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INTERNATIONAL REVIEW

OF THE

CANADIAN INSTITUTES OF HEALTH RESEARCH

Expert Review Team Report
for
Institute of Human Development, Child and Youth Health

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Chair, Expert Review Team
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Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Canada

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Summary

Achieving the mandate. The Institute's[1] mandate requires attention to all aspects of maternal-child health[2]. However, the limited funds available do not allow pursuit of breadth, and the Institute has used its dollars to focus on processes that are fundamental to normal development and, when disturbed, lead to ill-health. The Institute has skillfully leveraged its funds, taken advantage of the research strengths in reproductive, perinatal, and child-youth health in Canada, and greatly extended knowledge translation (KT) through exceptionally strong relationships with outside agencies that share mission and goals. Overall, we believe the Institute has successfully met the challenge of its broad mandate and of KT, and the result has been exceptional productivity.

Leadership. There was consensus that the Scientific Director, Michael Kramer, MD, has led the Institute with outstanding vision, judgment, creativity, and commitment to the pursuit of excellence. His stature as a productive researcher and ability to listen and to communicate honestly and persuasively has generated trust in the Institute and expedited mutually effective collaboration with other CIHR institutes and with outside agencies. Dr. Kramer will leave the Institute's directorship at the end of 2011. He was praised uniformly by scientists and stakeholders as possessing the qualities that a future Scientific Director should have.

Major over-arching achievements-Examples. (More specific achievements are summarized under Section 4 – Outcomes.)

- Institute request for applications (RFAs) have been framed to support multidisciplinary, team-based science, which has coalesced researchers across the Institute's relevant disciplines through collaborations and realization of common goals.
- The overall success of research efforts in reproductive and child & youth health has been reflected by increased publications and impact of publications over the last decade that have significantly exceeded world averages.
- The Institute has markedly expanded integration of outside agencies into its efforts to translate and extend the impact of knowledge gained from its research. The success with this integrative system makes it a model for other countries seeking more strength in translating research findings into improved public health.

Summary of recommendations (For details, see Section 6)

1. Continue to focus on research across developmental processes, on multidisciplinary partnerships, and on development of the next generation of researchers in this field. But begin the tenure of the new Scientific Director with a strategic review of the question of breadth versus more narrow foci for the research portfolio.
2. Resurrect the 30,000-subject pregnancy cohort study and move toward eventual funding.
3. Participate in currently ongoing CIHR efforts to improve peer review to secure the changes needed by IHDCYH.

4. Develop a strategic plan targeted at enhancing Institute capacity in healthcare services and policy research.
5. Address the insufficiency of jobs available to graduates of the Canadian Child Health Clinician Scientist Program in needed fields such as psychology, nursing, and dietetics; and create additional research capacity in maternal-child health through education of mid-career researchers.
6. Work with CIHR, other institutes, and stakeholders to remove the obstacles to usage of Canada's scattered health-related databases to allow research to determine effectiveness of interventions and progress toward improved public health.
7. With CIHR, develop and implement a process to track the impact on health behaviours and health itself of the Institute's research and KT programs.
8. Expand the reach and activities of the Institute's communications director to interact more vigorously with outside agencies, the public, and policy- and decision-makers.
9. Consider using the Canadian Academy of Health Sciences to frame policy from new research knowledge, particularly around issues that are contentious or that may lead to major change.
10. Insure IHDCYH institutional memory by fully supporting the newly appointed assistant director who carries this responsibility.

[1]The term "Institute" is used throughout this report to refer only to the Institute of Human Development, Child and Youth Health (IHDCYH).
[2]"Maternal-child health" is meant to include health across the breadth of developmental stages encompassed by the Institute's mandate.

Section 1 – Institute mandate

The Institute of Human Development, Child and Youth Health supports research to enhance maternal, child and youth health, and to address causes, prevention, screening, diagnosis, treatment, short-and long-term support needs, and palliation for a wide range of health concerns associated with reproduction, early development, childhood and adolescence.

Section 2 - Status of this area of research in Canada

What is the current state of this area of health research in Canada?

