



Child Health: Current Issues and Future Directions

Dr Pat Tuohy, Chief Advisor Child and Youth Health at the Ministry of Health was our guest speaker at our September Seminar hosted by Gillies Hospital. Pat kept an attentive audience engrossed for over an hour as he offered his personal view of current issues and future directions for child health.

Pat began by going back to the beginning and the beginning in New Zealand goes back a long way – at least to 1840 with the Treaty, which in relation to child health is an important document. It identifies a whole lot of issues and given that one of the biggest issues we have today in child health is the disparities between Maori, Pacific Island and European children

From the point of view of community child health, the setting up of the Plunket Society by Truby King in Dunedin in 1907 was the turning point, with one of the first outcomes being the reduction in infant mortality numbers.

In 1919 Health Camps were set up and in the following year the school dental service began to address the appalling state of our teeth. Having your teeth taken out was a common coming of age ritual in the first half of the 20th century. Now, for the first time in our history we have a generation of children who will grow up with their teeth intact.

The introduction of fluoride to water supplies in 1954 and hydatids control in 1957 were milestones. Hydatids was a nasty disease in children and completely preventable through the dosing of dogs. The fencing of swimming pool act in 1989 dramatically dropped the number of swimming pool drownings from about 17 a year to 4 a year. Child car restraint laws have also had a significant impact on the reduction in the number of children dying in motor vehicle crashes. In 1998 the Child Health Strategy, around which much of the child health policy of today is related, was launched.



Pat Tuohy

Hospital administrations being under funding pressure is not something new. A quote from 1877 echoes current feeling.

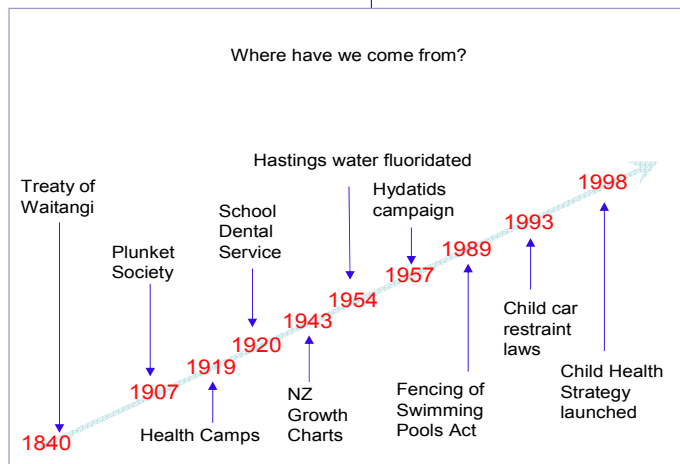
Management by committees elected by subscribers has much to recommend it but also has the drawback that the expenditure of public funds is placed in the hands of irresponsible bodies who in many cases, expend it in needless quantities, get into debt and then bring pressure on the Government to obtain funds for their relief.

The work of Grace Neal beginning in 1895 to clean up maternity care and Truby King's work on child nutrition were major influences on safer maternity and well child services. The passage of the Social

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A Pa scene painting of 1841, while perhaps romanticised somewhat, shows the whole spectrum of well child, from the mothers feeding their babies to family groups sitting around in a clean marae talking together with children involved. That is something we have lost over time. We see significant disparities today, but when the colonists came to this country the Maori were a strong and vibrant race and we should look forward to that emerging again.



Security Act by the first Labour government in 1938 set in place a situation in New Zealand where we were able to make huge strides in the next 3 or 4 decades. Until the 1960's when we were still a very prosperous country, our standing in child health on the world scene was either at the top or in the first five.

The New Zealand branch of the BMA resisted the first Labour government's move to free health care so we never got the level of primary care the government is trying to put in place right now. As a result, we did not get free access to primary health care then but it did bring in a good secondary care system. What that did, in the face of fee for service in the primary health system, was to tilt the direction of child health towards a secondary care model because the hospitals became the largest consumers of the funds. That has continued through to today. Quite clearly the advances we have made in curative medicine are tremendous and we could never be in a position where we could say we do not need them. But we are starting to look at the balance – and that is uncomfortable for some. The emergence of Primary Health Organisations and the opportunity for child health to work within a PHO model is promising but it is going to take some time.

