

# A BRIEF HISTORY OF THE INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF MENTAL DEFICIENCY (IASSID)

A. D. B. CLARKE Department of Psychology, The University of Hull, Hull England *Journal of Intellectual Deficiency Research*, 1991, 35, 1-12

## Introduction

The foundation of any scientific organisation is linked not only with developments within its particular disciplines, but also reflects the social and political influences preceding and surrounding its initiation. Therefore, in outlining the history of IASSID, it may be useful to sketch some of the factors which played a part in leading to its eventual formation. Of course, international scientific organisations only follow after major national developments have occurred and for the IASSID, this was especially evident from developments in the USA, the United Kingdom and the Scandinavian countries. In the first these, for example, the American Association on Mental Deficiency had existed since 1876, and had become very powerful (Sloan & Stevens, 1976).

Developments in the nineteenth century stemmed from the watershed in human thought provided by Darwin (*The Origin of the Species* 1859), who showed that in evolution the fittest became ascendant in the struggle for survival, passing on their characteristics to their progeny. The unfit had a smaller chance of so doing, and this biological theory was extended simplistically to cover social matters. The 'threat of the unfit' became the major factor in the move to sterilise or to incarcerate the mentally retarded in institutions. At the same time, correlates were often mistaken for causes, and thus tuberculosis and alcoholism were considered to be major etiologic agents of mental retardation. Moreover, Langdon Down (1886) who first identified 'mongolism', proposed a theory of 'atavistic regression' to explain the origin of various clinical conditions. By contrast, a number of educational and medical pioneers undertook work which gave a promise that mental retardation might be ameliorated.

Finally the beginnings of 'mental measurement' are to be found towards the end of the century. A decade later, Binet in France combined a deep humanism with a scientific objectivity in pioneering the assessment of backwardness and mental retardation.

Emerging from nineteenth century liberal concerns, and the eugenics movement of the early twentieth century, countries began to assemble information on the nature and extent of the problems posed by mental retardation. Some institutions became research centres (e.g. the Vineland Training School, USA; Stoke Park Hospital, UEC) and as laws governing societies' methods for dealing with this field came into operation, it became a relatively straight-forward process to collect information relating to prevalence, causation and treatment. Epidemiological studies in the 1920s, 1930s and 1940s proved to be informative and influential. In 1938, for example, the late L. S. Penrose published the famous Colchester Survey; among other far-sighted observations, this documented clear distinctions between the two sub-populations (severe versus mild impairment) in the field of mental retardation and also indicated that prevalence had strong age associations, with a marked decline after the school years.

In the immediate post-war period, several influences combined to accelerate scientific advances. Firstly, the spirit of optimism and humanism, characteristic of those times, caused many to become more aware of the disadvantaged to be attracted to these fields and to seek preventive or remedial measures. Secondly, the belief that scientific methodology had much to offer became more widespread, and its successes more obvious. Thirdly, the parents of the severely handicapped began to initiate pressure groups and to influence the laws and practices which catered for the mentally retarded.

In 1949, Penrose's *Biology of Mental Defect* proved to be a landmark in recording the already considerably advances in the biomedical field. A less impressive book, though a landmark in the sense of recording for the first time what was known in the psychosocial field, was S. B. Sarason's *Psychosocial Problems in Mental Deficiency* (1949). Of its 10 chapters, however, only one was devoted to treatment, the remainder being largely descriptive. Within a few years the situation had altered radically. An edited text by Hilliard & Kirrnan (1957)

included non-medical contributions, and Clarke & Clarke's (1958) *Mental Deficiency: the Changing Outlook*: was almost entirely written by psychologists. Here seven chapters out of 18 were explicitly concerned with training and other forms of treatment. By now, a surge of scientific work was taking place in all disciplines.

