A Comparison of Australian and Overseas Legislation Relating to The Rights of Children to Health Surveillance and Medical Care

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The notion of legislation being required to ensure compliance with preventive health surveillance programmes in infancy, may with some validity, be questioned on the grounds that handicap in children occurs less frequently than in previous generations. Physical handicaps like the limb weakness which followed poliomyelitis which was prevalent 30 to 100 years ago are virtually unheard of today but there is evidence that there are, particularly in the lower socio-economic groups in our community, significant numbers of children with hidden, undiagnosed disabilities such as deafness.

BASIC PREMISES

The evidence alluded to above suggests that an argument for legislation relating to preventive health surveillance can be based on the following premises:-

1. Early screening for certain defects is demonstrably effective.
2. Parents sometimes fail to recognise certain conditions.
3. Not all children have access to or utilise preventive services.
4. Early diagnosis and intervention have important cost-benefits.
5. Most preventive programmes are fundamentally harmless.

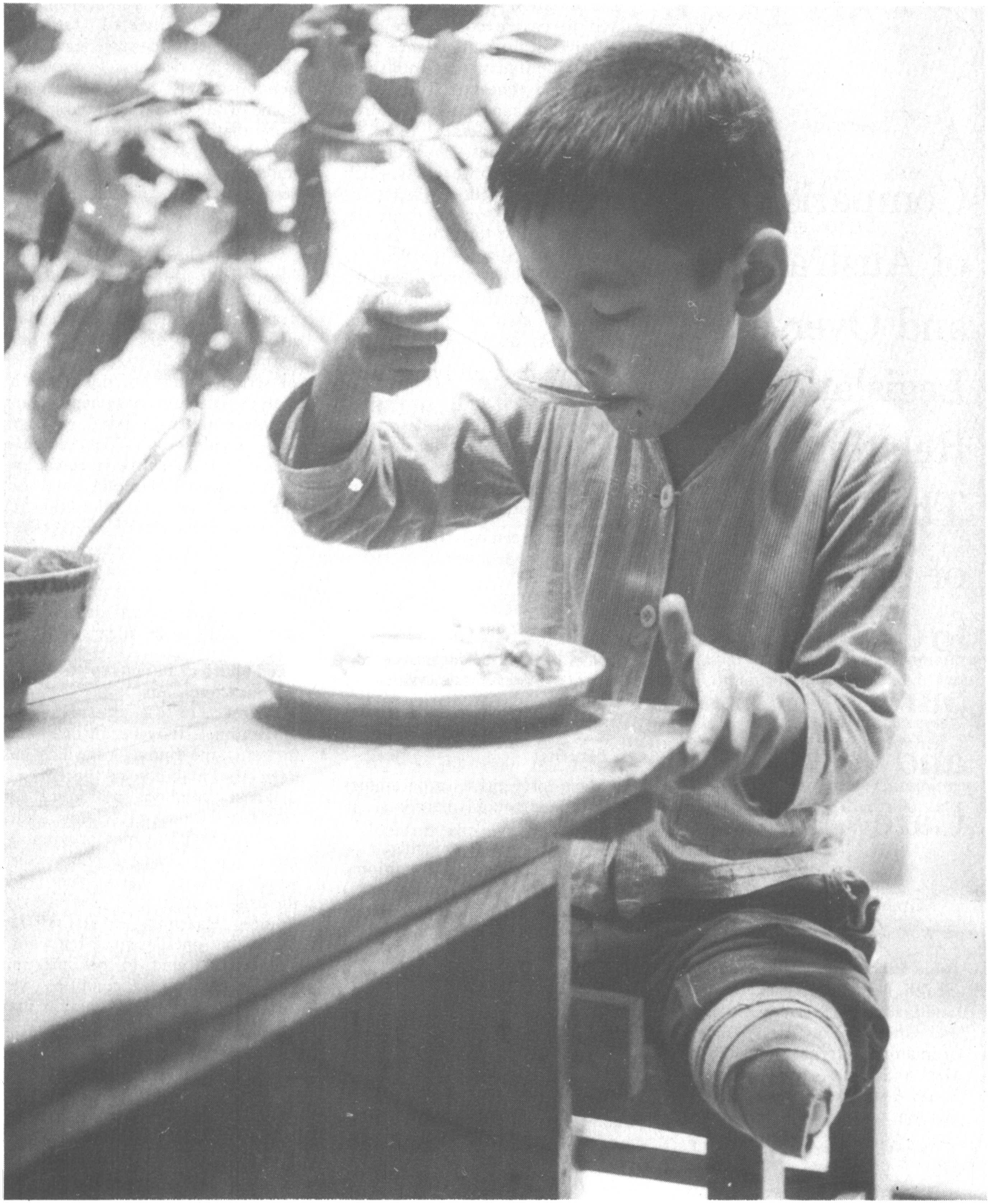
The Effectiveness of Screening

Screening for some conditions, for example phenylketonuria (PKU) — a cause of profound mental retardation — is a condition which meets all the accepted criteria for inclusion in a screening programme, but there are other conditions such as deafness where, when because of the tendency for the condition to sometimes be transient, screening tests tend to produce high rates of false positives or children with minimal lesions. Most pre-school and school clinic screening programmes identify about 50 per 1,000 children as suffering from a more than 30 dB bilateral hearing loss whilst the estimated ratio of Australian children sufficiently handicapped by deafness to require a hearing aid is 2.544 per 1,000.[1] Some of the cases identified in such programmes are almost certainly cases of "glue ear" — a form of middle ear disease which usually responds to medical or surgical management and only rarely progresses to result in permanent ear damage and hearing loss for which a hearing aid is required. Thus, the main impact of these screening programmes may be the identification of middle ear disease rather than permanent handicap. The low ratio of serious handicap should not be seen as a negative argument, in any debate concerning these programmes, since not only does 'glue ear' benefit from active medical intervention but as Upfold[2] points out the need for early detection of deafness is universally accepted as a means of ensuring the earliest possible commencement of habilitative measures vital for a deaf child's language and general development and ultimate social integration.

The Failure of Parents to Recognise Serious Conditions