In the 1940s nutrition was promoted in schools and children received half a pint of milk and an apple a day. We do not do that now, but there is a scheme in the Waikato where they are trying to bring back something similar with milk, fruit and an exercise programme in schools.

One of the issues we are trying to grapple with is how do we deliver a 21st Century health service to children in isolated communities where there are fragmented health services and no paediatricians. Rural health services are a real challenge and given that a large portion of our children who are most disadvantaged live in rural communities we still have to figure out how to get to them the services they need.

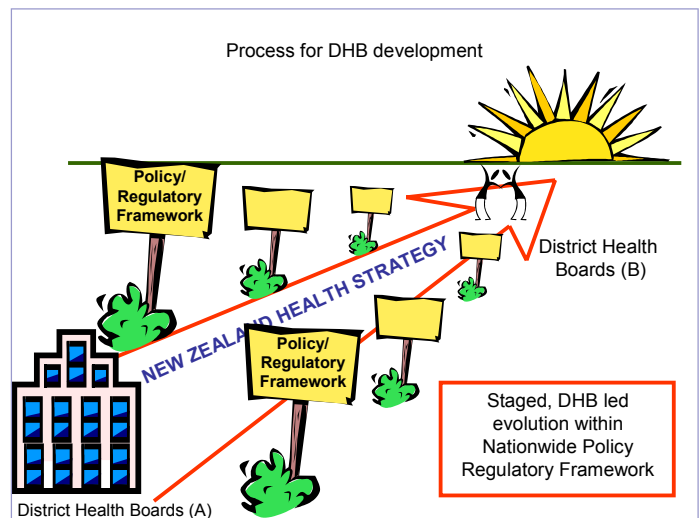
Health services stayed much the same from the 1950's through to the 1980's. Then we started to get international changes in the way health services were put together. The New Zealand government started to look at some of the things coming out of the USA and the U.K. under Thatcher. Market forces came in with all the new concepts about public choice theory, agency theory and managerialism. Roger Douglas was the agent of change. Within the Lange government these things started to come into place, then were put in place by the National government which followed.

This led us to the 1990's and the development of the Child Health strategy in 1998. The Child Health strategy had six forward directions, some of which are getting underway. The Child health Information strategy was published a couple of years ago. It is largely in place and being rolled out under the National Immunisation Register.

At the local level, the co-ordination of services has improved dramatically within DHBs. Paediatrics at the secondary and tertiary level involves only a small number of paediatricians so that requires regional and national co-ordination to make it work.

Things are improving but there are still some huge gaps. We still have work to do on workforce development and how we get a work force in place to deal with children in rural areas. It may well be that broadening the scope of development is what is required so we get more generalists in paediatrics able to work in rural areas. Certainly there is an increasing role for the nurse practitioner and there will be significant changes over the next few years on the way child care is provided in the primary sector.

The service requirements for prevention, early intervention and health promotion is where the child health strategy will mesh with the primary care strategy. That is really what it is going to be about when there is better primary care for children. Leadership is beginning to emerge in DHBs and specialities to improve child health.



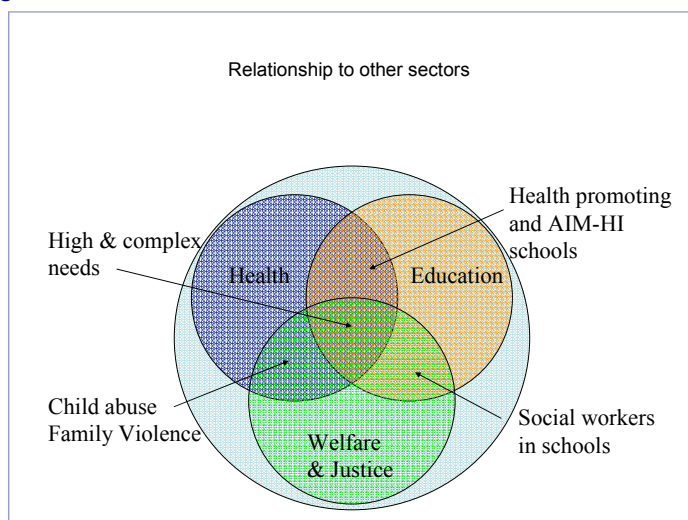
The new issues in child health are: the structural changes to the NZ health system - the Child health service infrastructure is significantly different; the monitoring of DHB performance; the emergence of Primary Health Organisations

