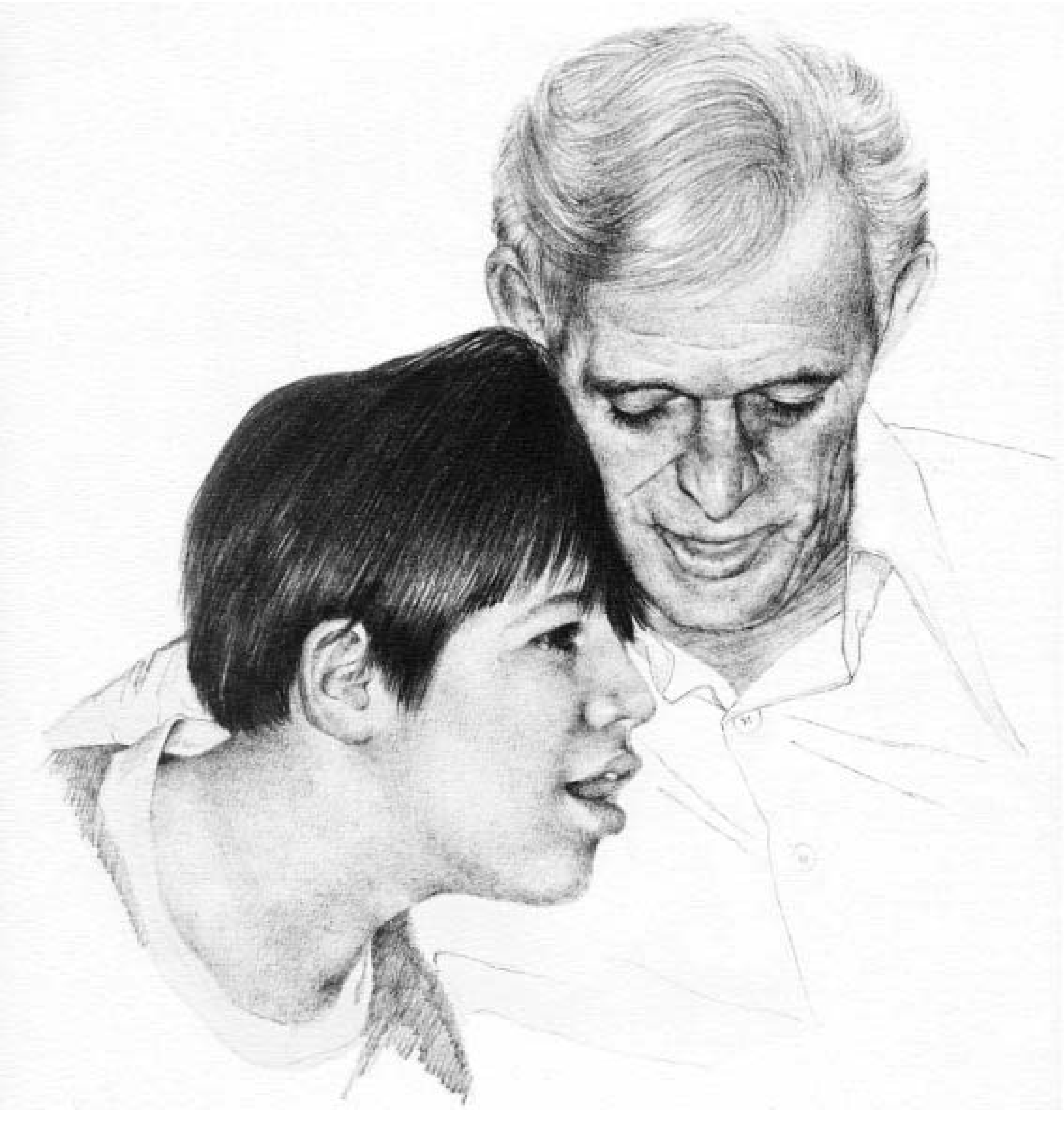

PERSKE

- *From Professions] to Shared Decision Making.* For years, parents were described as anxiety ridden, overemotional and unable to take part in deliberations that affected the future of their child. With changes being brought about by the normalization principle, the tables are being turned. Today, it is recognized that there is great value in allowing parents to participate fully in decisions involving their children. Furthermore, it is clear that the disabled person — even a child — should be allowed to decide issues independently insofar as he or she is able.
- *From Parental Control to the Recognition of the Handicapped Citizen's Rights.* As parents gain more of a voice in decision making, another problem emerges. It follows that there is a *limit* to parental power if retarded children are to have certain rights of their own. In some cases such rights will conflict with the choices of the parents. There is no precise formula as to when the parents' control should end and the child's rights begin. But questions were raised about parental power being so unquestioned and absolute that parents can arrange for the long-time institutionalization of their child when his or her quality of living could be remarkably better elsewhere.

Views From Participants

► In one country, when parents were advised that their newborn son had Down's syndrome they tried to place him in an institution immediately, but their request was denied. State law prohibited the institutionalization of infants. The infant was placed in a foster home. Later, the child attended the preschool of the local voluntary association. Finally, when the child was eligible for admission, the parents made formal application for institutionalization. This time, the local voluntary association, knowing full well the potential of this child, filed suit and stopped the institutionalization proceedings.

- When a family says "Our retarded child is ours by law, but we don't want him around," then we have a problem.
- As long as institutions are seen as solving *all* problems, there will be problems.
- Criticisms of the medical model should not be interpreted as a failure to recognize the need for good health care. Rather, opposition is being expressed to a medically controlled hierarchy and its unfortunate trappings (e.g., inappropriate utilization of medical terminology, such as "patient" in referring to persons living in institutions).
- It is often a parent's belief that because there are certain professional positions at the institution, a child is properly served by them. This isn't necessarily so. The analysis of the time each resident is given in each service he needs could be disillusioning.



