

Discrimination and Intellectual Handicap, a Report of the New South Wales Anti-Discrimination Board in accordance with section 119(a) of the Anti-Discrimination Act 1977 (New South Wales Anti-Discrimination Board, Sydney, December 1981), pp. 383 with Index.

Mental Retardation: Law, Policy and Administration, by SUSAN C. HAYES, B.A. (Hons.), Ph.D. (N.S.W.), Senior Lecturer in Behavioural Sciences in Medicine, University of Sydney, Honorary Psychologist, Royal Alexandra Hospital for Children and ROBERT HAYES, LL.B. (Melb.) Ph.D. (Mon.), Associate Professor of Law, University of New South Wales, Barrister of the Supreme Court of New South Wales. (The Law Book Company Limited, Sydney, 1982), pp. i-xxviii, 428 with Table of Cases, Table of Statutes, Glossary and Index. Cloth recommended retail price \$35.00 (ISBN 0455 20469 1). Paperback recommended retail price \$22.50 (ISBN 0 455 20470 5).

Despite their rather different origins and objectives, the Report and the book share a common interest in the kinds of services and provisions presently available to people who are mentally retarded or intellectually handicapped and a common belief that, in many respects, existing policies and practices fall well short of what is desirable. According to the Anti-Discrimination Board, the intellectually handicapped are "virtually second-class citizens and arguably the most impoverished and underprivileged people in our society" (p. 350). According to the Hayes', the law concerning mentally retarded people has been largely "hidebound since the Victorian era", although they do add, in a more encouraging vein, that there are recent indications that long overdue reforms are on the way.

There are many who would agree with this highly critical assessment. In the last few years we have witnessed a flurry of governmental inquiries and reports concerned with various issues associated with the rights of mentally retarded persons, following the United Nations Declaration which was proclaimed in December 1971. The Anti-Discrimination Board Report is but one example of this process in New South Wales. Under Section 119(a) of the Anti-Discrimination Act 1977 (N.S.W.), the Board is empowered "to carry out investigations, research, and inquiries relating to discrimination and in particular discrimination against a person or persons on the ground of . . . physical handicap or condition or mental disability". A study of discrimination and physical handicap was published in 1979 and the Anti-Discrimination Act amended in April 1981 to include this condition as a ground under the Act; the present Report represents the results of the Board's investigation of persons with intellectual handicap. Many areas in which discrimination may occur are examined for example in the provision of health services, education, accommodation, vocational training and employment, goods and services, and access to rights under the common law. As a consequence, the Board calls for substantial changes in the attitude of both individuals and governments towards intellectually handicapped people.

First, a number of statutory changes are recommended, including an amendment to the Anti-Discrimination Act 1977 (N.S.W.) to make discrimination on the ground of intellectual handicap unlawful in the provision of general goods and services, employment, education, health services, and accommodation. In December 1982 such an Amendment to the Act was duly passed by the New South Wales Parliament, although the scope of the Amendment did not go as far as was envisaged by the Anti-

Discrimination Board in its Report. The basic definition of what constitutes discrimination on the ground of intellectual impairment is almost *verbatim* the same as in the original Report, wherein two forms of discrimination, direct and indirect, are identified. However, in several areas covered by the Act, significant exceptions are permitted, predicated on the discriminator, having regard to the circumstances, believing it is "reasonable to rely, that the intellectually handicapped person would be unable, because of his intellectual impairment" to do the work or to use the goods or services concerned. The problem here is to decide what is reasonable. The Anti-Discrimination Board proposed in its Report that such decisions should be based upon an individual determination of the handicapped person's capacity to do the job, rather than solely on assumptions about the handicapped condition. Given the widespread nature of misconceptions about intellectual handicap, in the absence of such a direct test, a discriminatory decision could be made simply because the premises from which the judgment is derived are false, even though commonly believed. In other areas, the ambiguity in the Act is even greater. Thus, with insurance, the Anti-Discrimination Board recommended that discrimination on the ground of intellectual handicap be unlawful "except where it is based on reasonable actuarial or statistical data" (p. 274). However, the 1982 Amendment to the Act adds the further extra-ordinary exception: "where there is no such data, on such other data as may be available". A further possible omission from the 1982 Amendment concerns health services. Perhaps it is intended that these are covered by Section 49Z of the Act concerning the provision of goods and services, despite the fact that the Anti-Discrimination Board in its Report dealt with health services separately from general goods and services. If they are not so covered, then this is indeed a very significant omission since not only the Board but also the Hayes' in their book and the President's Committee on Mental Retardation¹ in the United States have identified this as a major area in which there has been discrimination against people who are mentally retarded.

