

INTERNATIONAL LEAGUE OF SOCIETIES FOR THE MENTALLY HANDICAPPED
Ligue Internationale des Associations d'Aide aux Handicapés Mentaux

S Y M P O S I U M

"Legislative Aspects of Mental Retardation"

Stora Skondal, Stockholm - 11-17 June 1967

C O N C L U S I O N S

TABLE OF CONTENTS

1. Introduction	1
2. Main conclusions	1
3. Terminology	1
I. Standards	
1. Prevention	2
2. Facilities	3
3. Services	3
a. Accommodation	3
b. Staff requirements	4
4. Exploitation	4
5. Integration of male and female adults	5
6. Financial aid to the family and to the individual	5
II. Implementation of standards	
1. System of control	6
2. Role of parents associations	6
3. Planning for the future	7
4. Co-operation between public and private agencies	8
5. Responsibility	8
III Individual rights	
1. General principles	9
2. Guardianship	10
3. Custody	11
4. Research	11
IV. International collaboration	
1. Information	12
2. The needs of developing countries	12
3. The experience of other countries	12
4. International co-operation	12
Appendix A	
Facilities	

CONCLUSIONS

1. Introduction

Discussion at the Symposium has served to emphasise the enormity of the study of the legislative aspects of mental retardation. Accordingly, in presenting its findings to the International League of Societies for the Mentally Handicapped, the Symposium wishes to state that its conclusions should not be regarded as final, rather, should they be used as the basis for further studies in detail, including examination of their full implication on retarded persons, their families and society in general.

2. Main conclusions

While there was a considerable degree of unanimity on the conclusions reached by the Symposium in general, three aspects of the problem stand out and are included here for emphasis. There was unanimous agreement

- a. that facilities for retarded persons should not be isolated in remote areas, which preclude the essential contact between them and the community and which would prevent their complete integration in society;
- b. that provision for the training and procurement of specialist staff is an essential pre-requisite for services for mentally retarded persons;
- c. that services for retarded persons demand a comprehensive, multi-disciplinary approach with emphasis on the educational, training and rehabilitation aspects.

3. Terminology

In examining the legislative aspects of mental retardation, the Symposium used the terminology accepted by the World Health Organisation in regard to the various degrees of mental retardation i.e.

	<u>I.Q.</u>
Profoundly retarded	0 - 17
Severely retarded	18 - 34
Moderately retarded	35 - 51
Mildly retarded	52 - 67

I. STANDARDS

It was clearly recognized that the wide variations in practices and in resources, both financial and in personnel, prevailing in different countries must inevitably result in the considerable modification of standards to conform with national circumstances. However, in addressing itself to the legislative aspects of the problem of mental retardation in different countries, the Symposium thought it essential from the outset to seek common agreement on the following desirable standards to which member nations should seek to attain.

I.1 Prevention

Bearing in mind that research into the causation of mental retardation is an essential feature of preventive measures, the Symposium recommends:

- a. that more well-directed and planned research is necessary;
- b. that public funds should be made available for the purpose and financial assistance from private sources should also be encouraged}
- c. that co-ordination of effort is desirable, but that this co-ordination should not extend to overall control}
- d. that the application of research to prevention should include epidemiological studies} testing for metabolic disorders (e.g. P.K.U.), genetic abnormalities etc} improvement of ante-natal services, especially for those women who suffer from any deviation from the normal during any stage of pregnancy; methods to prevent mental deterioration and the introduction of medical records for the individual}
- e. that there is a requirement to encourage the prompt application of new evaluated findings, which can result in the prevention of new cases of mental retardation (a prime example being the testing for P.K.U.). In this respect public authorities have a role to play in this effort and where necessary additional legislative authority should be sought.

