Contributions of IASSID to the Scientific Study of Intellectual Disability: The Past, the Present and the Future

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President, IASSID, 1996-2000

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Abstract

Since its inception in the early 1960s, the International Association for the Scientific Study of Intellectual Disabilities (IASSID) has played an important role in advancing the scientific study of intellectual disability, primarily in the developed world. Through its regular world congresses, and its NGO status with the World Health Organization, IASSID has served as a forum for bringing together scientists and professionals working the multiple fields of interest related to intellectual disabilities. Highlighted are IASSID's achievements throughout the past 40 years, with special reference to the trends of presentation content made at its regular congresses and discussed are the challenges facing the Association, which include reaching out to developing countries and involving more researchers from the non-English speaking world, maintaining its networking and informative role in acting as an information clearing house, and promoting the dissemination of research.
The Birth of IASSID

The Association was born out of three international congresses held in Europe and Scandinavia during 1960 to 1963. The first, held in London in 1960 in observation of World Mental Health Year, was sponsored by the Royal Medico-Psychological Association, the Royal Society of Medicine, and the British Psychological Society, in cooperation with the National Association on Mental Health and the (former) American Association on Mental Deficiency. A second congress was held in Vienna in 1961 and a third in Copenhagen in 1964 at which the International Association was duly formalized with a constitution that was published in the *American Journal of Mental Deficiency* (1965, 69, 599) and the *Journal of Mental Deficiency Research* (1965, 9, 150). The inaugural president was Harvey A. Stevens, at the time the president of the American Association on Mental Deficiency and Director of the Waisman Center at the University of Wisconsin-Madison, USA. He was followed by Alexander Shapiro of Harperbury Hospital, Hertfordshire, England. In honour of these early leaders of the Association, the IASSID established the Stevens-Shapiro Fellowships which enable young researchers to present papers at its congresses. These early congresses were held every three years subsequent to the Copenhagen meeting and then in 1988 the cycle went to every fourth year to coordinate with the quadrennial congresses of Inclusion International. The first official congress of the Association was held in Montpellier, France, in 1967. The twelfth congress held in 2004 returned to Montpellier. Table 1 shows the cities and dates of the eleven congresses held in the Association's history, together with the number of presentations at each.
<table>
<thead>
<tr>
<th>Location</th>
<th>Year</th>
<th>Presentations</th>
<th>Congress Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Montpellier, France</td>
<td>1967</td>
<td>403*</td>
<td>**</td>
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<tr>
<td>Warsaw, Poland</td>
<td>1970</td>
<td>348*</td>
<td>**</td>
</tr>
<tr>
<td>Washington (D.C.), USA</td>
<td>1976</td>
<td>339*</td>
<td>From Research to Practice in Mental Retardation</td>
</tr>
<tr>
<td>Jerusalem, Israel</td>
<td>1979</td>
<td>306*</td>
<td>Frontiers of Knowledge</td>
</tr>
<tr>
<td>Toronto (Ont.), Canada</td>
<td>1982</td>
<td>411*</td>
<td>Perspectives and Progress in Mental Retardation</td>
</tr>
<tr>
<td>New Delhi, India</td>
<td>1985</td>
<td>174*</td>
<td>Science and Service in Mental Retardation</td>
</tr>
<tr>
<td>Dublin, Ireland</td>
<td>1988</td>
<td>156*</td>
<td>Key Issues in Mental Retardation Research</td>
</tr>
<tr>
<td>Gold Coast (Qld.), Australia</td>
<td>1992</td>
<td>525</td>
<td>Sharing a Vision of the Future</td>
</tr>
<tr>
<td>Helsinki, Finland</td>
<td>1996</td>
<td>1060</td>
<td>International Advances in Research and Practice</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Global Problems- Local Solutions</td>
</tr>
<tr>
<td>Seattle (Wash.), USA</td>
<td>2000</td>
<td>1306</td>
<td>New Millennium</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Research into Practice</td>
</tr>
<tr>
<td>Montpellier, France</td>
<td>2004</td>
<td>1365</td>
<td>Towards Mutual Understanding, Person, Environment,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Community</td>
</tr>
</tbody>
</table>