An exceptionally important event in the biomedical field was the discovery of the extra chromosome (trisomy 21) in Down's syndrome (Lejeune et al 1959). This helped to open up the whole field of prenatal diagnosis and ultimately, with other discoveries in molecular biology, advanced the process of gene mapping. Genetic counselling could now more often provide exact rather than actuarial predictions. Following an international medical conference in Portland, Maine, USA, in 1959, the American Association on Mental Deficiency (AAMD) began, in collaboration with the UK's Royal Medico-Psychological Association (RMPA), to consider seriously the possibility of an international multi-disciplinary conference to be held in London in 1960. The key proponents were the late Harvey Stevens (USA), the late Alexander Shapiro (UK) and the present writer (UK). These three moved rapidly and set up an American Committee and a British Committee, the latter composed of RMPA. The Royal Society of Medicine and British Psychological Society representatives, together with a Secretariat provided by the IJK's National Association for Mental Health (NAMH). British Government interest was sought and obtained, and the stage was set for the first-ever multi-disciplinary international conference on mental deficiency.

### THE LONDON CONFERENCE ON THE SCIENTIFIC STUDY OF MENTAL DEFICIENCY 1960

For those concerned with its preliminaries, a learning experience, which was later to prove of considerable value, was necessary.

None of the small group of organisers had ever planned an international congress, each therefore had to sail in potentially dangerous, uncharted waters. A number of lessons emerged:

- (1) it was necessary to keep the roles of local organising committees and programme committees separate but with liaison between them;
- (2) deadlines for submission of manuscripts had to be set well in advance of the actual congress, and an editorial office had to be available throughout;
- (3) early financial planning was necessary, and guarantees concerning publication of Proceedings had to be sought.

Those who attended this highly successful Congress still recall the excitement of this, at the time unique event, not only in the scientific field but also in the social area: a dazzling Government Reception hosted at Lancaster House and a Congress Banquet at the Dorchester Hotel. Personal contacts, sometimes of life-long significance, were frequently made, and for the first time, international multidisciplinary meetings were achieved.

The Congress attracted around 700 delegates, drawn from 27 countries, and 11 aspects of mental deficiency were covered by the scientific contributions. During the meeting, the future formation of an International Committee was discussed and a provisional committee set up to take this proposal further. In the meantime, an admirable two-volume Proceedings was issued under the editorship of Dr B. W. Richards (1962) with sponsorship by May & Baker. They still repay reading in the light of developments since that time, especially the contributions of L. S. Penrose and Turpin & Lejeune.

### THE INTERNATIONAL COPENHAGEN CONGRESS ON THE SCIENTIFIC STUDY OF MENTAL DEFICIENCY 1964. THE BIRTH OF THE IASSID

The provisional committee mentioned above soon received an invitation from Denmark for 1964 and, once again, an impressively organised Congress took place, thanks to a very active Congress Committee of the Danish Ministry of Social Affairs. The excellent scientific programme, under 19 areas of research, was arranged by Dr. Annalise Dupont, and the two-volume Proceedings edited by the late Dr Jakob Oster (1965) was published miraculously just 5 months after the Congress. Once again, the social programme was outstanding.

The late Harvey Stevens and the late Alec Shapiro convened an invited meeting of around 20 people to formalise and found the IASSID. The former was appointed the first Chairman and Alan Clarke the Secretary-General. Stevens was empowered to produce a draft Constitution, and a decision taken that Congress should be

held every 3 years, a view which remained unchanged until 1988 after which a 4-year cycle was to be arranged. Professor Lafon of France offered Montpellier as the location of the next Congress.

#### THE FIRST CONGRESS OF THE INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF MENTAL DEFICIENCY MONTPELLIER, 1967

This first Congress took place in the University, and all lectures and residences were on the same campus. This greatly facilitated interchange, and has only been replicated once (Washington, D.C.) in a less satisfactory ambience. Apart from the scientific programme, two memories stand out. With the usual French sense of occasion, a large number of state and provincial dignitaries attended. Mrs Hubert Humphrey, the USA Vice-President's wife was also present, carrying with her a supportive message from President Johnson. Secondly, the social programme was superbly organised.

