

Men's health on the GP map (statistically)

'This informative report benefits the cause of men's health in Australia by its very existence', writes Professor John Macdonald in the foreword to *Male Consultations in General Practice in Australia 1999-00*, recently released by the AIHW and the University of Sydney.

Professor Macdonald is Foundation Chair in Primary Health Care and Director of the Men's Health Information and Resource Centre at the University of Western Sydney. The report is another from the AIHW's General Practice Statistics and Classification Unit (GPSCU) within the Family Medicine Research Unit at the University of Sydney.

GPSCU conducts what is known as the BEACH program (Bettering the Evaluation And Care of Health). BEACH is a continuous survey of general practice activity in Australia, covering 100,000 consultations every year (1000 doctors by 100 encounters each).

Professor Macdonald writes that while the BEACH program was not specifically designed to examine encounters between GPs and male patients, it nevertheless 'provides an accurate picture of male illness and treatment within the wider context of all general practice encounters'.

GPSCU Director Dr Helena Britt's view is that the results indicate there is reason to be concerned about the health of males in the population, especially in the younger age groups.

'Australian men might live longer and healthier lives if they change a few lifestyle factors and occasionally see a GP', she says.

'Our report shows that around 1 in 4 males have not seen a doctor in the past 12 months, compared with one in 10 females.

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The Male Consultations in General Practice author team, (L to R), Clare Bayram, Helena Britt and Lisa Valenti

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Report co-author Clare Bayram says that young men aged between 18 and 24 are the least likely to go to the doctor.

'But while they might be generally healthier than older men, they are the most likely to indulge in health risk behaviours such as daily smoking and drinking alcohol at excessive levels. One in three in this group smoke daily, and almost half of those who drink alcohol do so at risky levels.

'When young men do go to the doctor, it is usually for injuries and acute conditions such as colds. There is not much opportunity for a more general health assessment and education. This is backed up by evidence that GPs spend less time with male patients generally.'

According to Ms Bayram, all this could come back to 'bite' young men later through smoking-related chronic diseases, and overweight and obesity.

'And our report shows just that—chronic conditions such as high blood pressure and lipid disorders (usually high cholesterol) start to show up as common reasons for consultations in men aged 35–44 years. From 45 years onwards, chronic conditions are the most common problems managed.'

Dr Britt says that adolescence and young adulthood has been shown to be the period when health behaviours are formed. On the relatively few occasions when young men see a GP, GPs should perhaps 'try to develop a trusting relationship and use the contact to enquire about health risk behaviours'.

'But even so, more research is needed on why GPs are not better utilised by males in the community. And there would also be value in conducting more research to determine the influence of masculine roles and socioeconomic status on the health of all men.

'It is widely understood that health is influenced by multiple factors. Our study cannot capture the influence of all these factors on men's health. But what we can say from our study is that with respect to men, there seems to be potential to increase life expectancy and decrease death rates by targeting health risk behaviours, increasing men's contact with GPs, and examining the social constructs which form male health behaviours.'

Professor Macdonald concludes his Foreword with a hope that 'more [men's health] initiatives will be funded and will flourish in Australia and that GPs, as the first point of contact with the health system, will be helped in their task of contributing to the health of males'.



Professor John Macdonald



from the Director

I am pleased, in this first edition for the year, to warmly welcome a number of new friends, as well as some who are taking on new roles.

I am delighted to let you know of the appointment of three new members to our Board, each appointed as the nominee of our Minister, Senator the Hon. Kay Patterson. Those members are:

- Associate Professor Heather Gardner, Associate Professor, School of Public Health, LaTrobe University, Melbourne.
- Mr Ian Spicer, AM, who has made a significant contribution during his career both to Australian Industry and to the NGO sector—including currently as Chairman of the National Disability Advisory Council; and
- Dr Kerry Kirke, Executive Director, The Cancer Council South Australia

We look forward to their support and guidance.

A further welcome is to an old friend of the Institute, Dr David Filby, who has recently been appointed by the Community Services Ministers' Advisory Council (CSMAC) as Chair of the National Community Services Information Management Group. David, Executive Director, Strategic Planning and Population Health of the South Australian Department of Human Services, has previously chaired the National Health Information Management Group, and has made a significant contribution to the cause of high quality, nationally consistent information across the health and community services sectors.

Peter McLaughlin is our new Head of Business Planning and Management. Peter's background is health-based; his most recent role was with NSW Health as Director of Corporate Services for the Greater Murray Area Health Service.

We also welcome back Ms Lynelle Moon. Lynelle has spent the last two years working with the Organisation for Economic Co-operation and Development in Paris on the Ageing-related Diseases project. (A report on this project also appears in this edition of *Access*.) She now takes up the role of Head of the Cardiovascular Disease, Diabetes and Risk Factor Monitoring Unit.

A special delight this year was seeing our former Chair (1992–95), Professor Fiona Stanley, named as the 2003 Australian of the Year. Fiona was recognised for her dedication to research on the causes of major childhood illnesses and birth defects. Fiona wrote to me and staff of the Institute to say:

... I see this honour as recognising the importance of what I represent rather than an individual accolade.

I am very excited about the opportunity this presents to really raise the profile of important issues regarding the health and wellbeing of Australian children.