* Number of presentations recorded in the relevant Congress Proceedings
** No Congress theme
The Montpellier congress in 1967 was under the patronage of Monsieur le Général Charles de Gaulle, Président de la République Française. The President of the Local Organizing Committee was le Professeur R. Lafon, professor of The Faculty of Medicine at the University of Montpellier and mayor of Montpellier. Dr Harvey Stevens in his presidential address highlighted several issues that still resonate in our contemporary world, and in some respects were quite prophetic. For instance, his first point was directed to the rights of the individual with an intellectual disability. His exhortation was that,

We direct our talents and energies today toward developing services for mentally deficient individuals based upon a philosophy of “differing in need but equal in human rights”. In the not-too-distant past, the mentally deficient individual was viewed not as a “second-class” citizen, but rather, as one who presumed no citizenship. It was thought that he possessed the mental development of a child; the mood was that he fulfilled a child’s role in our society. (p xxxii)

Stevens’ second point related to the use of human subjects for research. He stated that,

If this field is to continue to deserve support for its research activities, it must assure its supporters and the public that adequate safeguards have been delineated and are being rigorously applied, particularly when using the mentally deficient as research subjects. (p xxxii).
Stevens called for the Association to assume an aggressive leadership role in delineating ethical guidelines for use in this field of science. The formation of an affinity group on research ethics and the recent development of the statement by the IASSID Ad Hoc Working Group on International Multi-Centre Research Ethics (IASSID, 2003) indicate that the Association has taken up this challenge albeit almost four decades later. A further challenge posed by Stevens was the need for the establishment of a uniform international statistical reporting system in collaboration with international governmental agencies concerned with world health problems such as the World Health Organization (WHO). Consideration, he indicated, should also be given to the initiation of international epidemiological studies. He also suggested that the Association might assume a leadership role in establishing some uniformity in the usage of the terminology and classification of intellectual disability in the various countries throughout the world.

A fourth issue raised by Stevens concerned the relationship between nutrition and intellectual disability. Undoubtedly, this remains a major problem today and may in relative terms be more serious than it was 40 years ago. Disappointingly, poverty and its related factors such as environmental hazards, malnutrition and disease continue to be among the major causes of intellectual impairment throughout the world.

Another significant issue raised by Stevens concerned the dehumanizing effects of institutionalization, which he defined as “the loss of dignity and the loss of qualities which forces the individual to become less than a man” (p xxxv). In this process one should be concerned with self concept, the dignity of the individual, the sense of his own
values and the opportunity for personal growth and development. Doubtless, the wealth of research on the effects of the lack of educational opportunities, poor sanitation, crowding, and other residual effects of ill-conceived institutional living has served to justify Stevens’ warnings and challenges to the Association.

It is interesting that Stevens in his comment on downsizing of the large institutions reported that in several countries in the 1960s, institution sizes in the order of 300 to 1000 people were still being seen as appropriate. However, again in a prophetic statement, Stevens commented it was not the size of the accommodation that was critical, rather its purpose and quality of the programs that were of significance.

Other issues canvassed by Stevens were the need for a multidisciplinary approach to the study of and service provision to people with intellectual disability; the need for appropriately skilled personnel to support these people; and the application of existing knowledge and information. In respect to the latter he suggested that,

… the major achievement in the area of prevention and in the development of services to the mentally deficient will not come from new knowledge that we will obtain in the next decade through research. Rather, it will be through the assimilation, integration, and application of the knowledge already available and lying dormant in our professional journals (p xxxix).

