

Part V: Toward New Service Models |

Chapter 7

The Normalization Principle and Its
Human Management Implications

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THE NORMALIZATION PRINCIPLE AND ITS
HUMAN MANAGEMENT IMPLICATIONS

The Normalization Principle . . .

In an earlier section of this book I have described some observations and reactions upon visiting public institutions in the United States. I will now attempt to describe the theoretical perspective from which my reactions to my observations stem.

My entire approach to the management of the retarded, and deviant persons generally, is based on the "normalization" principle. This principle refers to a cluster of ideas, methods, and experiences expressed in practical work for the mentally retarded in the Scandinavian countries, as well as in some other parts of the world. The normalization principle underlies demands for standards, facilities, and programs for the retarded as expressed by the Scandinavian parent movement. The papers by Scandinavian contributors Bank-Mikkelsen and Grunewald in this monograph provide specific descriptions of functioning programs which incorporate normalization principles.

To discuss human endeavors to create wholesome programs, facilities, and life conditions for other human beings in terms of one unifying principle might seem preposterous, especially when the mentally retarded are involved, a group which is characterized by wide variations in age, degree of handicap, complicating physical and emotional disorders, social backgrounds, and educational and personality profiles. Nevertheless, in the Scandinavian countries, a general principle which expresses the aims, attitudes, and norms implied in quality work for and with the mentally retarded has been found of value. As expressed by N.E. Bank-Mikkelsen of Denmark, this principle is given in the formula "to let the mentally retarded obtain an existence as close to the normal as possible." Thus, as I see it, the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society,,

This principle should be applied to all the retarded, regardless whether mildly or profoundly retarded, or whether living in the homes of their parents or in group homes with other retarded. The principle is useful in every society, with all age groups, and adaptable to social changes and individual developments. Consequently, it should serve as a guide for medical, educational, psychological, social, and political work in this field, and decisions and actions made according to the principle should turn out more often right than wrong. Some of the many facets and implications of the normalization principle are discussed below.

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

2. The normalization principle also implies a normal routine of life. Most people live in one place, work or attend school some where else, and have leisure-time activities in a variety of places. Consequently, it is wrong when a retarded person, for example, has his training classes, his structured therapies, and his recreation activities in the same building that serves also as his "home." Of course, even when vocational activities are conducted in a special building, it is not satisfactory if this consists only of a few hours of low-motivated activities for a few days a week. Activation of the mentally retarded, which is all-important, must convey the experience that the daily work routine has vigor and meaning and, consequently, fills a proper part of the day. The afterwork satisfactions of leisure-time activities, whether they are for pure relaxation and fun or have more personal, educational implications, may sometimes take place in institutional or special settings, but for habilitational purposes, use should also be made of the facilities of the regular society, thus lending these activities realism. With wider experiences and proper social training, the retarded thus will be able to use the normal leisure-time facilities of his society on his own, and also learn to cope with unprepared, unstructured situations without panicking (Avedon, 1967; Chigier, 1967; Nirje, 1967).

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

4. Normalization also means an opportunity to undergo normal developmental experiences of the life cycle:

a. Children should have available warmth of atmosphere, rich sensory stimulation and surroundings, and settings of proper proportions. Handicapped individuals especially need to be fed with stimuli which will nourish knowledge and abilities. In cases where a retarded child cannot live with his own family, this aspect is of special importance. In

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

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

c. For the mentally retarded, growing from adolescence into adulthood is often a longer, more painful,, and more uncertain process than for others. Their image of themselves often becomes warped and confused. They are not always accepted, treated, and respected as adults. Here, the attitudes expressed toward them by others are of ut most importance, whether these others are parents, relatives, or institution personnel. Thus, like everybody else, the retarded should experience the coming of adulthood through marked changes in the settings and circumstances of their lives. Just as it is normal for children to live with their parents, so it is normal for adults to move away from home and start a life of their, own, as independently as possible. Therefore, it is wrong for mentally retarded adults to live on the same premises as children and youngsters, because this serves as a constant reminder that they are different from other adults, and that they are as dependent as children. Training programs for retarded young adults should assist them to become as competent and independent in their personal daily routine as possible, and to develop social skills which will enable them to take part in the regular community life as much as they can.

d. The period of old age, when work is no longer possible or feasible, consists for most people of contacts with the familiar settings and acquaintances that have given life so much of its content and meaning. Therefore, alternate living facilities for the aged retarded should be arranged close to the place where they have spent their adult periods of life, in case they cannot remain in that very place.