I, along with many colleagues, am committed to finding real solutions to the very complex problems that are faced by many of our young people. I believe we must tackle these issues with a sense of urgency to ensure a brighter future for them, and for our nation as a whole.

We have a very big job ahead and I appreciate your continued support.'

The Institute has now established its own Aboriginal and Torres Strait Islander Health and Welfare Unit. The unit will bring together the many aspects of our work on the health and welfare of Aboriginal and Torres Strait Islander peoples. It is committed to working closely with these communities, as well as with other agencies in the field, including the Australian Bureau of Statistics. Dr Fadwa Al-Yaman has been appointed to head this unit. Other exciting work under way at the Institute includes a pilot test of the proposed Australian Health Measurement Survey and the development of a medical indemnity data collection (for the public sector in the first instance).

Finally, the Institute's new Corporate Plan, which sets our directions until 2006, is now complete.

The breadth of the Institute's statistical work has become very diverse and now covers most aspects of health and welfare in Australia. But more is wanted of us. Our information standards and skills are being sought to support an even wider range of uses, including information used in the direct provision of services. We need sound methodologies in many new fields as well as the infrastructure and technical and management skills required to support our diverse business.

Our new Corporate Plan succinctly collates these strategic imperatives (as we see them) for our constituents, and sets out what we propose to do about them, given our underlying values and objectives.

Our vision, incorporated in the new Plan is:
Better health and wellbeing for Australians through better health and welfare statistics and information.

I would like to thank everyone who contributed to the Corporate Plan, and look forward to its guiding Institute endeavours over the coming years.

Richard Madden, Director, AIHW

Director

AIHW involvement in international project

Over the last three years, a number of staff from the Australian Institute of Health and Welfare have contributed to the Ageing-related Diseases (ARD) project run by the Organisation for Economic Co-operation and Development (OECD) in Paris.

The ARD project was a ground-breaking study. It analysed three contrasting diseases important at older ages— ischaemic heart disease, stroke and breast cancer—to assess how these are managed in different countries. The study compared population-level information on treatment approaches, costs and health outcomes in 13 to 17 countries for each of the diseases. Given that the aim of the project was to assist the policy process, the focus was on policy-relevant information.

Institute people were involved in the project in a number of ways, including as members of the expert groups advising the OECD, and as participants in the final workshop that discussed the study results and implications. Ms Lynelle Moon (newly appointed as Head of the Institute's Cardiovascular Disease, Diabetes and Risk Factor Monitoring Unit) spent two years with the OECD team undertaking the disease analyses before her recent return to Australia. A complementary study on dementia is currently under way, with further involvement by Institute staff.

As an international study drawing on existing national data sources, the ARD study was a significant step forward. Many OECD countries, including Australia, have good health information systems which provide vital information on population health, health services and the outcomes and costs associated with these services. The three disease studies in the

ARD project were able to bring these national data together, providing important benchmarks and lessons for the future.

The study confirmed the potential benefit from international comparisons of this type. But it was a first step, with plenty of room for improvement in obtaining comprehensive and comparable information. Countries' health information systems have largely developed independently. This means there are some data gaps when these systems are directly compared. With more international coordination in developing national health information systems, there will be an even greater benefit derived from future studies of this type.

The ARD study did highlight that Australia has much to contribute towards the success of these types of studies. For example, we brought sound experience in the data specification and definition stages of the studies, good data in most cases, and valuable experience in compiling and analysing the information. But we also saw the advantages that other countries gained by having better data in some areas, particularly as a result of having data linkage and good health outcome information.

The reports of the ARD studies, along with material from the concluding workshop held in 2002, are currently in the process of publication.

For further information, contact Ms Lynelle Moon, AIHW, ph. (02) 6244 1235 or e-mail lynelle.moon@aihw.gov.au

Australian Centre for Asthma Monitoring

In February 2002, the Australian Centre for Asthma Monitoring (ACAM) commenced its program of work to monitor and report on a set of National Health Priority Area (NHPA) indicators for asthma. The main aim of this project is to help reduce the burden of asthma in Australia by developing, collating and interpreting data relevant to asthma prevention, management and health policy.

The team spent much of 2002 working on these indicators to develop a systematic approach to asthma surveillance. This work involved:

- identifying and evaluating available data sources
- identifying areas for data development
- developing operational definitions for the indicators
- establishing close working relationships with a number of state and Commonwealth agencies and with other collaborating units of the Australian Institute of Health and Welfare.

After extensive consultation and review, the year culminated with ACAM's first report entitled *Technical*

Review and Documentation of Proposed NHPA Indicators and Data Sources. The report has been well received.

ACAM is now concentrating on a report on the status of asthma in Australia. This report will collate and report on available information for all of the indicators recommended for collection, and will incorporate data from a range of sources, such as:

- National Hospital Morbidity Data Set
- National Mortality Data Set
- State and Territory Health Survey programs
- State Emergency Department collections
- Pharmaceutical and Medical Benefits data
- BEACH survey of GP consultations.

As well as age and sex differentials, the report will take account of Aboriginal and Torres Strait Islander status, cultural and linguistic diversity, and socioeconomic and geographic differences.