Wynn (1976)[3] describes a longitudinal study begun in France in 1969, one finding of which has been the inability of parents to diagnose childhood morbidity. Of 10,500 ten-month-old children participating in a screening programme more comprehensive than that which is routinely carried out under the existing legislative provisions in France, Hazeman **et al**, (1973)[4] found that one parent in ten whose child was found to be suffering from some morbid condition was aware before the examination that anything was the matter with the child.

> "The morbidity not previously diagnosed varied from only 6 out of 59 cases of serious disorders of the nervous system, to 98 out of 102 cases of ear, nose and throat disorders and 63 out of 74 cases



> of serious respiratory illness. Every case out of two severe and 77 moderate cases of deafness had escaped notice".

Not all Children Have Access to Preventive Services

As part of the 1974 **Australian Government Commission of Inquiry into Poverty**, Murrell and Moss[5] found a wide discrepancy in the utilisation of infant welfare services between different ethnic groups and social classes in South Australia. Two neighbouring inner city areas of Adelaide were delineated, one toward the upper end of the socio-economic spectrum and the other, in which there were relatively high numbers of several ethnic groups toward the lower end. In the latter area, 8% of the study population infants had not commenced any immunisation course. Of mothers in this population, 15% (mainly non-British migrants) indicated that their child had not been examined by a doctor in the first six months of life. Attendance at the Mothers and Babies' Health Association baby health clinics was also markedly lower in the low socio-economic study area. 25% of the Anglo-Australian mothers in the poorer area had never attended a clinic, compared to 3% in the better area.

The Cost-benefit of Early Diagnosis

Cost-benefit studies in France, published in summary by the French Minister of Health **(Economie et Sante 1973)**[6] have shown that even with an incidence of only 1 in 10,000, the cost of discovering and treating one case of PKU, estimated at about £12,000 was a significant saving in the lifetime cost of caring for one severely retarded, institutionalised individual, the estimated cost being about, £80,000. Similar arguments have been advanced with regard to early diagnosis of congenital dislocation of the hip —

> "Early diagnosis and treatment show a profit of about £1,000 per case by avoiding in the majority of cases the cost of later operations and apparatus which is otherwise inevitably incurred".

and in deafness where early diagnosis was shown to result in a net profit to the economy of over £12m per year.

The Harmless Nature of Preventive Programmes

Procedures such as immunisation do carry some risk in terms of individual idiosyncratic reactions to vaccines, and the remote possibility of infection through faulty vaccine or poor technique and it would therefore be ethically difficult to justify compelling legislation even if adequate compensation schemes existed. Nevertheless, in the U.S.A. legislation of this sort does exist in some states but it usually contains provisions allowing parents to refuse consent for the procedure to be performed. Under the provisions of such legislation children without proof of immunisation can be excluded from school.