Sometimes, new knowledge can cause people to do things they never did before. For example, when people believed the earth was flat, their laws and their living were conditioned by a dread fear that those who traveled too far would drop off the edge. Then a few intrepid souls dared to sail beyond those mythical limits, and returned. When the bits of new information they brought with them were pieced together, it dawned on humankind that the earth was round! This single principle inspired all kinds of people to explore new directions too numerous to mention in one book — or even a single library — and the world was better for it.

The principle of normalization has created that kind of stir among many who work with mentally retarded citizens. As fresh and imperfect as it is, people across the world have used the principle to diminish destructive myths about mentally retarded persons, to inspire a new level of human respect toward them, and to guide service delivery into more rational directions.

Many who came to the symposium at Airlie House brought with them an explorer's sense of urgency about how normalization was working in their part of the world. But time was short. As the symposium moved toward its scheduled conclusion, many felt there was more to discuss and resolve. With this in mind, the last session became a time for summation. Participants were asked to identify the new directions that were uppermost in their minds concerning normalizing environments, innovative services and areas of research. Some ideas were repeated many times, reflecting remarkable universality. The following is a composite of what they wrote:

Toward a More Normalizing Environment

It was clarified repeatedly in the symposium that *we do not* normalize people. We normalize environments. The participants gave top importance to the following suggestions for achieving the essentials of a normalized environment:

POSITIVE PUBLIC ATTITUDES

- Seeing and relating to retarded people in everyday community pursuits is the best education for the public.
- Traditional public relations programs are necessary but have minimal impact.
- Medical schools must be urged to teach about and to promulgate a healthy acceptance of retarded persons in the community.
- Students and teachers in regular public school classes should be trained very early in understanding and including retarded people in their ordinary relationships.
- Informational media should be monitored. False or prejudicial information should be objected to and corrected. Helpful and superior presentations should be praised.
- Attitude change will follow demonstrated successful integration. We cannot wait for public attitude to become accepting before initiating programs.
- Government personnel turn over rapidly. Therefore, assisting them to develop proper attitudes toward mentally retarded persons must be a continuous and long-range process.