5. The normalization principle also means that the choices, wishes, and desires of the mentally retarded themselves have to be taken into consideration as nearly as possible, and respected. In May 1968 a conference was arranged for mentally retarded young adults, IQs about 35-70, from eight cities in Sweden. In this conference, these young men and women, 18-30 years old, discussed vocational training and their leisure-time and vacation problems. They wanted a stronger voice in their own leisure-time programs, student clubs, and labor union participation. They objected to being included in activities with children below the age of 15 or 16, and to being in too large and too heterogeneous groups. In discussing group study tours and group vacation trips, they stressed their demand to be only in small homogeneous groups. They found communication in large groups unsuitable, as it is more difficult to hear and understand what is being communicated. Obviously, they had too often had the normal tourist experience of moving in herds.

6. Normalization also means living in a bisexual world. Accordingly, facilities should provide for male and female staff members. When it comes to the integration of retarded boys and girls or men and women, the 1967 Stockholm Symposium on "Legislative Aspects of Mental Retardation" of the International League of Societies for the Mentally Handicapped came to the following conclusion.: "Being fully mindful of the need to preserve the necessary safeguards in the relations between mentally retarded men and women, the members of the Symposium are of the opinion that the dangers involved have been greatly exaggerated in the past. This has often resulted in the unfortunate segregation of the sexes in an unnatural way and has militated against their interests and proper development.

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

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

Mixing of the sexes according to the normal patterns of everyday society results in better behavior and atmosphere, as more motivations

The League is an international federation of associations of parents of the mentally retarded. The symposium, published by the League, summarizes basic principles upon which practices in the field of mental retardation should be based. These principles were derived from a definition of the rights of the mentally retarded.

are added. And the mildly retarded sometimes suffer in a loneliness that has no sense, and as others, they may be better off married.

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

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

a. It means that the sizes of facilities should conform to what is normal and human in society. Especially, it should be kept in mind that a facility for the retarded should never be intended for a larger number of persons than the surrounding neighborhood readily assimilates in its regular everyday community life.

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

With normal locations and normal sizes, facilities for the mentally retarded will give their residents better opportunities for successful integration.

Some Benefits of the Normalization Process

All the above-mentioned facets of the normalization principle make a normalization of the life situation of individual retardates quite feasible: the normalization process can aid many in achieving complete independence and social integration; a great number will be helped in developing relative independence though they may always need various kinds of assistance to various degrees; even the relatively few who are severely or profoundly retarded, or who are afflicted with

complicating medical, psychological, or social handicaps will, no matter how dependent they may be, have life conditions, facilities, and services that follow the normal patterns of society,,

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

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

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

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

All these factors coincide decisively when the retardate in his development comes to the state of accepting himself as an adult and as a responsible person with a realistic self-confidence. These points are the more important, as becoming adult for the mentally retarded also means coming to terms with his own awareness of being mentally retarded (Cobb, 1966).

As almost every situation for the mentally retarded has a pedagogical significance and often is related to his slow building up of a self-concept, it is essential that the mentally retarded should be offered appropriate facilities, which assist his educational processes and development and which make it possible for him to experience

himself as becoming adult in his own eyes and in the eyes of others. This is a basic requirement for helping his life development come as close to the normal as possible.

Large institutions and the conditions we can observe in their back wards can never offer facilities of the kind and quality that are essential. In the large wards, the rhythm of the day reduces the retarded to an object in an empty, machinelike atmosphere. The normal rhythm of daily routines of occupation, leisure, and personal life is emasculated to surrogate activities, not integrated with a meaningful personal existence. The normal rhythm of the year is mostly dwarfed through the experience of monotonous confinement. The development of individuality is helplessly mutilated and crushed in a life in herds.

Application of normalization principles has profound implications not only to the retarded but also to the public, to those who work with the retarded, and to the parents of the retarded.