Whilst screening programmes which meet the guidelines which have been established to ensure harmful effects do not befall the screened population are not in question, not all the screening programmes presently advocated or practised meet these criteria. For instance screening for deviations in psychomotor development whilst seeming logical and sensible is questioned by North[7] on the grounds that —

> "neither diagnostic criteria nor effective treatments have been established for most of the conditions which lead to developmental delays. The possible dangers of mislabelling a child as "slow" or "retarded" are quite clear".

PRESENT AUSTRALIAN STATUTORY PROVISIONS

These five premises which form the basis of the argument for legislation concerning child health surveillance and preventive medical care are clearly relevant within the Australian context. What provisions, in Australian civil law, are there concerning child health?

There are no Federal statutes concerning child health or preventive programmes but some states have limited statutory provisions for child health surveillance. The legislation that does exist covers five main areas:-

1. The notification of birth
2. The intervention in known or suspected child abuse or neglect.
3. School health medical services, particularly in relation to verminous infestation.
4. Notification of infectious disease (including tuberculosis and venereal disease)
5. Authority for medical practitioners to initiate action in cases of life-threatening disease.

Birth Notification

A prerequisite for any universal health surveillance programme is a population register. Statutory birth notification provisions, which exist in all Australian states, enables a register of all newborn children to be maintained.

For instance, in South Australia, Section 14(1) of the Births, Deaths and Marriages Registration Act, 1966-1975, requires the occupier of the premises in which a child is born to furnish to the principal Registrar notice of the birth within seven days after the birth. Although not required by legislation copies of all notices are forwarded on to the Mothers and Babies' Health Association, enabling the mothers of all newborn infants to be visited and invited to participate in the health surveillance programmes of the Association.

The Queensland Health Act (1937-1967) with similar aims in mind **requires** that birth notices be forwarded to the district Registrar of all districts in which baby clinics are established. Indeed Queensland is the only state which enshrines in a statutory provision the practice adopted elsewhere of forwarding on such forms to the community based child health services.

Intervention in known or suspected child abuse, or neglect

All Australian states now have legislative provision designed to ensure the protection, intervention and taking into care of children subject to physical abuse or neglect.

For instance, the South Australian Community Welfare Act (1972-77) requires that medical practitioners, dentists, nurses, teachers, police officers and social workers should notify the Department for Community Welfare of suspected cases of non-accidental physical injury to children. The Department can require children so reported to be examined by a medical officer and if necessary detained in hospital for 96 hours without parental consent.

The Victorian Social Welfare Act permits a child "who is not provided with sufficient or proper food, nursing, clothing, medical aid, a lodging or who is illtreated or exposed" to be taken into care. Comparable provisions for the care of neglected children also exist in other states.

School health medical services, particularly in relation to verminous infestation.

Several states permit medical officers to examine any school child without parental consent. For instance, in the ACT, the Medical and Dental Inspection of School Children regulations not only allow authorised medical officers to examine any school child without parental consent but require parents or guardians to take appropriate action if notified by a medical officer or nurse of "verminous infestation". Failure to do so makes them "liable to conviction or a penalty not exceeding Twenty pounds (sic), and where the offence is continuing, a penalty not exceeding Two pounds for every day during which the offence continues."

Parents are also liable to be prosecuted in Western Australia if they fail to take action after being notified of a defect which requires medical or surgical attention.

Notification of Infectious Disease (including tuberculosis and venereal disease)

In the ACT, for example, there are provisions which enable medical officers of health or other authorised medical practitioners to intervene at their discretion in the areas of infectious disease, venereal disease and tuberculosis. The Public Health Infectious and Notifiable Disease regulations, the Venereal Disease Ordinance (1956-1975) and the Tuberculosis Ordinance (1950-1975) all have provision for action to be taken. Failure to comply with the requirements of the Tuberculosis Ordinance or the Veneral Disease Ordinance means a penalty of £200 (sic) or imprisonment for six months. These ordinances require the parents of minors (under 18 years) to ensure that their children comply with any requests made under the powers of the ordinances. Further Child Welfare Ordinance (1957-1975) 112.1 states:-

> "Where the Court has reason to believe that a child or young person is, or may be suffering from venereal disease, the Court may at any time order an examination to be made of the child or young person by a medical practitioner . . ."

Similar provisions exist in other Australian states.