A separate report will be published reporting on asthma data collected in the 2001 National Health Survey.

Public Service Medal for Dr Richard Madden

On Australia Day this year, Dr Richard Madden, Director of the Australian Institute of Health and Welfare, was awarded the Public Service Medal for his outstanding public service as Institute Director, particularly in improving national health and welfare data collection and standards.

The Public Service Medal is awarded annually. It recognises those who have consistently performed demanding jobs to the highest standards and made a major contribution to the Australian community. The medal is part of the official Australian system of honours and awards, and was established to recognise achievements of Commonwealth, state and territory government employees.

Dr Madden's experience across both health and welfare portfolios and the ABS and his doctoral qualifications in statistics have been crucial in forging a credible and valued national role for the Institute. He has provided exemplary

leadership in establishing the Institute as the pre-eminent statistical resource centre for health and welfare in Australia, and made a first-class contribution to international agencies in respect of health, welfare and housing data policy.

Since his appointment as Director in 1996, the Institute has been further recognised as the 'honest broker' between governments and agencies. Its role in this regard is vital: it meets the information needs of governments and the community, so that governments can make informed decisions to improve the health and welfare of Australians.

Prior to his current role, Dr Madden had already established a track record for significant public service, having worked in the health, community services and finance sectors for four governments (Commonwealth, NSW, ACT and NT). He was named Actuary of the Year by the Australian Institute of Actuaries in 2002.



Project 4

Psst—wanna represent your country? Progress towards an Australian Health Measurement Survey

For many years, health groups have been calling for national surveys that measure factors such as blood pressure, blood cholesterol and body weight—things that can't be measured by interview. After all, it's now well over ten years since the Australian Institute of Health and Welfare, the National Heart Foundation and the Commonwealth Department of Health ran the last of the nationwide Risk Factor Prevalence Surveys.

But this is a complex task as well as being costly. Can we do it, especially when people may be more reluctant these days to take part in such surveys?

Well, we've certainly come a long way towards finding out. The Institute, the Commonwealth Department of Health and Ageing and the ABS have joined forces to run an important pilot study. If it is successful and funding is agreed, the pilot will lead to a full national survey known as the Australian Health Measurement Survey (AHMS).

We expect the pilot, which covers Victoria and Adelaide, to collect a range of measurements on 500–600 Australians aged from 2 to 74. This is not a simple process. First the ABS randomly selects households, and interviews people as is done for a standard National Health Survey. Eligible people are then invited to take part in a further stage, run by the Institute, that involves two main processes:

- a nurse visits the home to take physical measurements and a saliva sample,
- the participant later goes to a pathology collection centre to give blood and urine samples.

As well, participants are invited to complete a mail-back questionnaire about the foods they eat.

Taking part in this pilot is entirely voluntary. Also, all aspects have been carefully reviewed by an ethics committee to check that the pilot will ensure fully informed consent, feedback and confidentiality.

The pilot is the result of a highly consultative and collaborative approach. There has been wide input from the states and territories and various experts, including the long-time support of many advisory groups. The Australian Health Ministers' Advisory Council and the National Heart Foundation, among others, have expressed their support for this initiative. We have enlisted the support, on a contract basis, of the International Diabetes Institute to conduct the AHMS fieldwork.

The vital issue for the pilot is the response rate: the proportion of those invited who choose to take part. To this end, Robert de Castella, as a health advocate and strong supporter of the survey, has agreed to his name being used to encourage a spirit of participation.

As this report is being written, the pilot is in the field. We eagerly await its results.

For further information, contact Mr Stan Bennett, AIHW, ph. (02) 6244 1141 or e-mail stan.bennett@aihw.gov.au

Project 5

Health and welfare sector collaboration in developing national data standards

New and evolving information and communication technologies are providing an opportunity to improve the delivery of health care and community services in Australia. Such technologies not only allow providers to better coordinate services, but also enable individuals to access their own information. There are thus distinct benefits for both service delivery and health and welfare outcomes. A number

of projects are, in fact, under way in Australia's public and private health care sectors that aim to harness online technologies for improved efficiencies and user benefits.

It is important, however, that a national collaborative approach be followed in adapting these new technologies to avoid significant duplication and the associated waste of effort and

money. A persuasive case for collaboration was presented in a recent paper prepared to inform the review of the Australia Health Care Agreements (www.health.gov.au/haf/ahca.htm):

'Fragmentation in the management of health information... is causing confusion, duplication of effort and contradictory advice on policy and infrastructure issues... Organisations are therefore facing considerable pressure on resources to participate in a myriad of projects (e.g. classification work and technical standards), and progress has been slow in incorporating standards and architectures into applications, in turn limiting the ability to share and reuse health data.'

Essentially, services are delivered in much the same way across the health and welfare sectors. As well, data collected across many sectors are often common (e.g. name, address, demographic details). A high-level conceptual model of the way in which information is collected and used should therefore be much the same.

The National Health Information Management Group and the National Community Services Information Management Group are collaborating on projects to ensure that the standards development process is integrated. Both groups have directed their standing data committees to work together collaboratively in developing a process that integrates the respective data dictionaries and information models.