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tions; and secondary and tertiary health care

The responsibility has gone from the Health Funding Authority as a funder and a decider and now lies with DHBs and they have the responsibility to make things happen. While accepting that the 'bottom line' is important, the DHBs need to have a vision. The Ministry role is to guide and monitor and we need a discussion on how clinicians and management interface and collaborate. The clinicians want to be part of the solution but they don't want to be involved in all the analysis. Clinicians need to work with managers on a set of principles on how the analysis is done. If that is done, when the solutions are brought back to the clinicians at the end of the day they will be much more in agreement with the direction that the analysis has gone.



Looking at the three sectors that work together, health – social welfare – and education, there are a number of intersectoral initiatives.

In secondary health care, community paediatrics is still in its infancy. There are a lot of people calling themselves community paediatricians but we have got no real agreement across the country as to what that should look like. There is a bigger role within Primary Health Organisations for community paediatrics and that will be the bridge between primary and secondary paediatrics.

A big emerging issue at the moment is respite care and parent support. The issue really sits outside mental, disability or personal care services. It is about how we deal with a family that needs support, irrespective of whether the child is an ACC graduate, has disability or mental health needs, or a medical condition.

In services for young people, sexual and mental health services are the two big areas where we are letting down our young people and need to do a lot more. Their general health is in reasonably good condition in the most cases.

The following is a list of World Health Organisations' s ambulatory sensitive admissions that are relevant for children:

Gastroenteritis, Infections Immunisation preventable admissions, Dehydration, Respiratory infections, Asthma, Dental conditions, Epilepsy, Ruptured appendix, Diabetes, Kidney/urinary infection, Cellulitis, Failure to thrive, and Nutrition (iron deficiency).

They are all things that are amenable to primary care when there is good community paediatric care available. There is also a huge opportunity for advanced nursing in managing these things. There are some good outreach programmes, like West Kids in Waitemata where there are senior nursing practitioners working in the community with paediatrician support.

If you look at ambulatory sensitive admissions by age group in 2001 – 2002 the figures for those in the 5 – 14 and 15 – 34 age groups have stayed much the same but for the under 5s, despite the things we have been doing since 1998 there has been an inexorable rise in admissions to hospital. The good news is that asthma is dropping but all other things are continuing to rise. Across the country Pacific people are highly over represented, Maori are both above and below the mean. The rate varies between 40 to 140 per 10,000 for different groups.

There is wide disparity across New Zealand. Even in such a small country it really comes down to individuals making a difference. Improvement in child health care is very dependant on the vision, drive and energy of individual paediatricians and child health managers in different regions making a difference. That is why leadership is so important.

Scanning the horizon, there a number of old problems we still need to deal with. Disparities in health status have been with us for a long time. There is some evidence that in adult health and in some areas of child health it is starting to reduce but overall disparities appear to be widening. The first beneficiaries in the improvement in the health system have been pakeha children. Rheumatic fever is still with us and depression and suicide are now at epidemic levels. Child abuse and bullying and nutritional disorders are still a problem.

Emerging conditions include behavioural disorders, maternal PND and attachment disorders, ADD/ADHD, autism spectrum disorder, nutrition and childhood/adolescent obesity and juvenile diabetes.

We are faced with a new workforce. There may be a reduced working week for doctors, possible restrictions from the Health Practitioners Competency Assurance Act with an ongoing requirement to keep up-to-date, and a rationalisation of disciplinary activities. There is a specialist scarcity, a new dawn for Community paediatrics, links to PHOs and roles for Nursing Practitioners.

There are also new opportunities through: the rationalisation of childhood screening programmes; the introduction of newborn hearing screening; the review of universal tympanometry screening; a review of vision screening; the expansion of neonatal metabolic screening (MCADD); the growth of regional and national paediatric networks; tertiary outreach clinics; and Telepaediatrics.