Authority for medical practitioners to initiate action in cases of life threatening disease

In South Australia the Emergency Medical Treatment of Children's Act (1960-1971) enables a legally qualified medical practitioner to give a blood transfusion or perform a life saving operation without parental consent provided consultation with at least one other legally qualified medical practitioner has taken place. Western Australian legislation also permits a blood transfusion to be administered to a person under 21 without parental consent.

This review of the areas covered by legislation is not intended to be exhaustive. Rather, it illustrates the widely varying power and content of the legislation which does exist in different states. It is clear that many widely practiced and beneficial programmes such as neonatal screening for PKU and routine immunisation have no legislative backing.

PROVISIONS IN OTHER COUNTRIES

Unlike that existing in Australia the legislation of many other countries, whether they be in the developed or developing world, whether they are democratic or socialist, reflects the value placed by those societies on many of the main preventive health strategies. What are some examples of this?

U.S.A.

In the USA, there is federal backing for neonatal PKU screening and instilling of antibiotic eyedrops (to prevent possible gonococcal eye infection) but in 50% of states there is provision for parents to withhold consent for this procedure.

The Early and Periodic Screening, Diagnostic and Treatment Programme (EPSDT), in operation since 1967 (which commenced as a result of an amendment to the Medicaid law to include curative and preventive health care for persons under the age of 21), is a further example of legislation aimed at the protection of children's health. This law requires each state offering a Medicaid programme to ensure the provision of EPSDT services to all children eligible for Medicaid. Medicaid itself was established by the Social Security Act passed by the American Congress in 1965. It is a medical assistance programme which pays the health care bills of low income or disabled families or individuals. Under Medicaid, state governments are required to reimburse the providers of health services. To a certain extent this programme has failed because of two "Catches 22". The first is that inclusion in the programme, even granted eligibility is in no way compulsory, and the second is that only children eligible for Medicaid are entitled to receive EPSDT services. Each state has the statutory power to determine eligibility **of the individual child** for Medicaid. In 1974, only 13m of 23.8m children under 21 whose families had financial means of less than $7,000 p.a. were registered with Medicaid. The fact that, according to the American Academy of Paediatrics only 25.8% of **eligible** children received EPSDT services and that a large proportion of needy children are considered ineligible demonstrates the inadequacies of a programme for which there is no standard Federal legislation and for which entry is dependent upon the unrewarded motivation of parents and other caretakers.[8]

Even given the apparent failure of the EPSDT programme to totally meet the criteria of Principle 4 of the UN Declaration of the Rights of the Child —

> "The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; . . . The child shall have the right to adequate nutrition, housing, recreation and medical **services**"[9]

the programme has been shown to support the argument for legislation presented above.

> " . . . most children screened by EPSDT are suffering from health problems and desperately need the services of EPSDT. Nationally, for every three screenings, two conditions needing followup care were found. Between 60% and 80% of problems found in screening were previously unidentified or not being cared for . . ."[10]

Evaluation data from the programme reveals a very low referral rate to EPSDT in **younger children aged less than six years** and the presence of problems in the over six year olds which could have been successfully treated at a secondary prevention level if the child had been examined at a much earlier age.

More effective and efficient models of statutory child health surveillance exist in some European countries.

Finland

In 1944, the Finnish Government instigated legislative provisions aimed at improving accessibility and uptake of maternal and child preventive health services which were justified at the time by the need for action to reduce the high infant mortality which was then 68.8 compared with 44.5 in Britain. Since the introduction of these provisions, despite extremes in living conditions and transport problems encountered in a country which is snowbound for six months of the year, the infant mortality rate had fallen in 1970 to 13.2 compared to 18.2 in Britain and 17.9 in Australia.

Local authorities, responsible to central government for provision of preventive services in Finland, have a statutory obligation to maintain at least one maternal health centre in each area. Antenatal care in Finland, as in many European countries, is routinely managed by midwives. The 1300 maternal health centres are staffed by midwives trained to select high risk patients (estimated at 40% of all pregnancies) and refer them to one of the 22 major hospitals in the country for antenatal consultation or management. 99% of all births take place in these hospitals, most of which have more than 2,000 deliveries per year. Whereas in 1944, only 31% of all pregnant women registered for antenatal care, by 1968 the proportion was 99%.