When residential facilities for mentally retarded children are constructed, located, operated, and interpreted as homes for children; when special schools for the mentally retarded are integrated into regular schools or are looked upon as no more than schools for children and youth; and when group homes and hostels for the adult retarded are looked upon mainly as homes for adults; then such direct and normal experiences will result in a normalization of society's attitudes toward the retarded. Isolation and segregation foster ignorance and prejudice, whereas integration and normalization of smaller groups of mentally retarded improve regular human relations and understanding, and generally are a prerequisite for the social integration of the individual.

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

Application of normalization principles also can serve to normalize the parents' situation. When residential centers, group homes, and schools of normal standards, sizes, and locations are available, as well as day centers and workshops, the parents of the retarded can choose placements according to the individual needs of the retarded person and the needs of the family. Their choice of placement can be accomplished freely and with an easier mind, rather than being an anguished and forced choice between the horrible and the impossible.

The closer persons in the decision-making bodies of society come to the mentally retarded, the more likely they are to render decisions

resulting in appropriate and efficient programs. It may be sobering to many Americans that in Sweden, programs based on normalization principles are not dreams but actual realities brought about by the decisions of "hard-headed" penny-pinching county council appropriation committees. For those who are interested in how normalization principles have been embodied in Swedish legislation, details are provided in the Appendix.

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APPENDIX THE NORMALIZATION PRINCIPLE IN

SWEDISH LAW

The normalization principle has grown out of Scandinavian experiences in the field, both from mistakes and errors of the past as well as from planning and development of new and better programs. The new

Swedish law on mental retardation, effective as of July 1, 1968, can be seen as an expression of the normalization principle. This "law about provisions and services for the mentally retarded," dated December 15, 1967, is printed in the Swedish Code of Statutes 1967 (Svensk Forfattningssamling), No. 940, published on January 31, 1968. The law can be viewed as a Bill of Rights for the mentally retarded, being based on what their rights are believed to be. It provides for a wider range of services, and stresses that these services should be given to each retarded person according to his personal needs.

The new law is more comprehensive than the previous one of 1954, and covers a wider range of community services for the mentally retarded. It not only reflects developments which have actually taken place but also shows a new line of thought concerning what county councils must do to bring about radically improved conditions. Some sections of the law are summarized, discussed, and interpreted below.

Section 1: "This law concerns those who, due to retardation in their mental development, need special care and services from the community for their education, training, and integration in the community."

If there is a need for the provisions listed in the law, there is also a right to receive them. Through this general wording, it is possible to provide borderline cases, for instance, former wrongly placed students of remedial classes for slow learners, in the regular school system with the services they may need.

Mental retardation is not necessarily seen as a life-long condition. If, for instance, it is possible for a person to manage without the care and services of the community after special school and training for daily living, this person is no longer considered mentally retarded.

The previous law dealt, mainly with the institutions the county councils had to establish. The new law has sections on both residential services and nonresidential services such as education and training. These provisions do not exclude but are complementary to one another.

Section 4: "Residential institutions, special hospitals, day centers for children, and occupational centers shall be provided for the care of the mentally retarded, and there shall be special residential institutions for those mentally retarded who need care in residential institutions with special arrangements.

"Mentally retarded who need care according to this law, but who do not need care in an institution as referred to above in the first section, shall be provided with care in their own homes."

Thus, mentally retarded who live with their parents shall have access to day centers for children, or occupational centers for adults,

with the care, training, and therapy being equal to the standards of good residential care institutions. The county councils have so far concentrated on various residential facilities, but a great deal has to be accomplished in Sweden in order to surpass, for instance, England in the matter of developing and extending nonresidential service facilities.

The right to be provided with services at home--involving one or several persons who visit the home regularly to give care and provide training or occupational activities--will, of course, serve as an additional spur to the county councils to invest in day centers and occupational centers.

Section 4 has been written so that parents, so far as possible, will be free to choose between different services and be able to decide on either care within or outside the home, according to the estimated needs of the mentally retarded and the family circumstances.

Section 5 contains one of the great new features of the law:

Section 5: "Accommodation in other private homes, boarding homes or student hostels shall be provided for those mentally retarded who cannot stay in their own homes but who do not need to live in a residential care institution or a special hospital."

