

# Towards a National Partnership for

*Key researchers in children's health and development attended a recent meeting, held at the Australian Institute of Family Studies, to discuss the formation of a new National Research Partnership for Developmental Health and Wellbeing.*

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**S**ome of Australia's key researchers from a variety of disciplines and interested in better outcomes for families, children and society generally attended a two-day workshop at the Australian Institute of Family Studies to debate whether they would create a unique new way of working.

Although their scientific backgrounds varied, some common themes and shared concerns facing Australia's communities, families and children drew the diverse group together. There was a feeling that while individually good research into relevant problems was being done, the singular contributions were not addressing these problems adequately, in ways that could properly inform effective interventions. Perhaps collectively, they could overcome these feelings of helplessness by doing research that was more powerful.

## **Common themes**

There were some common themes and concerns shared by delegates to the workshop.

**1** In spite of Australia's wealth and generally high level of education, many indicators of developmental health and wellbeing are showing adverse trends amongst children and adolescents. Rising rates are being observed for low birth weight, neurodevelopmental disorders, asthma, type 1 diabetes, inflammatory bowel disease, autism, mental health morbidities, child abuse and neglect, adolescent suicide, obesity, eating disorders, learning disabilities, behavioural disorders, aggressive behaviours and violence, school drop out and truancy, juvenile crime, illicit drug and alcohol use, teenage births.

Some of these problems (such as asthma and suicide) have trebled over the last 30 years and are higher than at any time in Australian history. What is it about modern Australia that is causing these increases? Such rising rates are not unique to Australia; most developed countries are observing similar trends. A unique aspect of the problem for Australia is that these indicators are worst amongst our Aboriginal and Torres Strait Islander (ATSI) communities and unlike other former colonies (New Zealand, Canada) ATSI outcomes are not improving at any age.

**2** There have been dramatic social changes for families and communities over the last 30 years. Social, technological, workplace and economic changes appear to have had most benefit for the wealthier groups in societies, with increasingly adverse effects on the growing numbers of families and groups in relative and absolute poverty.

Changes which have occurred in the distribution of wealth, markedly increased inequalities in health, educational and most other outcomes, increasing family breakdown and blended families, undervaluing and neglect of children, changing patterns of women's work, of child care and of the pace of work and life generally, tend to impact most negatively on those with least resilience.

# Developmental Health and Wellbeing

**3** The crucial importance of the early years is now being recognised across a range of outcomes – health, educational, behavioural, and criminal. Research from a variety of disparate disciplines, such as neuroscience, developmental psychopathology, foetal physiology, and early education, are all confirming the powerful influence of early environments to modify genetic influences and risks, either positively or negatively.

Compared with pathways formed early in life, later interventions and influences appear weak in their capacity to make permanent change. A broad program of research would build upon the similarity of early pathways to a variety of negative outcomes, to develop effective interventions which might impact on a very broad range of competencies and outcomes in children. Today's social and environmental influences are far more powerful in child educational, health and welfare outcomes than are the interventions, drugs or other treatments we have at our disposal to manage them.

**4** The realisation has dawned that the aetiological pathways to these increasing problems are extremely complex. Many paths appear to start in some aspect of social adversity and interact with a huge and changing variety of situations, factors and influences over the life span. Some poor outcomes become the antecedents of other problems later on. Many varied paths can result in the same poor outcome and other single factors have many adverse effects. The elucidation of the code for the human genome and the explosion of genetic and biomedical research actually makes this situation more concerning. Not only is there a huge international push to explain most diseases and risk factors as genetic, but if such new research is done and applied in complete ignorance of the global societal-cultural impacts it can have, then we are doomed to be damned by this new knowledge rather than blessed by it.

**5** There was a general feeling of dissatisfaction with the capacity of our own individual disciplines by themselves to investigate these complex problems adequately.