So what is the R_x for child health? Some will fall on Central Government and thankfully we already have most of it on the work programme at some place or another. We need to deal with the inequalities existing within our child and youth communities and adopt an intersectoral work programme with common frameworks and goals.

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A common IT infrastructure is emerging from the inter-sectoral work that is happening. That is about seeing that children are well known and followed and receive what they ought to be receiving. There are clearly still some issues around the sharing of information between Health, Education and Welfare. We therefore need to ensure that there is child and youth health integration within the new Primary care environment.

DHBs and provider groups need to identify the priority child and youth populations, collect and analyse the epidemiological data and engage key stakeholders to advise on the analysis and identified barriers to service for children and young people.

Finally, decide on your priorities for action in child health. Prioritise funding and service decisions to achieve equity of outcome for children and young people. It's a big task, but you can make a difference.

Canterbury Seminar

Michael Aitken reports from Christchurch that a small but highly intelligent group enjoyed the hospitality of Eures (NZ) at the Botanic Gardens Cafe followed by Laurence Malcolm FCHSE and Pauline Barnett presenting their findings on disclosure of adverse events in health. Their excellent presentation deserved a wider audience.

The presentation launched with some common clinical scenarios that highlighted the dilemmas - what if you know that no one will ever find out? What if the adverse event has not affected the patient? They then went on to outline the paper from Walshe and Shortell published in Health Affairs that examined the barriers to disclosure for clinicians and highlighted the remarkable similarity across countries. This strongly suggests that the problems and their potential solutions are deeply embedded in the nature of clinical practice, the health care professions, and the culture of health care organisations.

Why are health care organisations so slow to address these issues? Walshe and Shortell suggest that in contrast to commercial organisations, where failure may mean complete stoppage, health care organisations usually carry on their business. Also, in the health care industry many of its customers are already, or will be harmed by the disease process that brings them to treatment. Further, health care is controlled by powerful vested interests, hence the need for sustained government, media and public pressure.

The extent of the problem was brought into context with figures from a 1999 IOM report from the USA, which showed that the effects of unintended injury resulting from hospital care were the equivalent of 2 x 747 crashes every 3 days. That is, 1 x 9/11 every two weeks. Closer to home, the work of Peter Davis has concluded that patients with adverse events stayed in hospital an additional 9.3 days. This is 14.3% of all bed days and nearly 50% of these were preventable - to quote "Preventable adverse events have a major impact on patient outcomes and extent of hospital stay. A substantial proportion of these are system related and, hence, in principle susceptible to quality improvement." Imagine if we could reduce bed stay by 7%!

All is not doom and gloom. The 2001 Commonwealth Fund study of consumer perceived quality overall rating and responsiveness showed that New Zealanders rate their system as higher in quality, and higher in physician

responsiveness than Australia, Canada, the UK and the USA. Laurence asked the question again, where was the interest of the media in such "good news" stories?

Interviews with DHBs indicated that, for some, policies and practices had been in place for a number of years. An effective disclosure policy requires a large change in the culture of the organisation and in clinical practice. A board and corporate level approved disclosure policy, together with support systems, can help clinical staff feel more secure. Most DHBs reported management support for disclosure with a partnership approach between service managers and clinical directors.

Few DHBs had information systems that could comprehensively integrate reporting of adverse events, along with complaints to the HDC and claims to ACC. The need for such information systems was widely recognised and a number are working to improve current systems.

In follow-up interviews DHBs were strongly of the view that the risk of not disclosing is now significantly greater than doing so. However there was widespread recognition that this view was not widely shared by clinical staff who still retain fears of the risks associated with HDC complaints and ACC claims, especially linked to a finding of medical error.

It was also widely recognised that both complaints and, to some extent, claims were much more likely to arise from poor communication between clinicians and patients rather than from the adverse event as such.

Laurence and Pauline ended their presentation with a quote from Radio New Zealand health reporter Rae Lamb "It is more difficult to think up sensational headlines when the underlying story is essentially "error discovered: inquiry launched immediately."

At the conclusion of the presentation a lively discussion was led off by Dr Nigel Millar. Many "stories from the front lines" were shared.