I have drawn upon Stevens’ address to indicate that he, in many ways, foreshadowed the future directions that IASSID would take. Each of the issues he raised is as pertinent today as it was in September 1967.
An Increasing Multidisciplinary Focus

Another of the founders of the Association, the first secretary, fourth president and Distinguished Award holder, Dr Alan Clarke, in his insightful history of the Association (Clarke, 1991), suggested that a number of factors had accelerated scientific inquiry in our field in the post-World War II years. These included the spirit of optimism and humanism which attracted people to be more aware of disadvantage and to seek preventive or remedial measures as well as the widespread belief that scientific methodology had much to offer. Of significance, too, was the strong growth of parent-focused lobby groups such as the International League of Societies for the Mentally Handicapped (ILSMH) founded in 1960, which stimulated and impacted on policy and service provision within nations and at the international level.

Much of the early scientific research had been biomedical, typified by the epidemiological Colchester studies of L.S. Penrose in 1938 and his 1949 *Biology of Mental Defect*. A harbinger for the future broadening of disciplines involved in research into intellectual disabilities was the publication by Ann and Alan Clarke of their first edition of *Mental Deficiency: The Changing Outlook* in 1958. This was almost entirely written by psychologists and a significant proportion of the 18 chapters was devoted to training and other forms of treatment. This form of content was to become the pattern for the subsequent congresses of the Association. Table 2 shows a breakdown of the proportion of the presentations made at each of the eleven congresses across a number of the major themes. Over the years we have observed a decline in the proportion of
biomedical papers and a subsequent increase in the proportion of applied research.

Proportions of presentations in the areas of epidemiology, policy, early intervention, and vocational endeavors have remained relatively constant.

Percent Topical Distribution of Papers Presented at World Congresses of IASSMD/IASSID

<table>
<thead>
<tr>
<th>Year</th>
<th>Bio-medical</th>
<th>Epidemiology/Classification</th>
<th>Philosophy, Policy, Service Models</th>
<th>Applied Research</th>
<th>Early Intervention</th>
<th>Vocational</th>
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<tbody>
<tr>
<td>1967</td>
<td>33</td>
<td>8</td>
<td>16</td>
<td>37</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>1970</td>
<td>41</td>
<td>6</td>
<td>13</td>
<td>33</td>
<td>1</td>
<td>7</td>
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<tr>
<td>1973</td>
<td>29</td>
<td>5</td>
<td>15</td>
<td>45</td>
<td>2</td>
<td>4</td>
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<tr>
<td>1976</td>
<td>24</td>
<td>6</td>
<td>16</td>
<td>46</td>
<td>5</td>
<td>3</td>
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<tr>
<td>1979</td>
<td>19</td>
<td>8</td>
<td>14</td>
<td>50</td>
<td>4</td>
<td>5</td>
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<tr>
<td>1982</td>
<td>12</td>
<td>7</td>
<td>27</td>
<td>48</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>1985</td>
<td>24</td>
<td>8</td>
<td>12</td>
<td>51</td>
<td>2</td>
<td>3</td>
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<tr>
<td>1988</td>
<td>13</td>
<td>5</td>
<td>10</td>
<td>66</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>1992</td>
<td>15</td>
<td>6</td>
<td>10</td>
<td>61</td>
<td>2</td>
<td>6</td>
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<tr>
<td>1996</td>
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<td>2</td>
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<tr>
<td>2000</td>
<td>10</td>
<td>9</td>
<td>17</td>
<td>58</td>
<td>2</td>
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Despite the apparent multidisciplinary representation of presentations at each congress, it has been observed that our congresses appear to be bipolar, with discrete bio-medical and socio-behavioral themes seldom interfacing. The emergence of Special Interest Research Groups (SIRGs) that involve researchers from a wide range of disciplines studying a specific issue is possibly one of the more significant developments of the Association. The development, jointly by the Aging and Physical Health SIRGs, and the subsequent publication of *Ageing and Intellectual Disabilities. Improving Longevity and Promoting Healthy Ageing* (2000) by the World Health Organization is an excellent example of how a multidisciplinary approach can aid in framing and defining a specific public health and research problem. Subsequently, similarly developed position papers have been organized and written by the SIRGs on Physical Health, Mental Health, and Quality of Life and published in various journals (e.g., Beange, Lennox & Parmenter, 1999; Schalock, Brown, Brown, Cummins, Felce, Matikka, Keith & Parmenter, 2002).