As befitted the First Congress, an impressive scientific programme was produced, with a strong international attendance, especially from the USA. For the first time, a large Russian delegation attended, although half of its members were recalled on reaching Paris, and the remainder arrived late.

As usual, the Proceedings (Richards, 1968) make interesting reading, and as Harvey Stevens, the President, put it in an Opening Session, 'in the three short years since its creation, the IASSID has assumed a leadership role in the scientific communities of the world and (in) those national and international agencies concerned with the problems of mental deficiency.

The Council of the Association, now representing a large number of affiliated national associations had the task of deciding upon the venue for the next Congress. Having an offer from Poland, issued through our stalwart supporter, Dr (now Professor) Ignacy Wald, the Council decided with some trepidation to accept, insisting, however, upon written assurances from the Polish Government that visas would be granted to anyone who wished to attend, regardless of racial, religious or political affiliation. It was felt that an international association should be prepared to meet anywhere in the world provided such assurances were forthcoming. No one anticipated, nor could have anticipated, the dramas ahead.

#### THE SECOND CONGRESS, WARSAW, POLAND, 1970

Following the 1967 decision, a Polish Local Organising Committee, and an international Programme Committee commenced work, and arrangements were for an on-site visit in 1969 by the President (Shapiro), ex-Editor (Richards) and Secretary (Clarke). In 1968, however, the Warsaw Pact countries had invaded Czechoslovakia and quashed the 'Prague Spring'. At the same time, anti-Semitic activities were recurring in Poland. Doctor Wald, for example, who had made a strong protest about the Warsaw Pact's action, was removed from Chairmanship of the Local Organising Committee and replaced by an elderly Professor of Orthopaedic Surgery, ignorant of the problems of mental retardation. Perhaps Wald's stand marked the origin of subsequent difficulties.

Against strong opposition from some Jewish colleagues in the United States, and elsewhere the Council decided, by means of a postal ballot, to go ahead with the Congress. Opinions were no doubt much influenced by a letter from a large number of Nobel laureates which at about this time appeared in *Nature*, urging the maintenance of scientific links across the Iron Curtain.

It soon became clear that the local Organising Committee of which Dr Wald was now allowed to be Secretary, was operating under the Polish Ministry of Health and within grave constraints. All decisions had ultimately to be approved by the Minister. A request, for example, that an English volunteer secretary should be, as usual, invited without cost to all social function, took 6 months to be approved.

The 1969 visiting group found the Warsaw situation to be very oppressive; one member was invited secretly to meet a group of dissidents who gave a horrendous picture of repression of intellectuals, especially Jewish ones. Indeed, most of the small band of Jewish people who had survived the Holocaust had by then left. However,

with reservations and considerable doubts, the visiting group confirmed the possibility of the Congress going ahead.

Two further examples may be worth mentioning to illustrate the unusual features of this Second Congress. In May 1970, the Secretary received, within 2 days of each other, a letter and a telegram from an Israeli and an ex-Polish Norwegian, respectively, indicating that visas for the Congress had been refused. After consultation, a cable was sent to Dr Wald declaring that the Congress was now cancelled, unless the visas were issued within 10 days. This threat, of course, could not have been implemented, for arrangements were now complete, but it was expected that our Polish colleagues would be fully aware of this. However, it impressed the bureaucracy, and visas were promptly issued.