The next Canterbury meeting is the 27th of October with Rod Perkins from Auckland - more details to follow

Goat Pharming is the Future

While New Zealand has always been noted for innovative farming practices, our economy has suffered from farming being unable to add significant value to its basic products. Now times might be changing. It's enough to make the Greens choke on their breakfast muesli but technology looks set to turn a farm into a pharmacy factory.

The Economist asks the question in its September 18th edition: Will genetically engineered goats, rabbits and flies be the low-cost drug factories of the future?

Earlier this year, the regulators at the European Medicines Agency (EMA) agreed to consider an unusual new drug, called ATryn, for approval. It was developed to treat patients with hereditary antithrombin deficiency, a condition that leaves them vulnerable to deep-vein thrombosis. What makes ATryn so unusual is that it is a therapeutic protein derived from the milk of a transgenic goat: in other words, an animal that, genetically speaking, is not all goat.

The human gene for the protein in question is inserted into a goat's egg, and to ensure that it is activated only in udder cells, an extra piece of DNA, known as a beta-casein promoter, is added alongside it. Since beta casein is made only in udders, so is the protein. Once extracted from the goat's milk, the protein is indistinguishable from the antithrombin produced in healthy humans. The goats have been carefully bred to maximise milk production, so that they produce as much of the drug as possible. They are, in other words, living drug factories.

ATryn is merely the first of many potential animal-derived drugs being developed by GTC Biotherapeutics of Framingham, Massachusetts. The company has created 65 potentially therapeutic proteins in the milk of its transgenic goats and cows, 45 of which occur in concentrations of one gram per litre or higher.

GTC Biotherapeutics established a state-of-the-art goat farm and dairy facilities in Massachusetts in 1995. This site houses a clinic and barns for the production of transgenic animals as well as separate buildings for general animal housing, kid-rearing and milk collection. There are 7,200 square feet of dairy operations including dairy and processing facilities, with dedicated single-product milking parlors and processing areas.

The 300+ acre facility is home to about 2000 goats which

have been certified scrapie-free. **This herd was established through the importation of goats from New Zealand.** Animal welfare is assured by continuing high standards of



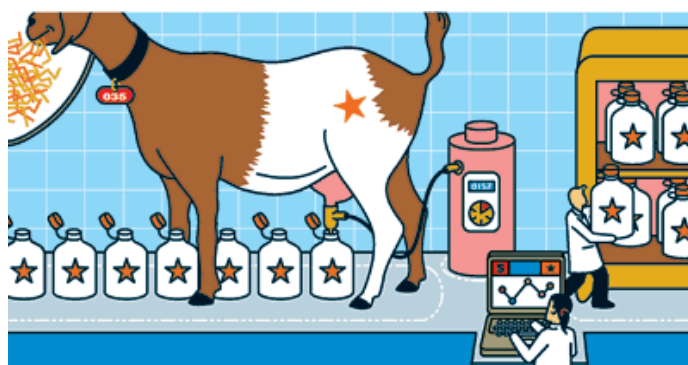
A production facility

care and husbandry. This farm is operated in accordance

with the FDA's "Points to Consider for the Production of Human Therapeutics in Transgenic Animals".

GTC claims female goats are ideal transgenic "biofactories" because they are cheap, easy to look after and can produce as much as a kilogram of human protein per year. GTC estimates that it may be able to produce drugs for as little as \$1-2 per gram, compared with around \$150 using conventional methods. Goats' short gestation period—roughly five months—and the fact that they reach maturity within a year means that a new production line can be developed within 18 months. Increasing production is as simple as breeding more animals.

GTC is not the only game in town. Nexia, based in Montreal, is breeding transgenic goats to produce proteins that protect against chemical weapons. TransOva, a biotech company based in Iowa, is experimenting with transgenic cows to produce proteins capable of neutralising anthrax, plague and smallpox. Pharming, based in the Netherlands,



is using transgenic cows and rabbits to produce therapeutic proteins, as is Minos BioSystems, a Greek-Dutch company, which is also exploring the drug making potential of fly larvae.