**Congresses of the Association**

There was great enthusiasm expressed by the early presidents of the Association that IASSID would play a major role in initiating and coordinating research activities within its member associations and beyond. For instance, incoming President Dr. S. Krynski from Brazil in his closing address at the Second Congress held in Warsaw suggested that the Association should:
• Train the technical personnel necessary to carry out scientific research and teaching programs

• Conduct epidemiological and statistical studies and research in the various fields concerning mental deficiency

• Publish a biannual newsletter, for a better contact with associated societies.

• Achieve a better economic infra-structure for the execution of our aid, teaching and research programs

• Prepare two international symposia to take place before the Amsterdam Congress: a Pan-Pacific Symposium with the participation of the nations of Asia and Australia so as to integrate them better into our scope of work, and the other to be a Pan-American Symposium, probably in Canada in 1972. If possible, a better alignment of the African group, stressing specific mental deficiency problems in that continent

• Establish closer links with the International League

• Obtain the cooperation of official international organizations such as UNO, UNESCO, WHO and others. It is well known that the problem of mental deficiency is of a bio-psycho-social nature. Isolated attempts at solving it will be of no avail if we do not have a global plan for the prevention of mental deficiency. We have been to the moon but we have not yet solved the problem of hunger in the world. And hunger is probably the main cause of mental deficiency in a world where malnutrition is the normal way of life. We shall
need national and international funds for a comprehensive program of biopsychosocial prevention

- Motivate world public opinion in relation to the problem of mental deficiency

Krynski (1971) stated, "Our aim is not to just hold congresses. We propose to tackle these problems."

Given the voluntary nature of the officers of the Association, limited resources, lack of a secretariat and the fact that many of the organizational members were not necessarily research-oriented, few of these laudable goals were immediately achieved. An exception was the proposal for closer links with organizations such as WHO. In the late 1960s an eight-person Joint Commission was established between IASSID and ILSMH and WHO. This led to the publication in 1985 of a WHO/Joint Commission document aimed especially at problems related to intellectual disability in the developing world. At the 1988 Congress held in Dublin, with the convenorship of Dr. Robert Guthrie, an ad hoc working group was established, under the auspices of the Joint Commission, to encourage world-wide preventive intervention, in areas such as iodine supplementation and WHO's existing Programme for Immunization of all children. The Joint Commission also produced for WHO a document on principles of assessment.

At the tenth Congress, held in Helsinki in 1996, the Council of the Association resolved to recommend to WHO the suspension of the Joint Commission and to seek instead non-government organization (NGO) recognition. Subsequently, IASSID was
recognized as having NGO status with WHO and an agreement was entered into whereby IASSID would produce working papers on a number of relevant issues. This relationship with WHO proved highly successful (as exemplified by the publication by the WHO of the aging research position paper) and currently being further developed and expanded.

Given the emphasis on prevention and the longer history of bio-medical research it is not surprising that the plenary sessions of the first three congresses were heavily biased towards research in this area. For instance, of the twenty plenary presentations at the First Congress thirteen were of a bio-medical nature. However, there were some significant figures from the behavioural area who presented. These included Skodak on early intervention; Leland, Nihira, Foster and Shellhaas on adaptive behaviour; and Goldberg on special education. Invited papers were presented in the areas of employment, learning, language, residential care, teaching, and architectural planning. Significant figures who presented in the bio-medical area included Berg, Waisman, Jervis, Akesson, Wald, and Penrose.

A similar pattern was evident in the next two congresses with well known figures including Penrose, O'Connor, Gunzburg, de Lorenzo, Opitz, Dybwad, Dupont, Richards, Watson, Lovaas, Clarke, Grunewald, Buchwald, Stein, Wolfensberger, Balthazar, Heber, Garber, Roeher, Chigier, Kiernan, and Bank-Mikkelsen. The congresses were organized with plenary sessions, symposia, invited papers and free presentations, a pattern which most subsequent congresses have followed. The emergence of the SIRGs has contributed
significantly to the depth and wealth of symposia presentations that reflect the outcomes of multi-disciplinary collaborations between the congresses.