More sinister was the action of the Government in relation to Dr Wald. A year earlier, he had been advised that he was to be proposed as an honorary Vice-President of the IASSID and at that time had informed the Minister of Health who raised no objection. This proposal was endorsed by the Assembly on the Saturday, and Dr Wald was duly elected. On Sunday morning, however, he indicated that 'he was no longer in a position to accept this appointment' and would say no more. Professor Penrose and others demanded that the Association should take action, and since a small delegation was to be received by the President of Poland, Marshal Marian Spychalski, 2 days later, a protest should be made. At this event, a bizarre situation unfolded. The delegation was led by the President, Shapiro, accompanied by Wald himself, Krynski (Brazil), Veerman (The Netherlands) and Clarke (UK), the latter being charged to raise the problem. The Marshal then offered to answer questions, but first wished to raise some himself. These were in fact questions produced for him by Wald. It was clear after some 50 min, that the Marshal was not going to answer questions, so the Secretary via the translator indicated his need to interrupt. This was allowed, and Wald's position outlined, with an indication that the veto imposed on a respected Polish scientist for a non-political honorary position would create a very bad impression. The Marshal made a few non-committal comments and promptly closed the meeting, indicating that between friends all matters could be solved. After the Congress, letters to the Minister of Health in Warsaw were unacknowledged, and the final card by the IASSID was therefore played.

A letter to the Polish Ambassador in London indicated that unless the problem was resolved within 10 days, a Press Conference would be called outlining the story. Rapid action by the Poles resulted. A cable from Warsaw indicated that no problem now existed because Dr Wald was currently abroad!

These examples (and there could have been several more) are offered as an indication of how a small international organisation can run into unexpected problems, and can on occasion put repressive bureaucracies to flight

The Congress itself attracted about 1600 delegates from 42 countries, and with a large Polish presence at the Opening Ceremony. Moreover, it had been hoped, perhaps naively, that the Soviets would come in force. This did not occur and one Polish delegate suggested that his country was regarded as dangerously liberal by the Soviets who were therefore not allowed to attend.

The scientific programme was comprehensive, and according to recent practice, involved plenary sessions, invited individual contributions and a large number of symposia. Most delegates would have been unaware of the sinister undercurrents which lay behind the Congress, and tribute must be paid to the courage of our Polish colleagues in their difficult and, for some very exposed situation.

Once again, an excellent Proceedings was issued in one volume, edited by Dr D. A. Primrose (1971).

## THE JOINT COMMISSION ON INTERNATIONAL ASPECTS OF MENTAL RETARDATION

Towards the end of the 1960s, the International League of Societies for the Mentally Handicapped (ILSMH) proposed a joint endeavour to obtain World Health Organisation approval as a Non-Governmental Organisation. This was achieved, and an eight-person Joint (ILSMH and IASSID) Commission was set up, with four members from each and a rotating chairpersonship. It was anticipated that the Commission might be able to

react to WHO proposals, to produce 'position papers' and to stimulate WHO's interest in the problems of mentally retarded individuals. Moreover, it could provide a link between ILSMH and IASSID.

### THE THIRD CONGRESS, THE HAGUE THE NETHERLANDS, 1973

Each Congress has been associated with particular problems, sometimes minor and sometimes, as in Poland, extremely difficult. The Hague Congress was no exception.

An active and enthusiastic local Organising Committee booked the expensive but superb Congress Centre, and employed a professional organisation to prepare the meeting. Unfortunately, disagreements broke out between these two parties, and the Congress organisation was sacked. Another one was then employed and expenses mounted. At this time and for some years thereafter, the IASSID finances, derived from Congress 'profits', the sale of Proceedings and national organisation fees, were in an alarmingly dangerous state. Nevertheless, this was another very successful Congress attended by more than a thousand delegates from 43 countries.

The major contributions, edited by Dr Primrose (1975), were published in one large volume. A second, smaller volume recorded contributions in memory of our first 'Honorary Vice-President, Lionel Penrose. F.R.S., who had died the previous year. This was a superb testimony to his role in laying the foundations of the major research advances then occurring in the biomedical field. Professor Berg's paper on Penrose's contribution to the field is an important historical account.

Another noteworthy event at The Hague Congress was a full meeting of the Joint Commission. Here it was decided to produce a major document on the whole research field, dealing, for example, with Prevention, Amelioration and Services, and with the aim of gaining WHO/Joint Commission sponsorship. This proved to be a considerable project, with many revisions and changes of emphasis, the latter at the behest of WHO. Many years were to pass before *Mental Retardation: Meeting the Challenge* (WHO, 1985) was published, but it remains the main contribution of the Joint Commission and has been translated into several languages.