(The National Health Information Model and the National Community Services Information Model are now many years old. They have not been reviewed for some time and lack relationships between entities, which many consider to be essential in an information model.) The Institute will shortly publish a paper on the National Health Information Model version 2.

The National Health Data Committee and the National Community Services Data Committee have met to consider where integration is necessary and possible. A joint Structures and Procedures Working Group has been established by these committees to oversee the integration process. Integration involves aligning data committee processes by using a single metadata registry for all data standards and a single entry for a set of 'integrated' data definitions.

The initial phase of work will see the integration, wherever possible, of the *National Health Data Dictionary* and the *National Community Services Data Dictionary*. This will mean that standards for information that cross sectoral boundaries will be the same. To achieve this outcome, it is proposed that, wherever possible, published data dictionaries would also contain the single version of an 'integrated' data definition. Version 3 of the *National Community Services Data Dictionary*, due in late 2003, will contain the first of these integrated definitions.

2002 Influenza Vaccine Survey

The 2002 Influenza Vaccine Survey was conducted in October 2002. It was the third national survey in a current series and the first to be managed by the Australian Institute of Health and Welfare. The AIHW published a report on the survey on its web site in April 2003.

The survey is part of the National Influenza Vaccine Program for Older Australians. Through this program, the Commonwealth funds free vaccine for Australians aged 65 years and older—the target group. In 2002, the Commonwealth gave each state and territory government sufficient funds to purchase one vaccine dose for each target group member in that state and territory. The Commonwealth reviews the program through an annual survey.

The Commonwealth Department of Health and Ageing funded the Influenza Vaccine Survey. The fieldwork was conducted by Millward Brown Australia.

Eight thousand Australians aged 40 years and older participated in the survey. They were asked about their recent medical and financial experience of influenza and influenza vaccination. From their responses, answers to four central questions were evaluated (see below) and some other analyses made.

Coverage

Coverage is the proportion of the target population vaccinated against influenza. It is estimated from the 2002 survey that, of about 2.4 million Australians in the target group, close to 1.9 million were vaccinated against influenza (see the Vaccinated box in Figure 1), giving an estimate of coverage of 76.9%.

Valid usage

Valid usage is the proportion of the target population vaccinated against influenza with program-funded vaccine. Again, it is estimated from the 2002 survey that, of about 2.4 million Australians in the target group, about 1.7 million were vaccinated against influenza with vaccine provided under the Program (see the Program box in Figure 1), giving an estimate of valid usage of 70.4%.

Leakage

Leakage is the proportion of program-funded doses administered to the non-target population. Of about 2.3 million funded doses, 158,100 were administered to

non-target Australians (see the Non-target vaccinations box in Figure 2), giving an estimate of leakage of 6.7%.

Unknown usage

Unknown usage is the proportion of the funded doses not otherwise accounted for in the report. It arises through administration to those beyond the scope of the survey or just remaining in refrigerators at the end of the 'season' (doses not used in the season are not used later) or through wastage (that is, loss or destruction).

Unknown usage is calculated as total program-funded doses less valid usage doses less leakage doses. It is estimated that 467,400 doses were not otherwise counted, giving an estimate of unknown usage of 19.9%.

FIGURE 1: INFLUENZA VACCINATION EXPERIENCE, PERSONS AGED 40 YEARS AND OVER, AUSTRALIA, 2002

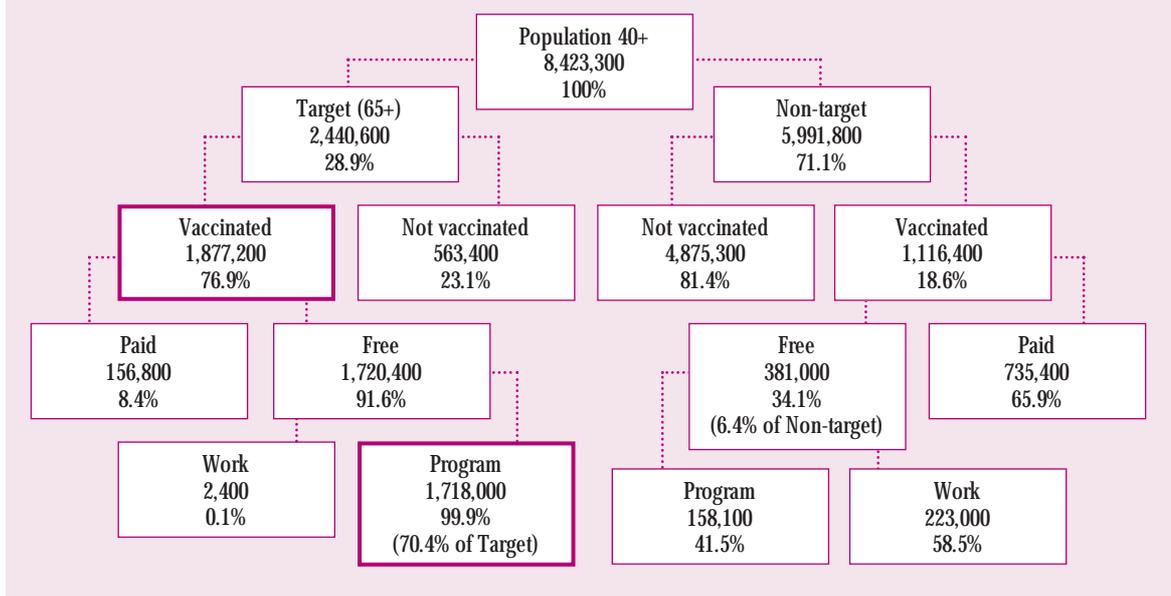
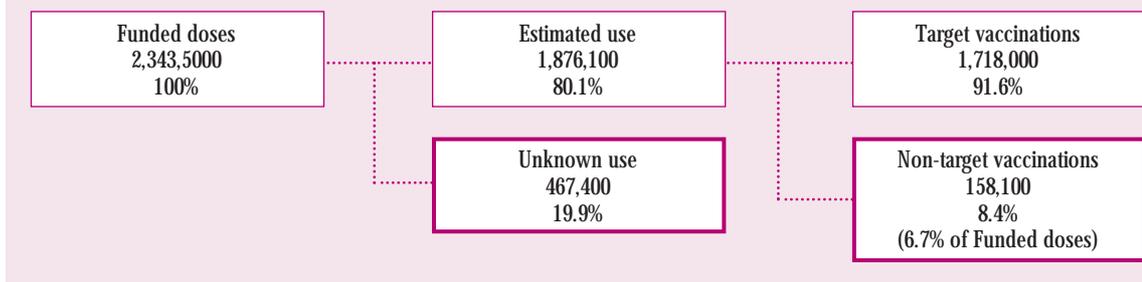