Research related to the Institute's mandate has steadily increased since the last review. It is likely that this has resulted, at least in part, from the Institute's investing in existing research strengths in Canada and by its encouragement of trans-disciplinary research. Evidence of Canadian strengths is provided by bibliometric indices for reproductive health and child and youth health (pp. 8 & 9, Institute internal assessment). In reproductive health, Canada falls about 20% above the world average in the mean number of citations (slightly below the US and UK, slightly above Australia, Fig 2), and about 14% above the average for the proportion of a country's publications in the designated area. For child and youth health, Canada has had a steady relative increase in publication number compared with the rest of the world, particularly since 2004 (Fig. 3), and the mean number of citations per paper doubled from 1990 to 2006. The Institute recognizes that some research published in its mandated areas was funded by other organizations than CIHR/IHDCYH or was "unfunded", so that these successes cannot be entirely attributed to IHDCYH. Of the top 25 most often cited Institute-supported papers, 13 are in Science, Nature, Cell, or the New England Journal of Medicine, an indication of quality in biological and clinical research.

Overall impression of the Canadian research landscape in this area

We conclude that Canadian research is particularly strong relative to the rest of the scientific world in reproductive biology, maternal & reproductive health, prenatal development, perinatal epidemiology, and child-youth health. Canadian research is not strong in the areas of health services and health outcomes research that leads to changes in health policy, at least in part because of a limited cadre of researchers with these interests. Canada has not developed the academic disciplines of general pediatrics and general obstetrics, which are the traditional homes of such researchers in other countries.

Section 3 - Transformative Impacts of the Institute

The Institute has expanded the perspective of Canadian maternal-child health research from disease-oriented to the fundamental processes of development and the biologic, environmental, and social influences on development that determine health or disease over the lifespan. Research targets within this framework include preconceptional health of parents, normal and abnormal embryonic and fetal development, preterm birth, pre- and postnatal cognitive development, and early origins of adult chronic diseases.

The Institute has transformed the approach to research funding from support only of individual or small-group grants to additional strong support of research teams and partnerships of researchers who are experts in the biologic, clinical, environmental and/or sociologic factors that influence development and health.

In line with the CIHR-wide emphasis on knowledge translation (KT), the Institute has improved translation by developing a truly remarkable relationship of respect and trust with a variety of outside agencies, including health-related foundations, professional societies, public health components of provincial and federal government, and academic centers. This relationship has taken results of the science to groups that have the potential to extend it to improve health of the public.

Overall Impression – to what extent has this Institute been transformative?

Legislators and the public in many developed countries have become impatient with the slow translation of public-funded basic and clinical research findings to improvement in health (i.e., KT). This Institute has transformed the approach to achieving effective KT through its strategic emphasis on developing interactive communication and partnerships with outside agencies. As far as we are aware, this model, based on interdependent respect and trust, is unique internationally, and, we think, highly likely to achieve success.

Section 4 - Outcomes

Some examples of specific outcomes of the Institute's programs are summarized here.

- Caffeine treatment of very preterm infants reduces the risk of bronchopulmonary dysplasia and of developmental disability (NEJM 2007).
- Contrary to common belief and practice, amnioinfusion does not decrease the risk of meconium aspiration syndrome (NEJM 2005).
- Multiple courses of antenatal steroids do not reduce mortality or morbidity from respiratory distress syndrome in preterm infants and restricts fetal growth (Lancet 2008). These three studies changed standard routine care of newborns internationally.
- Children and youth who sustain sports-related concussions can have neurological deficits up to a year after the injury. This study changed return-to-play policies.

- Helmet use by skiers and snowboarders protects against head injury without increasing neck injury (BMJ 2005, CMAJ 2010). This widely published study has led to increased helmet use for snow sports internationally.
- A small cachet containing powdered iron and other micronutrients can be added to food without changing taste, colour, or texture (PloS 2005). Its distribution to 4 million at-risk children in over 30 countries has been promoted by the World Health Organization, the United Nations, and the World Food Program.
- A clinical trial and systematic review of evidence regarding optimal duration of exclusive breast feeding led the World Health Assembly to revise its recommendation to 6 months (from 4 months).

Overall impression – to what extent has this Institute been successful in achieving outcomes?

The Institute has been highly successful in supporting research that has led to important changes in clinical practice, health behaviours, health policy, and health.

Section 5 - Achieving the Institute mandate

The Institute's mandate mentions all aspects of health related to mothers, babies, children and youth; but the $8.5 million budget does not allow adequate pursuit of such breadth. Moreover, the Institute is expected to contribute to RFAs emanating from other CIHR institutes, which reduces available dollars. Thus, the strategic decision has been to focus the Institute's support on life-course aspects of maternal-child health (e.g., early origins of cognition, social & physical influences on childhood obesity, and fetal influences on later health), and on developing the next generation of researchers across all aspects of the mandate. This focus minimizes Institute support of research into causes, prevention, and/or management of specific diseases. Moreover, the system of leveraging dollars through multi-group projects clouds attribution of the Institute's piece of the action. However, this leveraging has been responsible for major gains that have certainly been within the context of the Institute's (and CIHR's) mandate; and the Institute's strategic initiatives, convening of workshops and meetings, and educational efforts have been creative and widely recognized as highly successful.