As yet medicines derived from transgenic animals are commercially untested, and could yet run into regulatory, safety or political problems. However, for biotechnology firms, increasingly risk-averse in response to pressure from investors and threats of price controls from politicians, transgenic animal-derived medicines might be exactly what they need: a scalable, cost-effective way to make drugs that can bring products to market within a relatively quick time.

Plain sailing is not assured. While some people may regard the use of animals as drug factories as unethical, the use of genetic engineering to treat the sick might be regarded as more acceptable than its use to increase yields and profits in agriculture. Conversely, tinkering with animal genes may be deemed to be less acceptable than tinkering with plant genes. There is not even unanimity in the biotech industry on whether medicines made primarily from animal-derived proteins will ever be safe enough to trust.

Greenpeace and the Union of Concerned Scientists is concerned that transgenic animals might escape into the wild and contaminate the gene pool, triggering all kinds of unintended consequences. There is also concern that an animal

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Inform Editor Bruce Parkes

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from the wild could find its way into GTC's pens, make contact with one of the transgenic animals, and then escape to "expose" other animals in the wild, or that transgenic animals would somehow get into the human food chain.

Short of sabotage, none of these scenarios seems very likely. Since transgenic goats, for example, are living factories whose worth depends on their producing as much milk as possible, every measure is taken to keep them happy, healthy, well fed and sequestered from non-transgenic animals. As animals go, goats and cows are relatively unadventurous creatures of habit, are more easily hemmed in than horses, and are usually in no mood to run away when pregnant—which they are for much of the time.

Perhaps the most curious approach to making transgenic-animal-derived medicines is that being taken by Minos BioSystems.. While others concentrate on goats, Minos is using flies. A small handful of common house flies can produce billions of offspring. A single fly can lay 500 eggs that hatch into larvae, a biomass factory capable of expressing growth hormone, say, or antibodies, which can then be extracted from the larval serum. The set-up cost of producing antibodies using flies is estimated at \$20m-40m, compared with \$200m to \$1 billion using conventional methods.

The uncertainty over regulatory and public reactions is one of the reasons why, over the past four years, at least two dozen firms working to create drugs from transgenic animals have gone bust. For the moment everything hinges on GTC's goats. The EMEA's verdict is expected before the end of the year. Even if GTC wins final approval to launch ATryn next year, it faces a difficult task convincing the sceptics that transgenic animals are a safe, effective and economical way to make drugs. As Monsanto and other proponents of genetically modified crops have learned in recent years, it takes more than just scientific data to convince biotech's critics that their fear and loathing are misplaced

Seminar Programme

October 12th

@ Brightside Hospital,
Brightside Road, Epsom
5:30p.m. for 6p.m.

Challenges of the Canadian Health System

**Mark Rochon, CEO Toronto
Rehabilitation Institute**

**Non Members Welcome
Cost**

Members \$20
Non Members \$25

Our seminar programme is
supported by



Mark Rochon

Our October Seminar presenter is Mark Rochon, President and Chief Executive Officer of the Toronto Rehabilitation Institute. Prior to holding this position, he served two and a half years as C.E.O. of the Health Services Restructuring Commission in Ontario, Canada. In 1994, Mr. Rochon was seconded from Humber Memorial Hospital, where he was President and CEO, to serve as Ontario's Assistant Deputy Minister, Institutional Health Group. He is currently Chair and a member of the Board of Directors of the Institute for Work and Health. Mark is an Assistant Professor at the University of Toronto in the Departments of Health Policy Management and Evaluation, and Physical Therapy.



Toronto Rehabilitation Institute is Canada's largest academic hospital specializing in adult rehabilitation and complex continuing care. Its focus is to help those who experience disabling injury or illness to rebuild their lives, while also striving to advance the practice of rehabilitation science through research, education and knowledge sharing

Contributions Welcome

1. The Auckland Branch welcomes contributions to **Inform** on subjects of interest to managers in the health and disability sector. Articles may be longer researched contributions, comments on current practice, or shorter notes and/or reviews. The range of possible subjects is very wide.
2. The maximum length is generally 3000 words. Shorter contributions are very welcome. Please include an e-mail address so authors can be contacted and a brief list of key points or an abstract.
3. Copy should be provided by electronically
4. Contributions may be passed to the Editorial Committee for consideration.
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