FIGURE 2: DISPOSITION OF FUNDED INFLUENZA VACCINATION DOSES, AUSTRALIA, 2002



Current activities of the National Health Information Management Group (NHIMG)

The NHIMG has already had a challenging and very busy year. Current and recent activities are listed below.

- The *National Summary of the 2000 Jurisdiction Reports Against the Aboriginal and Torres Strait Islander Health Performance Indicators* is now complete.
- The NHIMG has developed a paper on statistical linkage in the national hospital morbidity collection, which was presented out of session.
- In 2003–04 the NHIMG is proposing to carry out the following projects, subject to funding:
 - Version 13 of the *National Health Data Dictionary* (NHDD)
 - Knowledgebase redevelopment
 - data development for the national minimum data sets (NMDSs) for mental health care
 - collation and reporting of data for the NMDSs for mental health care
 - 2002 summary of jurisdictions reports against Aboriginal and Torres Strait Islander health performance indicators
 - development of a joint national health and national community services information model and a review of the data dictionaries
 - audit and evaluation of the perinatal NMDS
 - functional outcomes data modules
 - appropriate tools for assessing social and emotional wellbeing in Aboriginal and Torres Strait Islander peoples.
- At the end of 2002, the NHIMG endorsed new data elements for Version 12 of the NHDD, including an emergency department NMDS, and changes to the alcohol and other drugs treatment services NMDS. Two clinical data sets (cardiovascular and diabetes) were endorsed for inclusion in the NHDD.
- The National Health Information Standing Advisory Council (NHISAC) and the NHIMG are bringing together people who have been working on health terminologies as a short-term group to report on appropriate processes for progressing issues in relation to health terminologies in Australia.
- NHIMG is actively working to adopt to new health information governance arrangements being developed by AHMAC. The goal is to integrate initiation across the information spectrum: electronic health records, information technology and statistics will all be included. AHMAC is working to ensure that NHIMG's strong work record can continue, with some of the inevitable overlaps with associated areas more efficiently handled—more a transcendence of NHIMG than its passing.

For further information, contact Ms Catherine Sykes, AIHW, ph. (02) 6244 1123 or e-mail catherine.sykes@aihw.gov.au



on John Goss

services without getting results. Our findings demonstrated that spending on Indigenous health at that time was only 8% higher per person than spending on health of the rest of the population, despite the much poorer health of Indigenous Australians. This finding contributed to consequent significant increases in Indigenous health spending.'

Apart from working on expenditure issues, John has been involved in a number of other projects, such as medical workforce modelling, and an evaluation of the cost-effectiveness of mammography and cervical screening in Australia.

John also produced several papers on the effect of the increases in tobacco excise on smoking rates, including specific work on the effects on low-income groups in the population.

'The research showed that people in low-income groups get more health benefits from increased tobacco taxes, as they are the first to give up smoking because of these increased prices', John explains.

Another interesting project took John to Turkey where, for a period of over nine months in 1995, he was a part of the team advising the Turkish Ministry of Health on health financing issues. This assignment gave him an opportunity to work closely with Professor John Deeble, co-founder of Medibank and Medicare. It was one of a number of projects that John and Professor Deeble collaborated on over the years.

As John explains, 'John Deeble's PhD thesis in early 1970s produced the first health expenditure accounts for Australia. I frequently drew on his expertise in my expenditure studies.'

John's passion for economics is driven by his belief that developing new health policies requires both an understanding of economic climates and an analysis of the economic costs and benefits of any proposals. But, he stresses that economics is not just about dollars. It involves understanding the impact of new policies on people's overall wellbeing.