SELF-DETERMINATION

- Mentally retarded citizens should:
  —serve on committees which develop new policies and services;
  —serve on monitoring and advocacy committees;
  —consult with groups which recommend new laws to governments;
  —participate in their own individual program planning.
- Agency and service professionals should:
  — be trained in the skills of assisting retarded persons to make responsible choices and to speak for themselves.

COMPLETE SERVICE DELIVERY IN THE COMMUNITY

- Crucial components in the early days of life are:
  —detection of mental retardation;
  —special service agency intervention;
  —family support;
  —integration of activities with other children of the same age;
  —utilization of as many generic opportunities as possible.

- Both generic and special services in the community need to be coordinated in:
  —developing individual program plans;
  —formal training courses for service personnel;
  —recreational programs, where special programs and special hours should be the last resort;
  —education, where the ideal setting is within the regular school building;
  —helping normalize home (own or foster home) environments with such family resource services as: in-home teaching and health services: relief and respite care programs; counseling support; and material aid (e.g., financial help, diaper service, appliances and transportation);
  —giving support to siblings, with such programs as special conferences, group counseling where needed, special training, and even structured camping experiences with the handicapped brother or sister.
- Residences of every type and level of independence, dispersed about the community, should be developed to fit the actual needs and potential of each individual.
- Vocational training programs need to be located in the industrial sectors of the community. To the greatest extent possible, such programs should be placed within regular industries and service trades and other employment opportunities such as in agriculture.


PERSKE

- Monitoring teams must be developed at the community level. They should include parents and advocates. The team should pay attention to the individual program plan and to what services are delivered and how well. The team should also monitor the human and legal rights of each individual.

Suggested Avenues **for** Research

- What are the measurable developmental differences among mentally retarded individuals who grow up at home, in an institution or in various types of community-based residences?
- What are the comparative costs of institutional and community services?
- What are the long-term effects of early intervention programs initiated shortly after birth on the learning potential of retarded individuals? Do children learn better in such programs if they are not identified as being handicapped?
- What teaching methods are most effective in introducing young, severely handicapped children to vocationally related skills which have relevance to problems of daily living?
- Are school programs where mentally retarded persons are integrated with their non-handicapped peers more effective than special, segregated programs?
- A more definitive answer was called for to the question of: What is the impact upon siblings of having a mentally retarded brother or sister?
- Are fathers, mothers, or a combination of the two more effective in a parent-to-parent counseling in the case of a newly identified mentally retarded child?
- What can be done to make the sheltered workshop setting less monotonous and more rewarding for severely handicapped retarded clients;
- Can we develop instruments (tests, behavioral inventories, etc.) which will enable us to obtain a more realistic assessment of the potential of severely and profoundly retarded individuals?
- How can modern organizational and systems theories be applied to facilitate the development and functioning of comprehensive community service systems aimed at furthering the goals of normalization and integration.

Epilogue

As this report ends, the reader may sense the intensity of discussions about principles of normalization and integration that took place in the summer of 1976. The reader may capture some of the participants' eagerness to communicate how this principle was working in their part of the world. The time was short but intense. All left feeling they had more they wanted to say. This is a good sign that much more will be said in the future, and all hoped that the ; Airlie experience will serve as a stepping stone for other discussion as the world moves on.

Normalization and its sister principle, integration, are neither absolute nor complete. Normalization has even been misunderstood as a tool for making persons normal when all it was intended to do was to cast a clear light on the quality of their environment: where and how they were forced to live, how people saw them and treated them.

Integration has been misunderstood by many who mindlessly pushed mentally retarded persons into society on short notice. They failed to plan properly. They sent retarded people into the community without the reasonable safeguards that were needed to help them make healthy adjustments to their rare, new setting. When this happens, it is false integration, or it is not integration at all. It should be called "dumping."

And so, those who spent time together at Airlie carried no false illusions about these two principles. They saw them as imperfectly and incompletely used. But, they also saw them as two of the most important principles at our disposal today. All found them still fresh and lively.

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