Secondly, the Anti-Discrimination Board makes a large number of recommendations calling for improvements in both the quantity and quality of services provided for people with intellectual handicaps. These range from areas of prevention and early intervention to conditions of housing, education, and employment. In many cases what is needed is not just more money to provide these services but fundamentally a new approach based on a set of basic principles relating to intellectual handicap. The first principle is that of normalisation, which states that intellectually handicapped people should enjoy conditions of everyday living which are as close as possible to the norms and patterns of the rest of society. A second principle is that of integration, which states that handicapped people should, as far as possible, be in close contact with those without handicaps: in other words, instead of approaches to accommodation, education, and employment which effectively segregate handicapped and non-handicapped people, services should maximise integration wherever possible. The third principle is that of habilitation, which states that programmes for persons with intellectual handicaps should have as one of their objectives to train or educate the person to achieve his or her maximum development of skill and independence. Implicit

1 M. Kindred, J. Cohen, D. Penrod and T. Shaffer (eds.), *The Mentally Retarded Citizen and The Law* (1976).

in this last principle in particular, is the assumption that intellectual handicap is not an illness, not even a mental illness, and thus not to be treated according to the conventional medical model.

It would be true to say that among policy-makers and professionals working with the intellectually handicapped there is now significant although by no means universal recognition of these fundamental principles. Thus Section 259 of the Community Welfare Act 1982 (N.S.W.) states: "The object of this Part is to ensure the provision in accordance with this Part of services for handicapped persons to enable them to live as normal a life in the community as their handicaps permit". Likewise, the Doherty Working Party 1982 Report on Strategies and Initiatives for Special Education in New South Wales proposes that "integration of all children with developmental disabilities and learning difficulties into the most normalised education setting feasible for each child within a neighbourhood school is a fundamental aim" (p. 17). And again the first recommendation in the 1983 Report of the Richmond Committee of Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled in relation to services for the latter group advocates:

"That the Minister of Health —

(i) endorse the principle that the provision of services for the developmentally disabled within the health administration should be based on:

- (a) promotion of maximum development and education of each individual;
- (b) pursuit of the objectives of normalisation and integration;
- (c) promotion of the rights of people with disabilities; and

(ii) recommend to the government their adoption and application to all areas of government policy relating to the care of the developmentally disabled" (Part 2, p. 2).

Moreover, the distinction between mental illness and mental retardation is also recognised now, not only in the Richmond Report but also in the Mental Health Bill 1982 which explicitly rules out "developmental disability of mind" as a sufficient ground for regarding a person as mentally ill.

Notwithstanding this apparent agreement concerning the basic philosophy underlying services to the intellectually handicapped, there is much that remains to be done to translate this into reality. Even if reports such as the Richmond Report are given government approval, the task of implementing the many changes recommended will take many years and a not inconsiderable amount of money. The depth of commitment of politicians and administrators to these reforms in the provision of services to intellectually handicapped people will surely be tested before these services are finally available to all. In order to maximise the process of change, the Anti-Discrimination Board suggests that greater accountability is required to ensure that the best use is made of the resources available, and also that mechanisms need to be established to enable handicapped people or their representatives to participate more in the planning and evaluation of services; these points have also been taken up recently by the Richmond Report in its recommendations regarding health services for the developmentally disabled.

Lastly, the Anti-Discrimination Board proposes that there is a need for a special authority to be located within the Premier's Department with the job of coordinating the development and delivery of services to intellectually handicapped people. This body would oversee and monitor the allocation and spending of funds, liaise with the

various state and federal government departments with specific responsibilities for handicapped people as well as with the voluntary sector to ensure that a comprehensive and integrated network of services is provided. Some states, for example, South Australia, have recently created such a body but New South Wales has yet to take any action in this direction although there is little doubt that fragmentation is a weakness of the present approach in this state.