I.2 Facilities

Having regard to the fact that it is necessary to develop and diversify facilities in such a manner, so as to ensure the maximum development of mentally retarded persons} to meet in full their needs and to permit of their full freedom of choice of facilities; the Symposium recommends:

- a. that services for the mentally retarded should be provided to cover all circumstances of their lives and should cater for all grades of retardation according to individual needs in order to ensure a maximum development}
- b. that services should include medical, educational, social, occupational and recreational provisions for mentally retarded persons and adequate services for their families. A list of desirable facilities is set out in Appendix A. (This list should not be considered as exhaustive.)
- c. that the services provided for mentally retarded persons should in no way segregate them from the rest of the community} for example, classes, workshops, recreational facilities, and living accommodation, should be integrated, as far as feasible, into those provided for other members of the community.

I.3 Services

a. Accommodation

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 standards should, at least, keep pace with the social development and living conditions of the country concerned;
2. that the structure of each facility planned should take into account the special needs of mentally retarded persons;
3. that facilities should not be sited in isolation, nor in such a manner that the mentally retarded persons for whom they are intended, would be deprived of normal contacts with the community;
4. that while there are differences of opinion as to the optimum size of multi-purpose complexes, such as residential centres 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.

(N.B.: 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.)

5. that having regard to the necessity to attract and retain in service adequate numbers of qualified staff, the maximum individual provision should be made for their accommodation.

b. Staff requirements

The Symposium recommends that each country should determine and proclaim the desirable staffing requirements of facilities for the mentally retarded, having regard to the following considerations:

1. that it is not sufficient to have staff personnel of good will, provision should be made for the employment of suitably qualified persons, where the specialist services so demand;
2. that all services should incorporate facilities for education and training;
3. that because of their greater needs for individual care and instruction mentally retarded persons will require a greater provision of staff than would be acceptable for persons not so affected;
4. that retarded persons need contact with both sexes, accordingly, facilities should provide for male and female staff members. Towards this end positive measures should be taken including the provision of financial and other inducements in order to encourage the recruitment of male staff in those appointments which up to now have been held customarily by females.

I.4 Exploitation

Being aware that many countries have experienced the problem wherein parents of retarded persons have been exploited by persons, who make extravagant claims for methods of treatment, often going so far as to promise "cures", the Symposium recommends:

- a. that the responsible authorities in each country should be made aware of any claims for new treatments so that they may be investigated at the earliest possible moment, In this regard international co-operation is recommended;
- b. that where feasible the authorities should have the right and the duty to prohibit the application of methods, which are harmful or clearly without value;
- c. that some measure of control is necessary before new drugs are used.

(N.B.: The Symposium recognizes the practical difficulty in assessing in all cases the benefits to be derived from the application of new methods for care and treatment on the one hand and those which are primarily motivated by financial gain on the other.)

I.5 Integration of male and female adults

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 centre and workshop situations, but also in leisure time activities.

(N.B.: Experience in some countries indicates the advantage of mixing men and women in hostels and other residential facilities in such a way as to approximate to normal life.)

I.6 Financial aid to the family and to the individual

Bearing in mind the heavy financial burden which is placed on the families of retarded persons, the Symposium recommends:

- a. that it is inequitable that the financial commitments of the retarded person and/or his family should be in any way greater than for other families;
- b. that any extra cost incurred in obtaining the required services should be met, regardless of the nature and degree of retardation or the age and mode of life of the retarded person;
- c. that such additional cost should be interpreted in the widest possible way and should include, inter alia, the cost of care, education, clothing, recreation and travel;
- d. if the retarded person has no family he should be provided" with sufficient financial resources to cover all his needs.

II. IMPLEMENTATION OF STANDARDS

Having reached agreement on standards desirable in the building up of services for mentally retarded persons, the Symposium thought it right to reach the following common understanding as to the best means by which such standards should be striven after and regulated.

II.1 Systems of control

Bearing in mind the necessity to ensure implementation, 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.

II.2 Role of parents associations

Bearing in mind that the aims of parents associations are directed towards:

- a, promoting the general welfare of mentally retarded persons, and
- b. encouraging the highest possible standards of their treatment, education, training, employment and living conditions, parents associations should involve themselves actively in ensuring that there is full implementation of legal provisions for the mentally retarded. The methods by which they can ensure the implementation of legal measures will vary from one country to another and may take, inter alia, the following forms:
 1. the creation of a favourable public opinion;
 - 2, active dialogue with public authorities and members of the practising professions;
 3. appeals to members of legislative bodies;
 4. appeals to the courts, where feasible;
 5. the nomination of parents on Boards of Control by the responsible authority, agency or ministry concerned.