Those who do not need to live in residential institutions should not. It is just as normal for an adult to live as independently as possible as it is for a child to live with his parents. Thus, society has to provide other accommodations as close to normal as possible. This rule is of special interest to older parents whose retarded children have grown up and can manage without too much supervision. In the future, there will be boarding homes not only for those working on the open market but also for those working in sheltered workshops or occupational centers who can manage without the more extensive care provided by a modern residential institution.

All the mentally retarded below school age have a right to pre-school training. At age seven, compulsory school starts and includes both "educable" programs for the mildly and some of the moderately retarded children (IQs between about 45 and 70) and "trainable" programs for most of the moderately and some of the severely retarded (IQs between about 25 and 50). Education is to be given for 10 years, followed by compulsory vocational school attendance up to age 21, which can be prolonged to age 23 in certain instances. Relevant sections of the law follow:

Section 24: "Special school attendance is compulsory for mentally retarded who can profit from education, but who are unable to participate in educational training within the general education scheme.

"Such compulsory education starts from the autumn term of the calendar year when he will be seven years old, and lasts as long as he needs training, although not longer than up to and including the spring term of the calendar year when he will be 21. However, if there are exceptional reasons, this compulsory education may be prolonged up to and including the spring term of the calendar year when he will be 23."

Section 3: "School education is provided for the mentally retarded in special schools, where they also shall receive personal and medical care as needed. Special schooling includes preschool, provision for the educable and trainable, vocational training, or several of these.

"Separate classes or schools shall be provided for those mentally retarded who are able to attend special education but have difficulties in adjusting to the activities of the school, or who need special arrangements for their education. Mentally retarded who are unable to participate in the regular work of the special school, due to motor difficulties, sensory handicaps, long periods of illness, or similar circumstances, shall be provided with educational forms specially adjusted to them,"

It should also be noted that compulsory education, i.e., the right to receive special school education, includes children residing in institutions and special hospitals.

Preschool education prior to the age of 7 is defined as a right of the child, but not compulsory to him. All mentally retarded children who can make use of preschool training have a right to receive it, regardless if they might later be compelled to attend special school or not. Early training is fundamental for mentally retarded children, and the county councils are counted upon to work actively in tracing these children.

The education given in educable programs (IQs 45-70) as well as in trainable programs (IQs 25-50) is intended for the ages 7-17. A new provision here concerns trainable programs intended for children who are unable to participate in educable programs, but who can make use of practical education and social training.

The right to attend school, as well as compulsory school duty, will in this way finally be implemented for those children who have, until now, been referred to "practical" classes or day centers, or who have not received any education and training at all. As a consequence of this rule, trainable programs will also be established at residential institutions for children. In other words, the law has made mandatory what is considered "trainable" education in the United States.

The autumn term of 1968 will then mean compulsory school for a larger number of retarded children and youths between ages 7 and 20 who previously did not receive any education and training at all. The county councils have a big task here. To begin with, a number of provisional measures must, of course, be approved by the authorities, but the essential fact is that there is a compulsory school duty in force from July 1, 1968. As far as the enforcement is concerned, the law, in Section 2, states: "The county council communities shall provide the mentally retarded residing within the county council community with education, care and other services made mandatory by this law, insofar as someone else does not provide for it." Section 6 states that "the activities of the county council community shall be administered in accordance with this law by a Board for the provisions for the mentally retarded. A committee which handles other administrative tasks of the county council community may be appointed to such a board." "Such Boards of provisions for the mentally retarded shall include appointments of a head of special schools, a head of care facilities, and a head physician."

Section 8 decrees that "the county council community shall draw up a plan for organizing provisions and services for the mentally retarded. This plan shall include the facilities needed for the mentally retarded." The plan shall be authorized by the King or by an authority appointed by the King. In accordance with Section 13, the Board of Education and the Board of Health and Social Welfare are the authorities responsible for the supervision of the actual implementation of the activities in accordance with the law.

Section 16 contains a summary of the tasks of the Boards for provisions:

Section 16: "The Board for the provisions and services for the mentally retarded shall:

work towards the attainment of the provisions needed by the mentally retarded residing within the county council community;

plan and coordinate the activities of the county council community according to the law, and work towards the satisfactory development of law,

administrate the facilities for the retarded which are under their management and other activities for them which are managed by the county council community, if not otherwise governed according to the second, third, and fourth paragraph of Section 6;

take charge of the local supervision of other facilities for the retarded according to the more detailed instructions given by the King;

bring before the county councils those proposals which concern provisions for the retarded as they are found to be needed."