Hospitals notify health centres of all deliveries, thus enabling early postnatal home visiting. Each mother has an average of 3.2 home visits in the immediate postnatal period. 99% of women have six-week postnatal checks at these centres, where the midwife has the added responsibility of encouraging the mother to register her child at the child health centre. Over 90% of children are registered by the age of one month and 97% aged between two weeks and seven years make use of the service provided. In order to maintain adequate staffing levels, local authorities (accountable to central government) must meet minimum staff requirements. This statutory provision limits their power to re-allocate resources away from preventive health services. Local authorities provide central government with data derived from standard performance indicators which are designed to assess service efficiency.

Maximum utilisation of services is ensured by legislation attaching conditions to the payments of maternity grants and allowances available to all women whose pregnancy extends beyond 180 days. All women who register at a maternal health centre before the end of the 16th week of pregnancy receive a grant currently equal to approximately A$160. This policy is based upon the evidence from Finnish and British studies showing a high correlation between perinatal mortality and inadequate antenatal care. There is a choice between cash payment or the allowance being "taken in kind" in the form of a substantial layette (worth considerably more than the cash allowance).

The fact that 93% of pregnant women register indicates that this form of incentive is effective. In Britain it is estimated that only 75% of women have attended for antenatal care by the end of the 16th week of pregnancy.[11]

France

In France, legislation to ensure adequate health surveillance of the pre-school child has been justified on the basis of cost-benefit studies which demonstrate the advantage of early diagnosis of handicapping conditions. Since 1945, a bonus has been paid to the mother who takes her child to a child health clinic, but, since 1970, the French Government has increased the protection of the child against the default of the parents. All parents are issued with a **Carnet de Sante** when registering their infant's birth. This contains pro formas for some 20 examinations scheduled between birth and six years. Three of these examinations at eight days, nine months and 24 months are associated with a **Certificate of Health,** which must be completed and signed by a medical practitioner. Failure to have this certificate completed results in the withholding of a significant proportion of the substantial family allowance. Measures of this kind have been employed in an attempt to reach the 20% of the population which, until 1970 had not made use of the preventive health services provided by the maternal and child health service and in which studies had shown a higher than expected prevalence of handicap. This legislation recognises the right of the child to health protection and provides legal sanction for limited protection of children against parental negligence or incompetence. There is also some legal redress for the child against doctors who may be penalised for incomplete examination or failure to fill in forms correctly. Another aspect of the French system has been the creation of new job opportunities for medical practitioners!

German Democratic Republic

The "Law on Protection of Mother and Child and the Rights of Women", in force in East Germany since October, 1950[12] resulted in the establishment of mother care centres throughout the State. At present, 95% of all babies are registered at these centres. Registration ensures:-

1. Financial support in the form of birth, pregnancy and delivery allowances;
2. Extensive health education, supervision and health protection in the antenatal period;
3. A visit from a State social worker in the four weeks immediately following delivery.

Infant mortality in DDR has fallen from 17.7 in 1972 to 14.1 in 1976[13]. Immunisation against small-pox, polio, diptheria, tetanus and T.B. are compulsory. All persons under 18 years of age are examined once a year and a step-by-step health certificate is given at each examination.

China

In China, as an example of a developing socialist country, women at the beginning of the third trimester of pregnancy, upon registration at a local women's clinic, are granted extra food allowances and free medicine. Registration at a neighbourhood clinic or rural prevention station is compulsory and easily enforced as the barefoot doctor or "lane" doctor responsible for running the clinic is usually a relative or neighbour and a member of the same work brigade. Women are given 56 days paid maternity leave, 14 pre- and 42 post-natally. The mother and infant have a full medical examination prior to her return to work. Immunisation against tetanus, diptheria and polio are compulsory. Again, yearly free medical examinations are performed through nursery, kindergarten and school years.

Mobile medical teams and the barefoot doctor system ensure maximum preventive health surveillance. Accurate data is difficult to obtain, but it is estimated that the infant mortality rate has, as a result of Chinese government policy of "taking health care to the people", shifted from 117 in 1949 to approximately 19.3 in 1976[14]. The apparent effectiveness of Chinese health surveillance is possibly due, in addition to state control and enforcement, to those characteristics of Eastern culture which foster responsibility for maintenance of personal health and emphasise the importance of the role of surviving children.