A dietitian by training, John first became interested in nutrition during a trip to Papua New Guinea as a university student. He went there to do some volunteer and statistical

Try telling John Goss that statistics are boring. He will give you plenty of examples of how they have influenced health policy and funding and, as a result, our health and wellbeing.

With over 20 years of experience in nutrition and health economics—16 of them with the Australian Institute of Health and Welfare, John, now Head of the Institute's Summary Measures Unit, has had a hand in redressing quite a few misconceptions in the health expenditure field.

Before taking charge of the unit in 2001, John was involved for 15 years in producing the Institute's health and welfare expenditure bulletins. These data are very relevant to health and community services policy.

'Work done on health expenditure and ageing helped to prove wrong the common belief that population ageing would create unsustainable increases in health expenditure.' John adds, 'We showed that ageing itself adds only 0.5% per year to total health expenditure'.

'Indigenous health expenditure was another significant project, commissioned by the then Department of Health and Family Services in 1996. The first report we produced was a landmark publication, dispelling the misconception that a lot of money was being spent on Indigenous health

work in hospitals. He says he was fascinated by the different nutritional patterns he observed in local villages.

'On returning to Australia, I obtained my Graduate Diploma in Nutrition and Dietetics. But I had always wanted to be a public health nutritionist, rather than a clinical nutritionist. My science degree included a major in economics, so it was relatively easy to go on from there to get an economics degree as well. Combining a health discipline with economics is very useful in undertaking health analyses.'

John's first job was with the Commonwealth Department of Health, initially in the Nutrition Section, and then in the food regulation area. He was involved with introducing the first nutrition labelling regulations in Australia in 1984. He also wrote a paper on the economics of reducing high blood pressure by reducing salt intake. After four years with the department, John moved to what was then called the Australian Institute of Health (AIH).

'The move offered me an opportunity to combine the knowledge of health I had acquired from my nutrition studies with an economics approach.

'I was initially the only person doing health expenditure work at the AIH, and things remained that way for quite a few years. But gradually the area grew, and more staff came on board. Then I was given the opportunity to head the new unit. I'm now with the Summary Measures Unit,

which was set up to enhance the Institute's ability to produce information relevant to policy work.

'Our work focuses on developing a more coherent system of health statistics to better monitor the health of the population, and the impact of the health system on our health. We collaborate with the World Health Organization in developing measures to enable valid international comparisons.'

John's unit is also updating the 1996 burden of disease estimates and the 1993-94 estimates of the cost of diseases.

'This information has been in great demand from researchers and health policy workers since its original release, so it is important to keep it up to date. The burden of disease statistics, for example, led to a much greater focus on people with mental illness, since they showed that depression, alcoholism, anxiety and other mental disorders were among the leading causes of disability in Australia. The Institute's burden of disease report, written by Colin Mathers, Theo Vos and Chris Stevenson, had major ramifications for government prioritisation of health services.'

And what about his interests outside work? John says that most of his free time is spent with his 15-year-old son.

But statistics and economics are never too far away. As a Uniting Church lay preacher, John, by his own admission, specialises in sermons which include statistics!



The Ninth Australasian Conference on Child Abuse and Neglect *Many Voices, Many Choices*

November 24-27, Darling Harbour, Sydney

The ninth Australasian Conference on Child Abuse and Neglect, *Many Voices, Many Choices*, will be held in Sydney 24-27 November 2003, hosted by the NSW Department of Community Services.

The theme of this conference recognises that child abuse and neglect is of concern to a wide range of people across society and that there are many ways to address child abuse and neglect issues. The conference will be relevant to anyone who has an interest in improving the life experiences of children and young people.

For more information visit the conference web site www.nsw.gov.au/acan2003

Promoting the health and wellbeing of informal carers: how effective are contemporary policies?

ELIZABETH LLOYD



Liz Lloyd,
School for Policy Studies,
University of Bristol, UK.

In Britain in recent years, there have been significant policy developments in the sphere of unpaid care, broadly similar to those found elsewhere in the Western world. I want to look at some of the problems associated with these policy developments and to argue for more fundamental change in order to promote the wellbeing of carers.

The policy context in the UK is broadly similar to that found in Australia and other parts of the

industrialised world. A key concern in many countries has been how carers can and should be defined. I want to argue that this preoccupation with definition has proved to be a stumbling block. We know that services fail to reach many people involved in caring and a major reason for this, I believe, is that we fail to recognise variations in people's caring arrangements. An alternative is to pay attention to the situations of people in need of care and to what needs to be done to enable them to remain at home supported by family and/or friends. Greater emphasis on the tasks and conditions of caring and on the environment of care is needed.

Even a cursory look at the tasks of caring reveals the hazardous nature of the work. The risk to health posed by lifting people or helping them into and out of the bath or bed is well recognised in the nursing profession. Frequent contact with toxic chemicals associated with nursing and housework may also pose a risk to carers. In relation to mental health, we know that regular breaks, adequate sleep and the ability to exercise control over daily routines are essential. Yet research demonstrates that these are the very issues that persistently concern carers (see, for example, Leat 1990, Parker & Lawton 1994, Twigg & Atkin 1994). Carers describe feelings of desperation at their inability to take even a five-minute break.