(N.B.: The latter method which is proving successful in Denmark is most desirable since it also provides the parents with the opportunity to determine positive policy in relation to coverage and standards.)

II.3 Planning for the future

If services for the mentally retarded are to be adequate in the future, both in their standards and in their sufficiency, they must be planned now. Having in mind the many changes in the situation brought about by emerging medical, social and educational advances, the difficulty in attempting to forecast future needs with accuracy is now widely recognized, particularly since it is general experience that improved facilities often serve to reveal hitherto unsuspected demands. The Symposium recommends:

- a. that planning of services for the mentally retarded must, of necessity, await decisions on policy, particularly in relation to the nature of the residential services proposed. Clearly authorities concerned with future needs for residential facilities will have to allow for a considerable change in demand if alternative accommodation for "able-bodied" retarded persons is to be provided in hostels, or other forms of sheltered living arrangements, through the acceptance of a policy of "community care";
- b. that in as much as the success of retardation services ultimately rests on the quality of the personnel, planning authorities will need to take appropriate steps to ensure a sufficient and continuing flow of trained staff;
- c. that apart from the senior professional workers involved, such steps must include adequate training colleges for teachers, nurses and auxiliary medical workers such as speech-therapists, physio-therapists and occupational therapists;
- d. that in view of competing demands for trained workers, salary scales might, with profit, be reviewed and special publicity campaigns in which parent organisations could play an important part, might be mounted with the object of drawing attention to the special claims for work with the mentally retarded;
- e. that all planning proposals should be made public so as to admit of comment and modification by parents and other interested groups;
- f. that energetic case finding, to determine the full requirements for facilities, is an essential feature of planning the provisions necessary.

II.4 Co-operation between public and private agencies

- a. Having in mind the general shortage of facilities to meet the full requirements of mentally retarded persons and taking into account the political and social structure obtaining in the various countries, private agencies should be encouraged to establish facilities for mentally retarded persons. Where such agencies contemplate the provision of, or are actively engaged in the provision of services the Symposium recommends:
 1. that the money necessary to finance their operations should be paid out of public funds;
 2. that the central and/or local government should ensure the co-ordination of private and public agencies not only in financial matters but also in the siting of facilities in accordance with requirements.

- b. The Symposium recommends that

where the "State" alone provides facilities, collaboration with voluntary agencies and particularly with parents associations is essential.

II.5 Responsibility

Stressing the necessity for the co-operation of all concerned with mentally retarded persons, including the disciplines involved and the parent associations; and bearing in mind that diffused responsibility invariably leads to deficiencies in the services required, the Symposium recommends:

- a. that overall co-ordination in the provision of services is necessary to ensure that there is a multi-disciplinary approach at State and/or local levels;

- b. that such co-ordination should be achieved by vesting responsibility in a special agency having unified responsibility for the provision of facilities.

(N.B.: Conditions in each country such as its area, population etc. will dictate whether unified responsibility should be placed at State or local level or operated through an inter-agency Council or Board. Denmark has a special State Agency for mentally retarded persons which is responsible for all kinds of provisions, including the transfer of social security payments to retarded persons and their families. It applies a multi-disciplinary approach having representatives for all interested Government Departments on its Board of Directors, which, in addition, includes representation for the Parents Association. There are Advisory Councils, similarly composed, in the regions. In most Swedish counties there is a special Board of Directors in charge of all special provisions for mentally retarded persons, except payment of social security benefits.