In stimulating the introduction of new legislation and contributing to a revised assessment of existing services for those who are intellectually handicapped, the Anti-Discrimination Board Report will be seen to have played an historic part in the process of upgrading the rights of these people. For their part, Susan and Robert Hayes perceive the present plight of retarded people as the result in part of a widespread lack of up-to-date knowledge about what mental retardation is, and about the kinds of laws, policies, and programmes that are appropriate in relation to such people. Referring to the legal profession, they say that "the level of ignorance involved in representing retarded people is astounding" (p. 413), and that most lawyers "have almost no knowledge of the special problems associated with being mentally retarded (p. 23). Similar comments apply to many other professions which really ought to know better. Ultimately this sad state of affairs is a reflection of the degree of ignorance about intellectual handicap within the community generally, and an indictment of those agencies whose responsibility it is to educate the public about this condition and to certify that those who will come into contact with intellectually handicapped people in the course of their work are properly informed.

With such an overwhelming absence of knowledge evident, an important task for anyone who seeks to bring about a sustained process of reform leading to increasing realisation of the rights of retarded persons, is to fill the information gap. This is the Hayes' primary aim — to educate all who are interested, on the nature of mental retardation, on existing Australian laws and practices concerning those who are retarded in this country, and to point out the respects in which these practices and laws fail to live up to what contemporary enlightened approaches to this condition would recommend.

As a textbook on the present status of mentally retarded people living in Australia, the Hayes' volume has no peer. It is comprehensive in scope, accurate in its analysis of mental retardation and of approaches taken or advocated towards it, authoritative in its appraisal of the legal position concerning retarded people and those associated with them, and written in a style which is succinct and clear. The fact that the citations referenced in the text are mostly from legal sources and the glossary at the back of the book contains mostly non-legal terms would suggest that the Hayes' are principally addressing themselves to those whose main occupation is connected with the law, that is, lawyers, politicians, bureaucrats and researchers. Nevertheless, as one who has no legal training, I did not find the book impossibly difficult to comprehend, and I feel that there is much in it which will be of benefit to others in a similar position — retarded people, their families and advocates, medical practitioners, teachers, psychologists, therapists, social workers, and other care-givers. At the very least, those without legal qualifications will be better prepared when approaching a lawyer where a mentally retarded person is concerned: (1) choose someone who understands that mentally retarded people are not a homogeneous group and who is sensitive to the

difference that the degree of retardation involved can make; (2) choose someone who knows the difference between mental retardation and mental illness; and (3) if still not satisfied, choose someone else if possible.

Inasmuch as they are in complete agreement with the Anti-Discrimination Board regarding the basic principles which should underlie policies and programmes for people who are mentally retarded, the Hayes' appear to be in total sympathy with the Board as to the direction and form that services should follow in areas such as medical care, education, accommodation and employment. However, in their review of the rights of retarded people under the common law they go significantly further than the Board, which in this area admits that it has relied largely on the findings of two previous inquiries² in other states. Many cases are described by the Hayes' which together lead to the inescapable conclusion that the legal system itself indirectly discriminates against retarded people by failing to provide effective mechanisms by which they can obtain access to rights which in theory they should have. In some instances there may be over-protection of the retarded person because of unverified and unwarranted assumptions about his or her incapacity, for example, to enter into financial and property transactions or to give consent for some medical procedure to be carried out. On other occasions there may be a lack of adequate protection of the retarded person who has been, for example, a victim of criminal abuse insofar as avenues for compensation and justice are inaccessible, perhaps again because of a presumption of an incapacity to testify or because the facts of the case cannot be obtained for other reasons.

This issue of protection raises what the Hayes' refer to as "one of the most difficult areas of the law affecting mentally retarded people" (p. 235), and that is the question of guardianship. In this regard it is significant that both the Hayes' and the Anti-Discrimination Board in its Report are strongly critical of the concept of ministerial guardianship for an intellectually handicapped person which is referred to in Part XI of the Community Welfare Act 1982 (N.S.W.). The objection to this approach is that it places the Minister for Youth and Community Services in an impossible position of conflicting interest whereby he is both the principal service provider for the intellectually handicapped person and thus the one to whom any complaints about such services must be put, and at the same time the guardian of the handicapped person whose responsibility it is to submit any such complaint. Notwithstanding the existence of an Intellectually Handicapped Persons Review Tribunal which is intended under the Act to examine *inter alia* guardianship cases, both the Anti-Discrimination Board and the Hayes' believe that a guardianship board set up along similar lines to those established in South Australia and Tasmania would be preferable. Even this approach has its drawbacks, however, since it may still be assumed that if a person is mentally retarded and requires a guardian, he is therefore incapable of making any decisions about his life or property, which is almost certainly not so in the majority of cases. In its favour, Section 262 of the Community Welfare Act 1982 (N.S.W.) does provide for the appointment of a person or organisation by the