A feature of the Third Congress was a memorial session in honor of the late Professor L.S. Penrose, who had been an honorary Vice-President of the Association and a strong supporter of its scientific objectives. In his dedication to this legendary figure, Dr Joe Berg wrote,

Few… need to be reminded of Professor Penrose's pervasive and salutary impact in the field of mental deficiency by his personal example, his scientific researches and his influence as a guide and a mentor (p vii).

The Fourth Congress held in the United States in Washington, D.C., in 1976 was the first to adopt a theme or as Alan Clarke described it "a catchy phrase". In this case it was From Research to Practice in Mental Retardation. Subsequent themes are shown in Table 1.

Peter Mittler, the editor of the proceedings, Research to Practice in Mental Retardation (1977), produced three volumes that were based on the major themes of the congress; Care and Intervention, Education and Training, and Biomedical Aspects. Whilst this congress witnessed a steady increase in the proportion of applied behavioral presentations, there was little evidence of interdisciplinary collaboration. This congress, the first held in North America, brought together some of the most significant players in the American intellectual disability research community, with a good representation from other countries. The support given to it by the American Association on Mental Deficiency contributed to its overwhelming success.
A reading of the opening and closing addresses by the Program Chair, Dr. Michael Begab and the opening address by President Alan Clarke is strongly recommended. Their analysis of the state of the art in scientific enquiry in those years resonates with earlier comments of Harvey Stevens. Begab, for instance, noted the relative imbalance between resources applied to services compared to research. But he also stressed that as research is conducted in the context of social, political and economic events, it alone cannot solve the problems facing people with intellectual disabilities. He also drew attention to the fact that the scientific community was showing little interest in the study of residential provisions from a social organization perspective. In particular he warned that,

… in the establishment of half-way houses, group care homes, and an increased use of foster family care, there has been no systematic effort to determine what factors within the various settings are most contributory to successful placement (p. 17-24).

Alan Clarke, in his presidential observations on the Congress theme lamented that the gap between research and practice, especially in helping to increase the functionality of people with intellectual disability was "extremely bad". He questioned why some professionals appear to be more successful than others "at releasing the social and learning potentials of the retarded". (p. A16)

By the time of the Fifth Congress in 1979, there was a growing recognition of the interdependence of basic and applied research, as advocated by Begab in his presidential address. He said, "We must never forget the vital interdependence of basic and targeted
research if we are to effectively combat mental retardation” (p. xxxv). He also recognized that knowledge is not the sole province of the scientist for we need to learn from professional practitioners, caregivers and families. It would be another 20 years before we recognized that we could also learn directly from people with an intellectual disability.

The Toronto, Canada, Congress was significant for IASSID in that the substantial profits from that congress helped to bankroll the organization for a number of subsequent years. Sadly, however, the President-Elect, Alan Roeher, was killed in a tragic accident aboard a plane before he was able to assume the office of President.

With later Congresses, we observed a progressively broadening and more nuanced set of presentations more accurately representing the changes in the tenor and nature of the intellectual disability related research being conducted throughout the world. A source for this broadening was a combination of the venues of the Congresses, with each host nation adding to the nuanced issues being studied, and the changing nature of research inquiry in the field. This thematic expansion was evident at the Cold Coast, Australia, Congress, both in terms of the variations on the traditional topics covered and in the number presenters covering new topics. The Congresses held in Seattle, USA, and Montpellier, France attracted even a more diverse lot of contributors coming from some 50 countries and broadened the topics covered in the sessions. At the recent Congresses, we have also observed more interests from researchers representing a variety of countries around the world. While originally there was strong representation from Western Europe, North America, Australasia and the Pacific Rim, we have now observed a
burgeoning interest by researchers and academics from Eastern Europe, Central and South America, Africa and Central Asia.