III. INDIVIDUAL RIGHTS

The Symposium considered that no examination of the legislative aspects of the problem of mental retardation would be complete without general consideration being given to the basic rights of the mentally retarded, not only from the standpoint of their collective rights and those of their families, but also from that of the individual rights of the retarded person as a human being. The Symposium affirmed the following:

III.1 General principles

- a. The mentally retarded person has the same rights as other citizens of the same country, same age, family status, working status, etc, unless a specific individual determination has been made, by appropriate procedures, that his exercise of some or all of such rights will place his own interests or those of others in undue jeopardy,' Among the rights to which this general principle may apply are: the right to choose a place to live, to engage in leisure time activities, to dispose of property, to preserve the physical and psychological integrity of his person, to vote, to marry, to have children, and to be given a fair trial for any alleged offence.
- b. The retarded person has, furthermore; a right to receive such special training, rehabilitation, guidance and counseling as may strengthen his ability to exercise these rights with the minimum of abridgement.
- c. Some persons may be able to exercise all these rights, in due course, even though they are, or may have been, at one time or another, identified as mentally retarded. Others may, as a result of a serious degree of mental retardation, be unable to exercise any of these rights in a meaningful way. There remains a number of retarded persons for whom modification of some or all of these rights may be appropriate.
- d. When modification or denial of rights is necessary, certain compensating special or alternative rights should be acquired. In cases where a number of fundamental rights are to be abridged, the special rights include the right to have a guardian appointed, who will have the legal and moral obligation to make necessary decisions on behalf of the retarded person who cannot act for himself.
- e. In respect to any right which it is proposed to deny or modify, the retarded person is entitled to the benefit of special procedures, in accordance with the general legal code of his country, which will ensure that;
 1. an evaluation of his social capabilities to exercise the rights in question has been made by persons professionally qualified to do so;

2. both he and members of his family or other interested persons are advised in advance of the process;
3. rights of appeal to higher authorities, and especially the courts, are kept open;
4. the benefits of these and related legal provisions are not limited by the economic status of the retarded person;
5. the possibility remains of restoring at a later date any right which is denied, should the circumstances later justify restoration;
6. there is provision for periodic review of the necessity to restrict rights;
7. the physical and psychological integrity of his person is preserved.

III.2 Guardianship

A retarded person, whether he is an adult or a child who is an orphan or abandoned, and who has a general inability to manage his life has a right to have a guardian who is legally and actually qualified to protect his interests and promote his personal welfare. The following points should be included in developing a system of guardianship for the mentally retarded:

- a. In the case of an adult there should be provision for having him declared a legal minor.
- b. The procedure should be as simple as is consistent with the proper weighing of the information concerning the actual and prospective intellectual and social competence of the retarded person and the qualifications of the prospective guardian.
- c. The procedure should be without cost to the retarded person or to his family.
- d. The guardian appointed should be one who will render conscientious service to the ward in the light of modern understanding of the nature of his condition; no person should be appointed who is responsible for rendering a direct service to the retarded person.
- e. There should be provision for continuity of the guardianship and in particular for the appointment of suitable successor guardians when no member of the family remains available. A representative or member of a parents organization or a parent may prove suitable.
- f. Guardians other than parents should be compensated for expenses incurred. In addition, they should receive fees

for their services to the person. These should be in accordance with the actual duties performed, rather than based only on the income of the retarded person." Basic costs should be paid from public funds.

- g. Guardians should consider the wishes of their wards to the extent these may be reasonable, having in mind the concept of an "extended minority".
- h. A guardian should, in general, be empowered to use his discretion on behalf of his ward to initiate and consent to any action which a competent adult might undertake for himself.

III.3 Custody

- a. A parent of a person under 21 years of age or a guardian of a retarded person may arrange for his admission to a suitable facility for his care, training or treatment, in which case the institutional authorities may exercise immediate custody and control over him during his attendance.
- b. However, without prejudice to a child's normal educational rights, no retarded person should be legally committed to any institution without his consent or that of his parent or guardian, unless it has been demonstrated, that his behaviour constitutes a danger to himself or others or that he is in need of special education and that such restriction of his activity is required in his own or in the public interest.
- c. In such a case he should be committed only to such a facility (whether it be an educational, psychiatric, penal or other rehabilitation institution) as has a programme adopted to his training and treatment needs.
- d. Indefinite commitments without provision for periodic review or renewal should not be permitted.