For example, in my own discipline of epidemiology, there is an intense debate going on about the limitations of modern epidemiology to serve today's public health. It focuses on a fairly rigid paradigm of analyses of risk factors in individuals using cohort and case-control studies without any intelligent *a priori* statement of how and in what contexts such risk factors might be arising. There are underlying naive assumptions that there are true universal individual level risk factors that transcend culture, class and context.

As a discipline, modern epidemiologists seem to have forgotten that to understand the causes of disease in a population it is essential to study its historical and social context and how diversity or cultural norms influence pathways. Our ways of analysing risk factors often mask the influence of more distant (distal) risk factors. This is because the more statistically powerful factors measured further along in the causal pathway (proximal factors) outweigh them. By controlling for what are

often seen as “confounding” factors, we not only ignore the earlier part of the causal path, we also ignore the important interactions between causes which may be so powerful.

The concept of pathways, in which the broader social, behavioural, biological and genetic interactions give rise to risk factors and their effects, opens up many more and possibly more effective, preventive strategies. And it demands a true multidisciplinary approach with epidemiologists working with sociologists, economists, psychologists as well as with clinical and biomedical researchers.

**6** There have been considerable changes in the global physical and biological ecologies as well as in the social environments described in the second point above. As the world's population has increased, the excessive consumption of energy and other resources has resulted in adverse environmental changes with real threats from global warming, rising salinity, air pollution, depleted energy, food and water sources, changes in the ozone layer etc. These, coupled with the social upheaval in society, are having profound effects on population health, social conditions and human development and must be better addressed in future research agendas.

**7** The response of governments, other agencies and the media to these current societal problems and rising rates tends to be far too simplistic, targeting solutions too close to the outcomes. Although often extremely expensive, these tend to be relatively ineffective, but demanded by the media and society which are apprehensive and poorly informed. (Two examples of late-in-pathway responses are: putting most resources into prisons rather than early interventions to reduce crime; and funding more and more expensive Neonatal Intensive Care Units, instead of focusing on the factors in populations which cause very pre-term births.)

**8** Australia has a rich collection of data which is available now to address many important research and policy questions in this area. Several groups have cohort studies, population surveys and record linked population databases, most of which are under-used for research. And there is a frustration that these research data bases do not serve a policy agenda for the nation. The National Health and Medical Research Council is concerned that in spite of the existence of many under-funded, small and unproductive studies, new cohort studies are being funded. Better national planning would result in more powerful and useful data in terms of output and capacity.

**9** A final perceived advantage of a research partnership was that collectively we may be more successful in obtaining research funding for large and important studies than if we still continue to work separately.

It was fascinating to talk together at the workshop, sharing these concerns and observing how common our situations and conclusions were. We came to a unanimous decision to establish a national collaborative effort, in order to work

collectively to inform a research and policy agenda, and to have a greater capacity to obtain more funding from both government grants (the Australian Research Council and the National Health and Medical Research Council) and non-government sources (philanthropy and sponsorship). There was also a sense that together we could develop new and more powerful research methodologies and make a unique international contribution.



### The future of the partnership: a possible structure for success?

In the 1980s, Australia was suddenly faced with the prospect of an HIV epidemic. This was considered a major threat, a crisis. The nation's researchers, policy makers, and state and federal politicians worked alongside those groups at highest risk of the disease to develop a strategy, and together mounted the most effective response in the world.

I suggest that we are facing an even bigger crisis today from the situations described earlier than we did from HIV/AIDS in 1980s. There are some similarities however. For HIV/AIDS, social behavioural research was equally, if not more, important than immunology, virology and other biomedical disciplines. But it was crucial that researchers from different disciplines worked together. A research and policy agenda was developed nationally, responsive to the changing nature of the epidemic, of risk factor behaviour and of new knowledge from Australian and overseas research. The education committee had the same status as the scientific committee, and for once, the States and Territories and the Commonwealth cooperated. A significant dedicated annual research budget for HIV/AIDS was made available from the National Health and Medical Research Council, which responded to priority driven and investigator initiated research. This national partnership was extremely successful: the spread of the virus was contained and HIV rates dropped in all Australian states.