**Publications**

Conference proceedings from each of the first eight congresses were published under the editorship of B.W. Richards (First), D.A.A. Primrose (Second and Third), P. Mittler (Fourth and Fifth), J.M. Berg (Sixth and Seventh), and W.I. Fraser (Eighth). Owing to the costs of production and the short shelf life of congress proceedings generally, it was decided to abandon the publication of proceedings effective with the Ninth Congress and invite journal editors to run special issues of papers of special interest. Generally, this resulted in a number of special thematic issues, published by the *Journal of Intellectual and Developmental Disabilities*, the *Journal of Gerontological Social Work*, and the *Journal of Applied Research in Intellectual Disabilities*. Starting with the Eleventh Congress, held in Seattle, Washington (USA) in 2000, a special issue of the *Journal of Intellectual Disability Research* is now devoted to publishing the congress abstracts. This was done at the instigation of Professor T. Parmenter, then the President of IASSID, who felt that the publishing of presentations by researchers in an official peer reviewed journal would be of importance for the careers of young researchers – once again fulfilling the aims of IASSID.

In addition to the published proceedings of the congresses, in 1994 the Association adopted the *Journal of Intellectual Disability Research* as its official journal in arrangement with its publisher, Blackwell Publishing, and MENCAP in the United
Kingdom, its title owner. Ten years later, in 2004, the Association established its own journal, the *Journal of Policy and Practice in Intellectual Disability*, also published by Blackwell Publishing with help from a development grant from the Tosinvest Sanità Organization in Italy.

Another recent initiative has been the publication of books developed and contributed to by IASSID members, which brought together authors from a variety of disciplines. One series with Blackwell Publishing includes texts by Walsh and Heller (2002) on the health of women with intellectual disabilities, Prasher and Janicki (2003) on the physical health of adults with intellectual disabilities, and Davidson, Prasher and Janicki (2003) on mental health, intellectual disabilities and the aging process. In addition, IASSID sponsored a text edited by V. Prasher on the biological correlates of Down syndrome and Alzheimer’s disease (Prasher, in press), which was developed in concert with Radcliffe Medical Press, Ltd. in the United Kingdom. The Association also uses its newsletter and electronic correspondence to disseminate information of interest to researchers worldwide. This is augmented by the work of the individual SIRGs which produce regular newsletters in electronic form.

**Organizational Changes**

A number of important structural changes were implemented by the Association in the lead up to the Helsinki Congress. In 1995 a special General Assembly was held in San Francisco to ratify a number of significant constitutional changes. These included a name change (that is, substituting the term “intellectual disabilities” for “mental deficiency”); the establishment of the category of membership for individual members;
the development of regional groups (RIGs); and the establishment of a number of special interest research groups (SIRGs). As of 2000, a new category of research centre membership was added and an active web site developed and maintained thanks to the energies of the Immediate Past President, Dr Neil Ross. In pursuit of its functions to facilitate networking between scientists, the provision of a venue for the presentation of emerging research, and to address public policy issues affecting intellectual disabilities as a non-governmental organization (NGO), IASSID promoted the development of regional IASSID conferences in between the quadrennial Congresses. For example, the IASSID-Europe regional group held a conference in Dublin in 2002 and has plans for another one in Maastricht in the Netherlands in 2006, while the IASSID-Asia/Pacific regional group has a conference planned for Taipei in 2005. In 2003, the IASSID Sud-America group organized a meeting in Buenos Aires, Argentina. To further the exchange of ideas and mix of background, the representation on the Council, the Association's governing body, has been significantly broadened from its original conception which included only representatives from organizational members; it now includes members representing the interests of IASSID’s individual members, special interest research groups, research centres, and regional groups, as well as national association members.