III.4 Research

- a. Mentally retarded persons, as well as normal or volunteer patients are first of all human beings and medical or psychological sciences should be deeply protective of human dignity, human integrity and human life.

Accordingly, the Symposium recommends that the Declaration of Helsinki (1964), Code drawn by the World Medical Association should be observed as follows:

"In the field of clinical research a fundamental distinction must be recognized between clinical research in which the aim is essentially therapeutic for a patient, and clinical research the essential object of which is purely scientific and without therapeutic value to the person subjected to the research."

The subject of clinical research should be in such a mental, physical and legal state as to be able to exercise fully his

- b. The Symposium draws attention to and recommends the adoption of the English law, in which parents or guardians have no right of giving consent to treatment if the procedure is not for the child's direct benefit.

IV. INTERNATIONAL COLLABORATION

IV.1 Information

Experience has shown that international collaboration in developing rights and standards for the mentally retarded has had already profound positive effects. Yet very much more needs to be done. Even the information base for systematic international action is largely non-existent. Indeed, there is a paucity of truly comparable data on provisions, standards and rights. There is an urgent need that a full picture be provided making it possible to appraise both achievements and shortcomings in different countries. While valuable material is contained in documents written for this Symposium, it is necessary that the League take steps to draw up a questionnaire in order to obtain more complete and uniform data in the very near future.

IV.2 The needs of developing countries

The mentally retarded and their families in developing countries have at least the same needs as in industrialized nations. In their case it is particularly true to say that no legislation can create the necessary resources overnight. This makes it all the more necessary to emphasize that development of provisions and rights for the mentally retarded must at least keep pace with the general economic and social development of these countries.

IV.3 The experience of other countries

Developing countries should avoid repeating the well-meaning errors in the development of the services for the mentally retarded that have been made in most industrialized countries, such as the segregation, often in isolated places, of the retarded person; the failure to pay sufficient attention to the crucial need for training of good personnel} or the former tendency to over-emphasise medical aspects of care instead of developing and activating a multi-disciplinary approach with due emphasis on training, general and vocational education, occupational day centres, sheltered workshops, planned leisure time activities as well as on medical treatment.

IV.4 International co-operation

Much of the international collaboration in the field of mental retardation should be devoted to development aid. Towards this end rich countries should devote larger resources than heretofore, both on a bilateral and multilateral basis, at the same time removing existing barriers which tend to restrict the trade of developing countries. This Symposium invites the League to call on

rich countries, as well as on the various organs within the UH family, in particular UNESCO, WHO, ILO, UNDP and IDA, to include programmes and projects in the field of mental retardation in their technical assistance work and in their other collaboration with developing countries. It will be necessary, also, for the developing countries to include programmes and projects of this character in their requests for development aid. Church groups and voluntary organisations as well have an important role to play in the international development work for the mentally retarded.

APPENDIX A

FACILITIES

1. Multi-disciplinary facilities including ante and post natal facilities for diagnosis and individual evaluation
2. Child Guidance Clinics and Observation Centres
3. Home training and family support
4. Family counselling services and parent education
5. Hospitals for the retarded persons who need medical and nursing care
6. Provision of residential accommodation for those unable to live at home permanently or temporarily (for example hostels, foster homes- short-stay homes, summer camps and residential institutions)
7. Educational establishments, to include
 - a. Nursery schools and classes
 - b. Schools and classes offering special education for varying degrees of retardation
 - c. Vocational training and acclimatisation courses for those retarded persons thought to be capable of working in open industry
 - d. Educational facilities in hospitals
 - e. Adult education
 - f. Art therapy, music and dancing

(N.B.: Religious instruction should be given, if wished)

8. Day care centres and night care facilities
9. Sheltered employment
10. Special transportation as necessary for the retarded person and transportation and short stay facilities for parents, who wish to visit their children in residential centres
11. Meaningful recreational facilities, sports and holidays
12. Special training for teachers, doctors, house-parents and others working for the mentally retarded
13. Guardianship and trusteeship
14. Geriatric care

(NOTE: This list does not purport to be exhaustive)