### THE FOURTH CONGRESS. WASHINGTON. D.C., 1976

A practice was now initiated of giving a particular flavour to congresses and to Proceedings by means of a catchy phrase. *From Research to Practice in Mental Retardation* became the theme, and ultimately resulted in a three-volume Proceedings under that general title, with each relating to (1) *Care and Intervention*; (2) *Education and Training* and (3) *Biomedical Aspects*. Professor Peter Mittler undertook the editorial task with the assistance of Mrs Jean de Jong, a faithful and highly effective volunteer technical editor, who remained with us from 1967 until 1985. In 1982, the Association honoured her for her magnificent service. The attendance at this Fourth Congress was very large, and much of the local organisation and publicity was carried out under the auspices of the American Association on Mental Deficiency.

The average delegate can have little appreciation of the vast amount of voluntary work carried out in the host country and in the various organisational and editorial committees, often under conditions of extreme financial constraints which limit the number of meetings at which planning takes place. This continues immediately from the end of one Congress in anticipation of the next. The Washington Congress stands out for the high level of many of its contributions, and for the comprehensiveness to the largest Proceedings the IASSID has published, in this case via University Park Press.

By now the pattern of Congresses was well established, hence only the sketchiest of details of more recent meetings will now be offered.

In 1979, under the title *Frontiers of Knowledge in Mental Retardation* the Fifth Congress took place in Jerusalem under the Presidency of Dr M. J. Begab. The Proceedings were published in 1981 in two volumes, edited by Professor Peter Mittler.

Three years later came the Sixth Congress, this time held in Toronto on the theme *Perspectives and Progress in Mental Retardation*. The President was Professor Åkesson and the two-volume Proceedings were edited by

Professor Berg (1984). Doctor G. A. Roeher was nominated as President for the years 1982-1985, but after his untimely death in an air accident, Dr Annalise Dupont occupied this post for much of this period. IASSID International Awards were initiated at this meeting.

The Seventh Congress (1985), entitled *Science and Service in Mental Retardation* took place in Delhi, providing many Europeans, Americans and others with their first taste of the East. It had been preceded a few years earlier by a Regional Conference held in Bangalore, which served as a trial run. The one-volume Proceedings, again edited by Professor Berg, was published in 1986.

*Key issues in Mental Retardation Research* formed the theme for the Eighth Congress (1988) held in Dublin and the Proceedings were issued in early 1990, edited by Professor W. I. Fraser with a translation into Spanish completed late that year.

The editorial task in all cases has been immense, even though supported by an Editorial Board and by the technical assistance through much of this period' by Mrs Jean de Jong. The Association stands in very great debt to all its editors.

The Ninth Congress (1992) will take place in Australia. This represents the first international meeting in the new 4-year cycle.

## RETROSPECT AND PROSPECT

As indicated in the 'Introduction', many influences led, directly or indirectly, to the foundation of the IASSID. These included research advances, social and political changes, the evolution of parental pressure groups and the existence of a few national professional associations, notably the AAMD. As in other fields, one can echo the sentiment that we stand on the shoulders of others.

The main executive bodies of the Association are the Council. and at Congresses also the Assembly. The Council's officers, the President. President-elect, Vice-Presidents, Secretary, Treasurer and, in addition, the Editor of the Proceedings. carry the main burden, and meet as and when opportunities arise. The remaining members, drawn currently from some of the 38 national associations, are rarely able to foregather. Thus, the main contacts are by post or at major conferences.