**Thoughts on the Future**

IASSID has made steady progress from an organization whose main activity was, for 25 years, the conduct of a triennial or quadrennial congress and the publication of the proceedings of these congresses; to one that has diversified its activities to the extent that it is now a more powerful international force in the creation and dissemination of
knowledge in the field of intellectual disabilities. In the context of the socio-cultural, technological, economic and political trends which are accompanying us into this millennium, IASSID has a vital role to play in ensuring that people with intellectual disabilities continue to see improvements in their quality of life. While discipline-based research will continue independently, IASSID has the ongoing responsibility to assist in the coordination of research and in its dissemination. The promising signs of an integration of basic biological and behavioral research need to be further fostered. Neuroscience, suggested Stephen Schroeder (1991), represents a fusion of several scientific disciplines – biophysics, biochemistry, physiology, anatomy, pharmacology, genetics and psychology – and serves to focus on an understanding of the relationships between the brain and behavior. New developments in brain imaging techniques are providing powerful means for studying the complexities of the human nervous systems. Another area where the integration of the biomedical and behavioral sciences occurs is in the area of behavioral phenotypes. An increasing challenge for the Association will be in its role to provide a forum for the ethical and moral debates that are surrounding the application of human genome research.

Just as important we need to encourage a wider engagement of the research community in the field of intellectual disabilities in issues that affect the wider community. We have had a tendency to look inwards with a “ghetto mentality” at times. In other words, we need to be more inclusive in our research efforts. Obviously, we need to ensure that the special physiological and psychological needs of this population are addressed, but these investigations need to be informed by research efforts in the wider community.
We may need new research paradigms and new methodologies in order to meet this challenge. The plea for a better articulation of research into practice has not diminished in the forty years of the life of the Association. This was identified as a major challenge by Harvey Stevens and while many advances have been made in the discovery of new knowledge, the gap to practical applications appears to be widening. The solution to this dilemma may lie in a careful examination of the statement by Ann and Alan Clarke in the preface to the 1958 edition of *Mental Deficiency: the Changing Outlook* that, "mental deficiency is a social-administrative rather than a scientific concept, varying in different countries and within a given country at different times" (p xiv).

IASSID, as a non-governmental organization, serves the world’s interests by providing a forum for the interchange and exchange of dialogue centered on research ideas, needs, and dilemmas. It also provides the important linkages for our diverse range of researchers in framing, organizing and implementing multi-national, interdisciplinary studies in the area of intellectual disabilities. A good example is the research of Paul Aison, Arthur Dalton, Mary Sano, and colleagues on the examination of the potential protective effects of vitamin E on adults with Down syndrome who are at risk of Alzheimer’s disease (Dalton et al., 2004). This multi-million dollar study funded by the National Institute on Aging in the United States drew from a broad and diverse network of IASSID affiliated researchers interested in Alzheimer’s disease and Down syndrome and brought them together into a multi-site network collaboration unfettered by national boundaries. Other such efforts have brought together IASSID-linked researchers within
Europe and have led to several multi-national studies funded under the European Union. I certainly envision more such efforts over the years to come.

Finally, IASSID needs to reach out to developing countries by encouraging and supporting indigenous research efforts. The partnering of established research institutes and centres with those newly forming in developing countries should be explored. However, in doing so, we need to be cautious in imposing western solutions and practices to cultures that have different histories and mores. We need to listen and observe how other cultures solve their own problems. To achieve this goal the Association may need to work in closer partnership with other agencies and bodies such as WHO, Inclusion International, and the World Bank. In this vein, IASSID has sought out and recently developed inter-association affiliative agreements with other like-minded international organizations, such as Alzheimer’s Disease International, Down Syndrome International, and the International Association of Child Neurology.

As an organization that has relied entirely on the goodwill and energies of a small band of dedicated volunteers, IASSID can be proud of its achievements over the 40 years of its existence. I believe the dreams of its founders have been, in large measure, realized. The challenges ahead are for us to work steadily on those things that are achievable, keep reaching for those that are yet to be achieved, and promote a better understanding of the nature of intellectual disabilities and the people affected by them. We need to accomplish this both within the resources and capacities that are available to us, and within our capacities to extend our efforts by advising and advocating for sufficient national and international resources to achieve our ends.
Footnote

1. Formerly the International League of Societies for the Mentally Handicapped (ILSMH).

References