2 South Australian Committee on Rights of Persons with Handicaps, *The Law and Persons With Handicaps, Vol. 2, Intellectual Handicaps* (1981); Victorian Committee on Mental Retardation, *Report to the Premier* (1977).

handicapped person to act as his or her representative or advocate, although this innovation also is not without its difficulties.

In the course of this review, I have used the terms "mental retardation" and "intellectual handicap" interchangeably. With respect to the books under review, however, it is not strictly correct to regard these terms as synonymous with each other. The Hayes' have adopted the definition of mental retardation originally put forward in 1973 by the American Association on Mental Deficiency³, which refers to "a significantly sub-average level of general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period". Elsewhere⁴ an identical definition has been given as the meaning of "intellectual handicap". However, in the case of the Anti-Discrimination Board Report and also the Anti-Discrimination (Amendment) Act 1982 (N.S.W.), a person who is intellectually handicapped refers to someone "who, as a result of disabilities arising from intellectual impairment, is substantially limited in one or more major life activities". In this context "intellectual impairment . . . means any defect or disturbance in the normal structure and functioning of the person's brain, whether arising from a condition subsisting at birth or from illness or injury", and the "major activities include self-care, receptive and expressive language, learning, mobility, and self-sufficiency" (p. 4). It should be noted that the Anti-Discrimination Board's usage of "intellectual handicap" is a much broader one than that normally encompassed by this term as it is employed in other legislation and in the literature generally, since it includes quite specific deficits in cognitive functioning as well as more generalised manifestations of retarded development. For the purposes of the Anti-Discrimination (Amendment) Act 1982 (N.S.W.) this broad application of the term is understandable. However, it has been a regrettable feature of much past legislation that mental retardation has tended to be confused with other conditions, and it is to be hoped that in this instance no such confusion will result from the particular interpretation adopted in the Anti-Discrimination Act of the Words "intellectual handicap".

Finally, while on the subject of defining mental retardation and intellectual handicap, it is appropriate that, as a psychologist, I should lodge some protest against the Hayes' endorsement of the criticism of the use of IQ scores in the classification of this condition to be found in the 1976 volume sponsored by the President's Committee on Mental Retardation⁵ (p. 5). It has been fashionable in some circles to question the meaningfulness of IQ measurement. Sometimes this questioning has been quite constructive and has served to clarify some of the factors that can affect the results of such measurements as well as to bring into sharper perspective the significance of the score obtained as it predicts the rate of an individual's educational advancement. That it does predict the rate of such development better than any other single measure, however, is an empirical fact. It is therefore absurd to say that "an IQ score is one of the least helpful facts available to the professional"⁶. To be sure, it is not the only

3 H. J. Grossman, *Manual on Terminology and Classification in Mental Deficiency: 1973 Revision* (1973).

4 South Australian Health Commission's Final Report of the Intellectually Retarded Persons Project, *A New Pattern of Services for Intellectually Handicapped People in South Australia* (1981).

5 M. Kindred, J. Cohen, D. Penrod and T. Shaffer (eds.), note 1 *supra*.

6 *Ibid.*

criterion on which the determination of mental retardation is based, by definition, but it does have the advantage of being rather more objective and standardised in its estimation that is adaptive behaviour or social maturity, and in this sense is likely to be more reliable and less subject to hidden biases. To dismiss the use of IQ scores would be a retrograde step indeed if we are to have any reasonable way of identifying whether someone is retarded or not and thus to decide upon the particular form of service or programme required.

A more appropriate and serious concern is to ask about the consequences that ensue when someone is identified as being mentally retarded. This is the really important issue being examined in both of these books. Everyone with an interest in the welfare of those who are mentally retarded in our society, therefore, will welcome the contribution they have to make to this cause.

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