Figure 1 shows how a similar model could work for a focus on developmental health and wellbeing.

This proposal could have profound implications for both our research and prevention agendas. Using my own discipline again, modern epidemiologists would argue that there have been some successes with the individual risk factor approaches in prevention and treatments

(vaccination, smoking and lung cancer in males, incidence of heart disease, peptic ulcer management, folic acid and spina bifida, cot death and sleeping position).

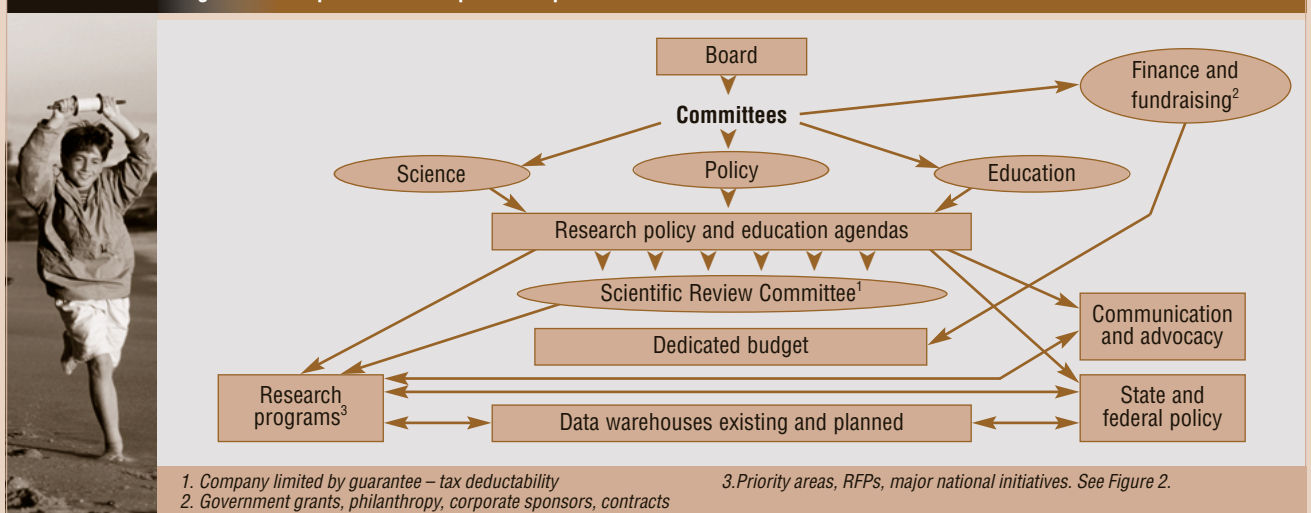
However, the success of risk factor epidemiology has been more temporary and more limited than many claim. For example, on a global basis the achievement of the public health movement has been to shift the problems (such as smoking related illnesses) from rich to poor people within countries, or from rich to poor countries. This is a direct effect of the limitations of an epidemiology based on individual factors (tobacco smoking) rather than on population factors (tobacco production, advertising and distribution, and socio-economic influences on consumption). Concentrating all of our efforts on reducing the use of illegal drugs by individuals to prevent suicide and mental ill-health in our young people, whilst ignoring the complex chains of population influences, will ensure that drug taking and other poor outcomes will continue to rise in our societies.

Those profound changes which have occurred in the social and demographic structures of communities and populations and the environment add further complexity and also a sense of urgency to our work. Changes in work patterns, family structure, and the social security system, the consequences of globalisation and environmental degradation, the rise of racist sentiments: all these and more have potential to impact adversely on developmental health and wellbeing, and to do so in complex and interacting ways. Simplistic research paradigms which ignore the multilevel and complex nature of pathways, and policies and interventions which focus on a limited number of "risk factors" at some point along these pathways, are not going to serve us well. Hence we need to move rapidly, but carefully.