In terms of the physical environment of caring, evidence suggests that British carers have poorer standards of housing and higher levels of overcrowding. They also incur financial costs because of limited working hours and the loss of future pensions. The risk to health through poverty is therefore an issue for both the present and the future.

Recent developments in the British policy context

There is now greater recognition in UK policy of the importance of informal care and of the value of the unpaid carers' contribution unpaid workers make to community care. The 1995 Carers (Recognition and Services) Act gave carers the right to a separate assessment of their needs, recognising that carers may be at risk of poor health, and reiterating the responsibility of health and social care professionals for dealing with this.

The 1999 National Strategy for Carers (DoH 1999) promotes the provision of regular breaks for carers, training and guidance in how to prevent illness and injury that might arise in the course of caring, and improved access to aids and adaptations to housing.

The financial costs of caring are recognised and pension rights are provided for some carers. The needs of carers in paid employment are acknowledged and the government exhorts employers to adopt carer-friendly employment practices such as flexible working arrangements and opportunities for staff with caring responsibilities to take a break from employment without loss of status.

Current policies therefore appear to address the issues raised above. However, whilst increased recognition of the importance of unpaid care is welcome, I would argue that the policies still fail to address adequately carers' health and wellbeing for the reasons outlined below.

The ambiguous position of carers

Carers are still in an ambiguous position in relation to service providers. On one hand they are regarded as providers within the network of care. On the other hand, when practical assistance is needed to protect their health and wellbeing, they are regarded as service users and are dependent on means-tested, rationed services. Thus, their need for health-promoting conditions of caring is not translated into a right but is measured as a need against eligibility criteria determined by service providers.

For example, the provision of equipment and adaptations to people's houses would promote unpaid carers' health and safety, but is sadly lacking. In contrast, where disabled people are supported at home by paid carers, funds are made available for such equipment and adaptations, because employers have to comply with European Union health and safety legislation. Unpaid carers have no such rights as workers, since they are regarded as clients or service users in these circumstances.

Carer categories

The many and varied forms of caring relationships that exist are simply not recognised in British policies. For example, only a small minority of non-employed carers will benefit from additional pension rights—those already in receipt of other benefits or with an income below the current National Insurance Lower Earning Limit. Whilst this may lift some carers over the poverty threshold, it still leaves many in financial difficulties.

This situation is exacerbated by the policy focus on those in greatest need. The 1995 Carers (Recognition and Services) Act focused on the 1.5 million in Britain who provide care for more than 20 hours a week. Of course, it is undeniable that to be a sole full-time carer is likely to pose a greater risk to health than to be a part-time or occasional carer. But focusing on this group means that other caring arrangements are left out of the purview of service providers, and hence left unsupported. In addition, the way services and benefits are provided can influence the ways in which families organise their care. Strict eligibility criteria may mean that individuals within families are obliged to take on the role in order to gain access to the benefits.

The location of care

For many carers, the home is not only the place where they work but it is also the place where they live. However, where work is carried out in the home, rights that apply in other spheres are overlooked. For example, whilst care within institutional settings is subject to inspection and regulation, care provided at home is not. This has serious implications for people receiving care (Land 2002).

Perceptions of carers

The notion that caring is a self-sacrificing vocation is still prevalent. Two members of the UK Royal Commission on Long Term Care made this statement:

'Most care without giving thought to the financial cost of caring. It somehow demeans them to reduce their dedication to cash amounts' (Royal Commission on Long Term Care 1999:133).

This perception is a serious impediment to promoting properly funded services that would promote the wellbeing of both carers and those cared for.

Resource rationing

Underpinning all of the above is the persistent problem of insufficient funding. As a consequence of this, resources are concentrated on those who do not have family carers, leaving those in informal caring relationships to manage relatively unsupported. Rationing resources is managed along the lines of securing 'best value' for taxpayers' money. The focus of attention is always on the most needy and it becomes increasingly difficult to engage in the kind of preventive work that would benefit carers and service users alike. For example, the provision of regular breaks has not been satisfactorily implemented because of lack of funds in local government.

Conclusion

Contemporary policies in the UK do not take adequate account of the extent and variety of caring arrangements. Service provision is reactive rather than preventive, and interventions often occur at times of breakdown. Often people do not identify themselves as carers until the intervention of formal service providers. This means that we have a partial picture of caring that is unsatisfactory as a basis for policy-making. The emphasis needs to shift from identifying a category of carers who are eligible for particular services to identifying circumstances in which care and support are needed and how these can be provided without detriment to the wellbeing of anyone involved in providing care. Unless a more extensive view is developed, caring will remain in the shadows as a marginal activity rather than being recognised as a vital ingredient of family and community life.

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Children, Youth and Families Unit

The Children, Youth and Families Unit of the Australian Institute of Health and Welfare is a good place to start for some facts about Australian families and the close to 7 million children and young people who make up these families.

The unit's work covers areas such as child care, child and youth health and wellbeing, child protection, adoption and, more recently, juvenile justice. Child and youth health were moved into the unit in 2000 to allow better joint monitoring of the health and welfare of children and young people. This initiative—to merge statistical reporting on relevant health and welfare issues—reflects the more holistic approach of governments in recent years to developing strategies that span both across and between departments.