Japan

Japan has some provisions for health surveillance of children in the form of the Maternal and Child Protection Law[15]. Under this law, every expectant woman is required to report her pregnancy to a health centre which gives medical, dental and general health guidance as well as regular free medical examinations. In rural areas, 626 Maternal and Child Health centres have been established. Each of these has a consulting clinic and some beds for confinements. Low income families in Japan, that is those who do not pay income tax, receive, on registration, a nutrition service in the form of free milk or milk powder for 9 months. A child who weighs below 2,500 grammes at birth is expected to be reported by his or her parents to the health centre and domiciliary care services are then put into action. The prefectural governor issues, through the health centres a "pocket-book" for mother and child health to each pregnant woman. This is similar to the French **Carnet de Sante** but is not directly related to the payment of social security allowances. There is a system of automatic recall and followup for a complete medical examination at the age of three years. There is, unfortunately, no information available on how effective this is in terms of percentage of surviving children presenting for their three year old examination. Immunisation is provided to all children under six under the Preventive Vaccination Law (1948) for polio, diphtheria, whooping cough and small-pox. BCG Innoculation is given to all children under the Tuberculosis Control Law (1951).

CONCLUSION

Geographic and other variations in the infant mortality rate in Australia and available child morbidity data indicate that some of our children are not receiving optimal preventive health care. It is also incontestible that in terms of cost effectiveness, early detection of handicap through mass screening programmes and the initiation of remedial action costs far less than institutional management and support. Does legislation therefore have a role in Australia?

It is true, that enacting a programme into law is no guarantee that the mandated services get to the intended beneficiaries or that the intended beneficiaries are going to capitalise on the fact that the programme and the law exist for their benefit. Any programme for preventive health surveillance is only as good as the way in which it is administered, enforced and presented to the community. Extensive planning, manpower and resource determination and allocation are essential. Legislation can define areas of responsibility, and thus minimise the potential for unnecessary and wasteful duplication.

Arguments against legislation of this sort will inevitably be couched in those terms regarding basic civil rights with which seat belt, swimming pool safety and emergency treatment of children legislation have all had to contend.

It is also true that the introduction of legislation similar to that existing in France without other forms of social intervention aimed at reducing class differentials in health programme participation would be considered as demeaning to the poor — another example of 'blaming the victim'. Low motivation it is argued by some, is but one manifestation — rather than the cause — of the poorer health status of low socio-economic groups which results — as do other class differentials in other aspects of social lifestyles such as income, housing and education — from the different relationships different groups of people have to the means of production in society. These other strategies should include attempts to involve people in the process of making decisions which determine the availability of resources and giving them the skills through which they can influence change at legislative and public policy levels.

It is worth remembering not only in the International Year of the Child, but always, the principles stated in the United Nations Declaration of the Rights of the Child that **all** children are entitled to — "Special protection, opportunities and facilities to enable them to develop in a healthy normal manner, special treatment, education and care if handicapped and protection against **all** forms of neglect and discrimination". Statutory legislation for child health surveillance could help bridge the gap between advocacy and action.

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References

1. Upfold L.J. **The Early Detection of Childhood Deafness.** Med. J. Aust. 1978, **2:** 507-510
2. Upfold L.J. **Op Cit.**
3. Wynn W. **Health Care Systems for Pre-School Children** Proc. Roy.Soc. Med., Vol. 69, May 1976, 340-343
4. Quoted in Wynn A. **Op Cit.**
5. Murrell T.G.C., and Moss J. **Health Care for Infants and Mothers** Aust. Government Commission of Inquiry into Poverty: Social/Medical Aspects of Poverty Series: — Family Planning and Health Care for Infants and Mothers. Aust. Govt., Canberra, 1977.
6. Quoted in Wynn A. **Op Cit.** p. 341
7. North A.F. **Screening in Child Care** Amer. Fam. Physician. Vol. 13, Feb. 1976, 85-95
8. Children's Defense Fund, Washington Research Project Inc. **EPSDT. Does it Spell Health Care for Poor Children?** (1978). Ch. 3.
9. United Nations General Assembly. **Declaration of the Rights of The Child.** U.N. New York, 1959
10. Ibid.
11. Annotation. **"A look at Antenatal Care".** The Lancet, Vol. 1, 1979, p 1307
12. **What is done to protect the peoples' health?** Prof. Dr. sc.med. K. Kicht. Panorama DDR July, 1976.
13. Op Cit.
14. Blood A. **Maternal and Child Health in China** Australasian Nurses' Journal, June, 1978
15. Japanese Ministry of Health and Welfare — **Report on Child Welfare Services in Japan, 1977.**