Delegates to the workshop envisage a huge research agenda. For example, for social issues to be researched, we need to tackle conceptual issues (what are the relevant attributes of groups?) and practical ones (how do we create data sets with sufficient level specific detail or power?); the theoretical (what is the appropriate unit(s) of analysis? how best to analyse causal pathways?) and the methodological (how can lag times between exposure and health status be incorporated into the analysis, while at the same time allowing for changes over time in status or circumstances).

The difficulties in measuring such things as societal changes and other distal risk factors may explain why they

Figure 1 Proposed national partnership structure



have been excluded from aetiological models. Now we need to be challenged to tackle problems at higher levels of aggregation. This stuff is really crucial as we think about how best to use existing data bases and embark upon new cohort studies. So instead of dividing our disciplines into narrower competing ones (for example, for epidemiology, into social, infectious disease, molecular or genetic epidemiology and so on), we need to bring in new paradigms that serve the endeavours of all the collaborating disciplines.

The implications here are considerable. We need to look at this with the eyes of those with whom we want and need to collaborate – sociologists, economists, environmental scientists, neuroscientists, geneticists, educational researchers, and so on. This partnership represents a chance, not only for epidemiologists but for all of us, to start a dialogue and the process of learning to “see through others’ eyes” in the cause of improving child health and wellbeing.

Figure 2 shows how the overall work program could develop over the next few years (with thanks to Jane Dixon and the Health Inequalities Research Collaboration).

These issues are also of profound importance to the development of policy and where best to put efforts and resources to make the most improvements. Causal pathway thinking opens up many more possibilities for prevention, many of which may be more effective and cheaper than more proximal solutions which may be too close to the disease outcome to influence it significantly. For example, the most effective preventive strategies for improving low birth weight and infant death rates in indigenous mothers may be to tackle the disempowerment, despair, discrimination and dislocation of indigenous communities rather than going into such communities with an anti-smoking or nutrition program targeted at women, who may feel victimised and further undermined.

## Summary

In summary, a national research partnership for developmental health and wellbeing is being planned for Australia. It aims to bring together a range of scientists from different disciplines to create a research and policy agenda to inform the best ways to enhance successful and healthy development of children. We believe that collectively much more will be achieved than by isolated groups working in silos and far away from the policy or action end of the spectrum.

The functions of the research partnership could include:

- prioritising an intersectoral and interprofessional agenda for population-based research into early human development and its consequences for developmental health and wellbeing throughout the life-cycle;
- bringing together cross sectoral and cross institutional research groups to undertake collaborative research exploring emerging interface aspects of early human development (for example, links between genes, biological changes and early environmental experiences);
- promoting more effective use of existing data sets to describe patterns of problems, to refine hypotheses, and to inform the national policy agenda for families and children;
- facilitating specific research initiatives such as undertaking a stocktake of existing data linkage initiatives and exploring the feasibility of establishing more extensive linkages between existing data sets;
- ensuring the establishment of a clearing house to disseminate results of new research findings;
- establishing a listserv, newsletter and website for promoting access to online materials and information resources;
- disseminating research results to broad audiences at national conferences and workshops and to various stakeholder groups;
- acting as a scientific reference group to the National Longitudinal Study of Children; and
- advocacy and fund-raising with government, business and philanthropy to underwrite research into the impact of early human development on developmental health and wellbeing throughout the life-cycle.

The next six months will see the establishment of the partnership as a legal entity; presentations and communications to inform all relevant groups in the community of our existence; a major fund raising activity to secure a future sustainable program; and debate and decisions about how the partnership will actually work. We also need a catchier title, so please put some thinking caps on!

Professor Fiona Stanley is the Director of the TVW Telethon Institute for Child Health Research at the University of Western Australia, and interim Chair of the newly formed National Partnership for Developmental Health and Wellbeing.

Figure 2 Proposed national partnership work program