The establishment of the unit also recognises the increasing prominence, in both research and policy development, of matters to do with children, youth and families. These matters were placed even more firmly on the national agenda this year when Professor Fiona Stanley was named by the Prime Minister as the 2003 Australian of the Year. Professor Stanley, Director of the Institute for Child Health Research in Perth, was the Chair of the Institute's Board from 1992 to 1995.

To a significant degree, the health and wellbeing of young adults are outcomes of the knowledge, attitudes and lifestyles of the families who cared for them as children. Given this link, it is recognised that many childhood diseases and adverse social outcomes could be avoided. Much work has yet to be done, though, towards achieving such objectives.

The Children, Youth and Families Unit produces reports on child and youth health and wellbeing. They include health and welfare data from a wide range of sources. The most recent publication in this area was *Australian's Children 2002: Their Health and Wellbeing*. Another report on Australia's youth will be published towards the end of the year. We also collate and publish state and territory data on child protection services and adoptions. The latest relevant statistics can be found in the publications *Child Protection 2001–02* and *Adoptions 2001–02*.

Another ongoing activity is to develop and publish data on child care and preschool services. The most recent publication in this area was *Trends in Long Day Care Services for Children in Australia 1991–99*. Last year, we took on the task of developing national juvenile justice data

and performance indicators. As well, we contribute to both of the Institute's flagship biennial publications—*Australia's Health* and *Australia's Welfare*.

Members of the Children, Youth and Families Unit (in alphabetical order) are:

- Fadwa Al-Yaman, who has a PhD from the John Curtin School of Medical Research and a Masters of Population Studies from the ANU. Fadwa had an established career in immunology when she joined the Institute. She also spent four years with the Papua New Guinea Institute of Medical Research setting up the immunological side of the first major trial of a blood stage malaria vaccine for children. After finishing the AIHW report *Australia's Children 2002: Their Health and Wellbeing*, Fadwa is now working on a similar report for youth.
- Seniz Aydinli joined us as a new graduate in 2001, having completed her Honours degree in Social Science Research and Policy at the University of New South Wales. She relocated from Sydney to take up her position. Seniz is mainly involved in work on child care and preschool services.
- Anne Broadbent has worked in various units of the Institute on and off since 1995 (in between overseas trips and contract work for other organisations). In the Children, Youth and Families Unit, she has worked on child protection, child care and, most recently, juvenile justice issues. Anne is certainly our fittest member. She thinks nothing of slipping in a 40 kilometre bike ride before work!
- Meredith Bryant completed a Masters degree at the ANU, and then worked with the Australian Institute of Criminology (with a short stint in ACT Corrections). She now works on our child and youth health reports. Meredith has just returned from a three-month sightseeing holiday in the United Kingdom.
- Antoinette Janicska has been providing staunch support for our unit, and for other Welfare Division units of the Institute, since December 2001. She cheerfully looks after all the odd jobs that the rest of us don't want to do! Before this, she worked as an executive assistant and in retail management.



The Children Youth and Families Unit. (L to R)
Helen Johnstone, Meredith Bryant, Sally Middleton,
Fadwa Al-Yaman, Helen Moyle, Seniz Aydinli,
Anne Broadbent, Susie Kelly and Antoinette Janicska

- Helen Johnstone has been working on child protection data for the past five years. During this time she completed a Graduate Diploma in Epidemiology and Population Health. Prior to this, she was involved in evaluating the impact of government labour market programs, and before that in developing income support policies for unemployed people. Helen is interested in social policy and justice issues, and enjoys animated discussions over coffee and chocolate.
- Susie Kelly previously worked directly with children and young people when employed as a psychologist with the Child and Adolescent Mental Health Service at Queanbeyan. She also worked with youth in residential care in Canberra. Susie has a Graduate Diploma in Applied Psychology. She says that solving data problems is easier than solving people problems.
- Sally Middleton was with the unit for three months at the end of 2002 then returned full time as a graduate in February 2003 after completing her Masters of Population Studies at the ANU. Sally is absorbed in work on *Australia's Youth* and the unit's contribution *Australia's Welfare 2003*.
- Helen Moyle has headed the unit since 1994. Prior to this, she worked for several years as a social policy researcher at the Australian Institute of Family Studies in Melbourne. She has a Masters degree in Sociology. Her family, located in different parts of the world, provide her with a good excuse for regular overseas visits.



Overhaul of services for children and young people

The NSW Commission for Children and Young People has recommended an immediate inter-government, sector-wide overhaul of services to improve the wellbeing and health of children and young people.

The Commission has recently tabled in NSW Parliament its Report of the Inquiry into the best means of assisting children and young people with no one to turn to.

'Kids and the adults who care for them and work with them told us that many services are neither accessible enough nor working together effectively to look after their young vulnerable clients,' said Gillian Calvert, NSW Commissioner for Children and Young People.

The Report recommends that all services work together over the next two years to build a Service Charter basing funding and evaluating services on their ability to build relationships with children and young people.

'Kids have told us that relationships are most important to them, regardless of background, age, gender or culture. All workers in this sector need to be trained in building trusting relationships and acting as advocates for kids who are at risk of physical and mental harm because they have no one to speak up for them,' said Ms Calvert.

The full Report is available on www.kids.nsw.gov.au/publications

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