The Constitution of the IASSID imposes an especially heavy burden on the President whose (up until 1988) 3-year term of office is normally preceded by 3 (now 4) years as President-elect with responsibility for the Scientific Programme Committee. The Secretary's post is also very demanding, for the term of office is 6 years, and should it happen that the Secretary becomes President-elect, a 12-year period (now 14) as an officer results. This has already occurred once. One of our Presidents, Dr Annalise Dupont occupied this latter position for almost two terms following the tragic death of Dr Allan Roeher. Similarly after the resignation through ill health of the Secretary, Dr Ignacy Goldberg. Dr David Primrose's 6-year term of office lasted some 9 years. In addition, he had edited the 1970 and 1973 Congress Proceedings. These examples are offered as an indication of the Association's special debt to individuals like these. Such continuities, though very demanding, serve to promote an experienced administration for our endeavours.

After more than 25 years' existence, what can the IASSID claim to have achieved, and what are its weaknesses? There are two linked areas of obvious success. First, it has provided a regular forum for International exchange for personal interactions and for a world-wide influence through the printed word. Second, with the ILSMH it achieved in the Joint Commission official recognition by the World Health Organisation. This led among other things to the publication of an important. WHO/Joint Commission document aimed especially at problems of mental retardation in the developing world (WHO. 1985). Moreover, the Joint Commission is now regarded as a useful consultative channel, currently producing for WHO a document concerning the principles of assessment. More recently, an ad Hoc working group convened by Dr Robert Guthrie under the auspices of the Joint Commission has recommended the encouragement world-wide of preventive intervention. The criteria for such action are seven in number: easily understood: means are simple; many cases exist; cost is reasonable; little controversy; successful programmes exist; and progress

easily measured. Among the targets identified and endorsed at the 1988 Congress were: (a) iodine supplementation by whatever means is appropriate with, and on the advice of, those expert and experienced within such activity (and) (b) provide as much support as possible to W.H.O.'s existing Expanding Programme for Immunisation for all children, including those with an existing disability, together with whatever support that may be appropriate to other immunisation programmes, e.g. rubella and maternal tetanus immunisation.'Contact has now been made with appropriate persons in a few selected countries to see that these interventions are initiated.

The weaknesses of the IASSID reside in the unavoidable fact that its officers are all busy professional people with many other demands upon their resources. Our funds do not as yet allow for a salaried administrative officer and a part-time post would be very valuable. To be more ambitious than we have been in the past, while desirable, would impose even greater burdens upon a few people.

Finances have been a source of considerable worry until recently. Here tribute must be paid to past Treasurers. Dr Annalise Dupont (1979-1982) and Dr Alice Bernsen (1982-1988), who rescued the Association from a chaotic situation arising in the 1970s. Income depends on modest annual fees from national scientific associations affiliated to the IASSID, upon a subvention from Congress registration fees, and from royalties from Proceedings. Expenses range from secretarial costs to the funding or partial funding of Programme Committee meetings.

Some scientists believe that the era of large international gatherings is coming to a close. Such a view is arguable, especially in the light of travel and accommodation costs. For the IASSID, however, the new, longer, 4-year cycle of congresses from 1988 onwards, may go some way to answering the problem. It could be that in the future such meetings might be partially replaced by more limited regional conferences. These are certainly desirable in their own right, especially since problems may need regional discussion and regional solutions (e.g. in different parts of the developing world).

It became clear at the Dublin Congress that the Council and its associated committees are in process of reappraising current. For example, a Working Group on the Elderly Mentally Handicapped is likely to be set up and a major revision of our Constitution has been undertaken by Drs de Jong and Primrose, and the future of Congress Proceedings is being reconsidered in the light of publication costs, sales, the needs of special interest groups and the relatively short shelf-life of some contributions.

In a nutshell, the IASSID is alive, well and active; there seems to be no shortage of interested professionals from many disciplines who will build upon and develop the work of the past. Apart from this all-important human input, the main priority must now be the encouragement and recruitment of more national associations and the further improvement of our financial resources. In keeping with its name, the Association must maintain its position as the major organisation for advancing and reviewing multi-disciplinary scientific endeavours in the field.

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