

Institute of Neurosciences, Mental Health and Addiction

Canadian Institutes of Health Research

Round Table on Research Collaboration

Ottawa, Ontario

Report of Proceedings

June 23-24, 2001

Institute of Neurosciences, Mental Health and Addiction
Round Table on Research Collaboration

Part A

Summary

Welcome and Introduction

The *Round Table on Research Collaboration* was sponsored by the Institute of Neurosciences, Mental Health and Addiction (INMHA) of the Canadian Institutes of Health Research (CIHR). This was the first of several proposed Round Tables planned for the summer and fall of 2001 in various parts of Canada.

Phil Upshall, a member of the Institute Advisory Board, welcomed the participants and outlined the purpose and background of the *Round Table*. The Canadian Institutes of Health Research (CIHR) is in its infancy: as such, it is breaking new ground. Its broad mandate and limited funding means that that partnerships are a *must*, and not an option. The Board of the INMHA is very interested in the proceedings of this meeting as input to its work.

The purpose of the *Round Table* was to provide the opportunity for the Institute and volunteer organizations to develop a collaborative relationship with regard to research programs, funding and dissemination. The objectives of the *Round Table* were:

1. To increase awareness among the volunteer organizations of the mission and goals of the Institute of Neurosciences, Mental Health and Addiction (INMHA).
2. To increase awareness among the Institute and the volunteer organizations of the related activities of other volunteer organizations.
3. To investigate the means by which the volunteer organizations can effectively collaborate with each other and the Institute on research-related issues.

Approximately forty volunteer organizations representing a wide range of neuroscience, mental health and addiction health issues were invited to the *Round Table*. Each was invited to bring materials about his/her organization to share with others.

The *Round Table* was organized into five sections. Remi Quirion, the Scientific Director of the INMHA and Astrid Eberhart, Institute Liaison of the INMHA, presented an overview of the CIHR and INMHA.

All organization representatives took the opportunity to introduce themselves and their organizations. Each provided a brief statement regarding his/her organization's mission and interest in research collaboration through the INMHA.

Small group discussions took place on collaboration, communication and dissemination followed by presentations and discussions with the entire group. The *Round Table*

concluded with the discussion of future partnerships and recommendations to establish the process of collaboration and to ensure ongoing communication. As the meeting ended, participants were asked to complete the "Follow-up Form", on which they could indicate how their organization might contribute to the future of the INMHA.

Overview of the CIHR and INMHA

Dr. Quirion explained that the CIHR consists of thirteen "virtual" institutes, of which the INMHA is the largest in terms of scope. The goal is to promote interaction amongst these thirteen institutes, so that they work together, rather than individually, on common issues. He reviewed the vision, mission and objectives of the INMHA. (See the section on "INMHA" for more details.)

Dr. Quirion reviewed the main challenges facing the Institute and the structure of its budget. The Institute Development budget includes the fixed costs of salaries, operations and travel, as well as the expenses of the operation of the Institute Advisory Board, and of Institute development. The "Strategic Initiative Envelope" for each of the CIHR's thirteen institutes in 2000/2001 is \$800,000.

Dr. Quirion focussed particularly on the funding programs to be sponsored by INMHA in 2002: Training Grant Program, the New Emerging Team (NET) Program, and Interdisciplinary Health Research Teams (IHRTs). He outlined the following key deadlines for the upcoming months:

- Training Grant Program
- Letter of Intent (LOI) July 15, 2001
- NET Program
- Early Summer 2001

Dr. Quirion concluded by reminding the participants that, since the INMHA is in its infancy, its strategic outlook is still in development.

Astrid Eberhart welcomed the participants to the *Round Table* with greetings from the INMHA, and provided a summary of the organizational and administrative challenges involved in establishing the INMHA and CIHR. Astrid gave a brief outline of her role as the principal contact for the NGOs with the Institute, and encouraged everyone's patience as programs and initiatives unfold over the next several months.

Introduction of Participants

In all, twenty-seven volunteer or Non-Government Organizations (NGOs) sent representatives to the *Round Table*. In addition, two members of the INMHA Advisory Board and five observers attended.

| | |
|--|--|
| Alzheimer Society of Canada | Centre for Addiction and Mental Health |
| Autism Society Canada | Eating Disorders Foundation of Canada |
| Brain Tumor Foundation of Canada | Epilepsy Canada |
| Canadian Alliance of Brain Tumor Organizations (CABTO) | Foundation Fighting Blindness |
| Canadian Centre on Substance Abuse | Hearing Foundation of Canada |
| Canadian Chiropractic Association Research Committee | Heart and Stroke Foundation of Canada |
| Canadian Mental Health Association | Learning Disabilities Association of Canada |
| Canadian National Institute for the Blind | Multiple Sclerosis Society of Canada |
| Canadian National Society of the Deaf-Blind | Muscular Dystrophy Association of Canada |
| Canadian Pain Society | Neuroscience Canada Foundation/Partnership |
| Canadian Palliative Care Association | Ontario Neurotrauma Foundation |
| Canadian Psychiatric Research Foundation | Parkinson Society Canada |
| Canadian Spinal Research Organization | Spina Bifida and Hydrocephalus Association of Canada |
| | Vision Research Council / National Coalition for Vision Health |

Non-government organizations (NGOs) are involved in many diseases or disorders affecting millions of Canadians. They undertake a wide variety of activities and enjoy varied levels of resources. The discussions of the day indicated a great level of enthusiasm and commitment toward working with the INMHA.