Overall impression – to what extent has this Institute achieved its mandate?

We believe that IHDYCH has, in general, met the challenge of its broad mandate exceptionally well. It has grown to be recognized in Canada as a central and respected source of support for research in maternal, neonatal, and child & youth health. It has achieved this status through outstanding leadership, highly impressive leveraging of its modest budgetary allocation, strong support for developing the next generation of researchers in reproductive and child health, and a clearly expressed desire to entertain from outside agencies new ideas for research targets and for collaboration in addressing common goals. The extraordinary trust that the Institute has developed in various outside

agencies, including federal and provincial public health agencies, pediatric and obstetrical professional groups, and private foundations has gained, in turn, strong fiscal and collaborative support for Institute-initiated efforts.

Section 6 - ERT Observations & Recommendations

1. The breadth of the mandate has been a challenge. The Scientific Director questions whether they have tried to do too much across too many areas and feels that they have not adequately addressed the need for research related to healthcare, health policy, and illness prevention. He questions whether the Institute should focus on a few major targets in the area of the mandate. We were favorably impressed with the quality of what the Institute has achieved, which has been consistent with increasing evidence that developmental processes and transitions are fundamentally important to susceptibility to disease, not only in childhood and adolescence but also in adulthood. Thus, we strongly support the Institute's focus on developmental processes, as well as on funding initiatives that utilize Canada's existing strengths in reproductive biology, pediatrics, and obstetrics/gynecology. But we did not otherwise feel it appropriate to judge breadth versus focus. We recommend that the Institute's next Scientific Director start construction of a strategic plan with a full analysis of this question, using input from experts and all relevant stakeholders. The ongoing visioning process at National Institute of Child Health and Human Development (NICHD) in the US may be useful to the new Scientific Director when identified.

2. A cohort study of 30,000 pregnancies with offspring followed for 20 years, was framed to study environmental contaminants, epigenetics, and much more, vigorously reviewed by the appropriate experts, and approved up the line through CIHR and above in 2007 - but left unfunded in the end. The price tag of $200 million over 20 years was clearly substantial for CIHR but cheap for the unique and highly important nature of the new information that it would yield. We recommend strongly that it be put back on the table for eventual funding in full.

3. We understand that peer review of multi-disciplinary, team-based, and cross-theme grants is not optimal and that it is being investigated by CIHR. These collaborative activities are particularly important to IHDCYH, and they should be encouraged and enhanced by constructive and broad-based expert review. Thus, we enthusiastically endorse the efforts at improvement undertaken by CIHR and encourage careful attention to the needs of IHDCYH in this process.

4. There is an urgent need, emphasized by the key informants and stakeholders we interviewed, for the evidence base that is fundamental to improving major challenges in Canadian healthcare. Examples include causes of the Aboriginal maternal & child health disparity, maternity care, management and prevention of childhood obesity, child abuse and other injury, and mental health. The Institute recognizes that its efforts in this area (Theme 3) are the weakest among the four themes. We recommend that IHDCYH develop a strategic plan to enhance its capacity in healthcare services and policy research.

5. IHDCYH and the SickKids Foundation collaborated in planning and funding the Canadian Child Health Clinician Scientist Program (CCHCSP) in order to build essential human capacity to support research across the full span of necessary expertise, including in epidemiology/outcomes research, psychology, nursing, and nutrition. However, many of these individuals have been unable to find employment. We recommend that this serious barrier to improving research in Themes 3 & 4 be addressed by the Institute, CIHR, and stakeholders, including the federal government. One suggested mechanism would be a system to support further development of CCHCSP graduates and mid-level researchers in the related fields.

6. There was a uniform view that Canada has an excellent database infrastructure to capture information about health outcomes. Yet this information is largely province-based and difficult or impossible for investigators to access because of privacy and other concerns. These databases represent a unique resource for research that can lead to improved healthcare and health of Canadians. We recommend that the obstacles to use of these databases by legitimate researchers be identified and a concerted effort be made by CIHR, its individual institutes in targeted areas, and its partners to remove the obstacles and allow access. The challenge of dealing with multiple agencies and federal and provincial governments will be formidable, but the return on this investment could be huge.