This "energy section" of the law aims at actively engaging the Board for provisions and services for the benefit of all retarded in need of the provisions ensured to them by this law. A prerequisite for this is the dissemination of information, and active cooperation with child care centers, agencies working with the mental hygiene of children and youths, district physicians, district nurses, children's hospitals and child clinics, Swedish parents' association for the retarded, etc. The Boards for provisions shall also be responsible for the development of services in a satisfactory manner, as, for instance, the supply and training of personnel, and the application of new methods and practices in the training of the retarded and their integration into the community,

The old painful system of registration is eliminated; the new procedure will be to register at the residential institution or special hospital of residence or in the school attended. In the rest of the cases, only the Boards for provisions will only keep a record of all known mentally retarded and will there make a notice of the different kinds of provisions supplied in each special case.

While the Swedish law offers a basis for the creation of decentralized, differentiated, specialized smaller institutions, hostels, and boarding homes for the retarded, some conditions still exist in Sweden that are not consistent with the normalization principle. For example, there are still about half a dozen institutions for more than 400 persons, the largest having as many as 740 residents. These institutions, as well as some in the 200-400 range, are institutions for heterogeneous age groups from early childhood to senescence, and two of them still even have special schools on the grounds. (All the other 25 special boarding schools have independent locations.)

More than half of the mentally retarded living in institutions in Sweden do so in facilities built after 1954, when a special law on mental retardation services was enacted. These newer institutions usually provide single and double bedrooms, and occasionally 4-bed rooms. Most of the older institutions have been modernized and rearranged according to modern standards. However, there still are a few deplorable regional institutions in Sweden where the retarded have to live as many as 10 to a room, with large, inadequate dayrooms which serve as many as 25 or 30 persons. These institutions are satisfying neither to the retarded nor to the Swedish parents--nor, for that matter, to the authorities.

There are also institutions which, even with modern communications, remain isolated from the mainstream of community life. One of

the main conclusions of the previously mentioned Stockholm Symposium was "that facilities for retarded persons should not be situated in remote or secluded areas, which preclude the essential contact between them and the community and which would prevent their complete integration in society."

With regard to residential accommodations, the following conclusion was reached: "The Symposium recommends that each country should determine and proclaim the desirable standards of accommodation for mentally retarded persons having regard to the following considerations :

1. that the structure of each facility planned should take into account the special needs of mentally retarded persons;

2. that facilities should not be sited in isolation, nor planned in such a manner that the mentally retarded persons for whom they are intended, would be deprived of normal contacts with the community;

3. that while there are differences of opinion as to the optimum size of multi-purpose complexes, such as residential centers which incorporate education, training and treatment functions, there is general agreement:

a. that it is much more difficult to fulfill the rehabilitation programme in all its aspects in a big institution than in a relatively smaller one;

b. that the living, dining and recreational units of such complexes should be small, with living accommodation for numbers not exceeding some 15 to 20 persons;

c. that, on the other hand, there is a necessity to determine a minimum size for each facility, commensurate with its purpose and special needs;

"It has been the experience, at least in the Scandinavian countries that large institutions tend to counteract the social integration of the mentally retarded person and militate against his individual needs for education and training and that, further in the relationship between effect and cost, the smaller unit is preferable and more economical in the final analysis."

The Symposium also stressed the necessity to ensure implementation and concluded:

"Each country should formulate and put into effect that system of control best suited to its governmental structure, in order to

exercise supervision of the implementation of legal measures regarding the care, education, training and employment of retarded persons. The aims of such control should be:

a. to ensure that full coverage is provided for the retarded population, and that every retarded person regardless of his personal means or those of his parents or guardians is provided with the facilities which he needs;

b. to ensure that the standards of facilities provided are adequate and that all services conform to the standards promulgated."

Both our service structures and our service concepts must continually evolve. It is hoped that Swedish provisions will improve further so as to be fully consistent with the Stockholm and normalization principles. It is further hoped that by that time, there will be even more advanced principles to challenge us.