From the presentations, it was apparent these Non-Government Organization (NGOs) were involved in a wide range of activities, including:

- Advocacy re: awareness, stigma, services and access, and research/funding
- Research Funding
- Fundraising
- Research Dissemination
- Training
- Surveillance/Population Statistics
- Best Practice Identification
- Information Dissemination and Resource Development
- Partnerships
- Community Support

For more detail on the organization activities, see section "Self-Description of Participant Organizations".

Each organization estimated the number of Canadians affected by their health problem/issue:

| Issue | Number of Canadians |
|---|---|
| Alzheimer's | 150,000 |
| Autism | 60,000 |
| Brain Tumour | 10,000 new each year ? # of existing |
| Injection Drug Users | 125,000 |
| Other Addictions | ?? (Many people) |
| Back and Related Conditions | 6,000,000 (20% of population) |
| Blind/Visually Impaired | 600,000 |
| Mental Illness | 6,000,000 |
| Deaf-Blind | 4,000 |
| Chronic Pain | 10,000,000 |
| Palliative Care (People dying, plus loved ones) | 1,200,000 |
| Spinal Cord Injuries | 35,000 - 40,000 |
| Eating Disorders | 8,000,000 |
| Epilepsy | 300,000 |
| Retinal Problems | 100,000 |
| Hearing Problems | 3,000,000 |
| Heart Disease and Stroke | 40,000 die each year |
| Learning Disabilities | 3,000,000 - 4,500,000 |
| Multiple Sclerosis | 50,000 |
| Muscular Dystrophy and Related Muscle Problems | 10,000 |
| Brain Trauma | 400,000 |
| Parkinsonism | 100,000 |
| Spina Bifida and Hydrocephalus | 1 in 750 livebirths |



Origins of the CIHR

During the lunch period, Dr. Franco Vaccarino from the Centre for Addiction and Mental Health and a member of the Interim Governing Council of the CIHR spoke about the development of the CIHR. When the CIHR was first proposed, he noted that there was a sense of "learned helplessness" among scientists and organizations. He has been encouraged by the fact that the CIHR will be shaped essentially through the creation and operation of partnerships. In addition, the establishment of the INMHA within the CIHR represents the first time that the neurosciences, mental health and addiction are on the front of the government agenda. The future of the CIHR is now looked at with optimism because of collaboration.

Discussions on Collaboration between NGOs and the INMHA

The participants met in four small groups to discuss the mission and objectives of the INMHA, and collaboration, communication and dissemination. For a detailed summary of the small group discussions, see section entitled "Small Group Discussions".

While the NGO representatives generally agreed with the mission and objectives of the INMHA, they gave some specific suggestions for improvement, such as broader reference to brain and spinal cord functions, co-morbidity research, and the social scientific field and qualitative research.

The representatives expressed strong support for collaboration among the NGOs. By working together and pooling resources, and by working on co-morbidities and common topics, NGOs can create a synergistic effect, so that the whole will be greater than the sum of the parts. (Or to coin a catch-phrase of the day: "1+1 will equal 3").

Collaborating with the INMHA would bring additional advantages. The NGOs will gain credibility, undertake joint projects, exchange research information, recruit researchers more effectively, and share resources to even greater effect (1+1+1=10!). In the immediate term, the NGOs place the greatest importance on working with the INMHA in priority setting and information sharing. Other activities can be developed over time. In terms of communication, formal mechanisms are needed through the creative use of the World Wide Web and the Internet. The holding of an annual meeting, attended by both NGOs and researchers, received strong support.

Conclusions and Recommendations

This, the first of several *Round Tables* proposed to be held across Canada, was by all accounts, a very successful meeting. For detailed comments, see the section entitled, "Evaluations of the INMHA Round Table". Participants revealed their organizations' great enthusiasm and interest in working in partnership with one another and the INMHA. Many had come on very short notice - in itself an indication of the eagerness that NGOs representing the neurosciences, mental health and addiction in collaborating in research, advocacy and promotion.

All appreciated the opportunity to meet face-to-face in an atmosphere of collegiality. They came away with a greater understanding of the Canadian Institutes of Health Research (CIHR) and the Institute of Neurosciences, Mental Health and Addiction (INMHA) and its staff. Through the formal and informal discussions, they recognized not only their common goals, concerns and opportunities, but also the benefits inherent in creating partnerships as a means of successfully pursuing their goals. They expressed their desire to build further collaboration with and through the INMHA, through further development of the liaison process (10 organizations), participation on a liaison committee (10), and functioning as a corresponding member (4) of the INMHA. The challenge will be achieving a balance between collaboration and the need for autonomy of the NGOs.

The following recommendations were made:

1. That a staff person be assigned, dedicated to communication between the NGOs, researchers and the INMHA.
2. That a focussed review of existing models of collaboration and co-operation be undertaken to clarify the optimal model for the INMHA.
3. That a formal liaison process be developed for the NGOs, not only within the INMHA but among other institutes within the CIHR.
4. That a meeting of NGOs, researchers and the INMHA be held annually. (There was a consensus that the month of April may be the best time in the calendar year.
5. That, where possible, communication via the World Wide Web and the Internet be used.
6. That specific projects be funded to facilitate the integration of groups into networks of like-minded issues and to support workshops that bring researchers and NGOs together to identify research themes and share research findings.