7. The innovations in support of maternal-child health research instituted by IHDCYH have been extraordinary, and these have had notable success in gaining new knowledge and applications in numerous areas. It is not so clear, however, what impact these have had on health. Although obtaining these outcome data will be a strenuous exercise (probably requiring access to databases, recommendation 6), these data will be required to determine future directions for research and to continue to receive public, tax-based funding. We recommend that CIHR, and IHDCYH within its mandated area, begin to develop a strategy, then process, to address this need.

8. We understand that there is a communications director in Ottawa who represents the interests of the Institute but that the range of his/her responsibilities and activities is limited. Stakeholders expressed a strong need for informed help in communicating the importance of their collaborative efforts with the Institute and of maternal-child health research in general to provincial and federal policy-makers, potential co-funders, and the public. In addition, the Institute might better communicate its needs to potential partners, with the hope of better ideas in return; and perhaps most importantly, the Institute's partners could be guided in the ultimate step in KT, using new knowledge to change health-related behaviours and healthcare practices. We are aware that recent efforts to communicate more vigorously, e.g., by the NICHD and Institute of Medicine in the US, have significantly improved implementation. Accordingly, we recommend that the Institute expand the scope and purview of its communications functions to include more travel and direct contact with important stakeholders and the public at large.

9. The Institute has used consensus workshops to develop RFAs, and these can be used to develop policy recommendations from new knowledge. We recommend that the Institute also consider for this purpose using the Canadian Academy of Health

Sciences to develop policy, particularly when there is a need for independent, open-minded, arm's-length analysis of level of evidence, strength of causal relationships, and the like around issues that are contentious or likely to lead to major change.

10. Transition to a new Scientific Director in a new location will occur in 2011, a recently appointed Ottawa-based assistant director will be expected to ensure institutional memory. This is obviously a particularly important function considering the complexity of IHDCYH's programs, partnerships, and collaborative funding. We encourage CIHR and the Institute to support this function fully and to allow optimal time at the Institute's offices in Montreal.

Appendix 1 - Expert Review Team

Chair - Dr. Richard B. Johnston
Associate Executive Vice President of Academic Affairs at National Jewish
Associate Dean for Research Development
University of Colorado School of Medicine USA

Expert Reviewer – Dr. Roberto Romero
Chief of Perinatology Research Branch and Program Director for Obstetrics and Perinatology, Division of Intramural Research of the NICHD/NIH
Professor of Molecular Obstetrics and Genetics, Wayne State University
Detroit, Michigan USA

International Review Panel – Professor Fiona Stanley
Director, Telethon Institute for Child Health Research
Chair, Australian Research Alliance for Children and Youth
Professor, School of Paediatrics and Child Health
University of Western Australia
Perth, Australia

Appendix 2 - Key Informants

Session 1 – Review of Institute

1. **Dr. Michael Kramer, IHDCYH Scientific Director**

2. **Dr. Jean-Marie Moutquin, Chair – Institute Advisory Board**
   Research Director, Centre Hospitalier de l'Université de Sherbrooke
   Professor and Department Chair, Department of Obstetrics and Gynaecology
   Université de Sherbrooke

3. **Dr. Victor Han**
   Director, Child Health Research Institute
   Professor, Departments of Paediatrics, Obstetrics and Gynaecology, Biochemistry, and Anatomy, and Cell Biology
   University of Western Ontario

4. **Dr. KS Joseph**
   Professor, Department of Obstetrics and Gynaecology
   University of British Columbia

Session 2 – Consultation with researchers

1. **Dr. Bruce Murphy**
   Director, Université de Montréal Centre de Recherche en Reproduction Animale
   Professor, Faculty of Veterinary Medicine
   Associate Professor, Department of Obstetrics and Gynaecology
   Université of Montréal

2. **Dr. Bernard Thebaud**
   Professor, Department of Physiology
   University of Alberta

3. **Dr. Bonnie Stevens**
   Professor, Faculties of Nursing and Medicine
   University of Toronto

Session 3 – Roundtable with stakeholders

1. **Dr. Catherine McCourt**
   Director, Health Surveillance and Epidemiology Division
   Public Health Agency of Canada

2. **Mrs. Claire Fortier**
   Former Vice President, Grants and Finance, SickKids Foundation

3. **Dr. Vyta Senikas**
   Associate Executive Vice President, Society of Obstetricians and Gyneacologists of Canada

4. **Mrs. Marie-Adèle Davis**
   Executive Director, Canadian Paediatric Society