Inadequacies of the law

Section 24 of the *Coroners Act 1958* (Qld) provides that the purpose of an inquest is to establish so far as is practical the fact that a person has died, the identity of the deceased person, and when, where and how the death occurred. Section 34 of the Act provides that no evidence shall be admitted by the coroner unless in his opinion the evidence is necessary for the purpose of establishing one of these matters.

In Shane's case the only matter at issue was how his death occurred. Traditionally, coroners in Queensland and elsewhere have sought to limit the extent of inquiry on this matter to the immediate cause of death. Shane's parents, however, required answers to questions going beyond the immediate cause of death and which went instead to the nursing practices and staff culture within the DPW, which they believed made such a death foreseeable.

The evidence

Despite the usually restrictive interpretation given to ss. 24 and 34 of the Act, counsel for Shane's parents was able to introduce evidence on a range of matters which would normally have been inadmissible in an inquest. This evidence related to the adequacy of nursing practices within the DPW, the adequacy of staff numbers, the lack of any 'socialisation' programs within the DPW and the corresponding reduction in residents' capabilities. It also addressed the philosophical divide between the 'medical model' of care for people with disability and a 'normative' model of care emphasising the residents' abilities and community inclusion. Introducing evidence of this sort was made possible by a coroner who allowed himself to be fully informed, and because of the police prosecutor's misunderstanding of and lack of preparation for his role of assisting the coroner. If counsel for the Department of Health had been present, as provided for in the Act, there would no doubt have been objections to much of the evidence given and the coroner would not have been free to make the riders he did.

The coroner's riders – a pointer to the future?

The coroner found the immediate cause of death to be aspiration of vomit with epilepsy, cerebral palsy and intellectual disability contributing to but not related to the cause of death. He then made 'riders', not deemed to be part of his finding but designed to prevent the recurrence of similar events (s.43(5)). They were:

- a finding that Shane would have participated in 'socialisation' programs if they had been available to him;
- an expression of concern that the situation in the DPW as at Shane's death had not changed;
- a recommendation that the depositions and exhibits be forwarded to the Queensland Minister for Health;
- a recommendation that the DPW be either upgraded in facilities and staff, or closed, to avoid any repetition of such a death;
- a recommendation that if the DPW is not to be closed, then the Minister's attention should be drawn to the current system of feeding and changing within the DPW, and that these procedures be reviewed to ensure that no resident is left unattended for any period of time in the vicinity of one hour and twenty minutes, as in Shane's case.

Conclusion

For so long as people with disability continue to live in institutions which exercise control over all or most aspects of their lives, they will remain vulnerable. Advocacy efforts should be directed to the properly managed and resourced closure of such institutions and enforcement of the right of people with disability to live within and fully participate in the community, with any necessary support. While these advocacy efforts are, of course, ongoing, advocacy efforts should also be directed to safeguarding the rights and lives of those people with disability still living in institutions. A comprehensive and coordinated system of investigation into and public hearings regarding institutional deaths is one such safeguard.

Shane's case is included here with the permission of his parents. Shane was planning to leave the DPW for supported accommodation in his local community, near to and with the support of his parents, shortly after the date of his death. The program which was to make this possible was placed on hold last year due to lack of funding and political will.

Matthew Keeley is a lawyer with Queensland Advocacy Inc.

CRIMINAL JUSTICE

'Shareware' for crime fighters

TONY WOODYATT argues that the CJC should establish a comprehensive database to underpin the policy-making process.

Good policy development requires a foundation of good information, yet Queensland criminal justice policy-makers do not have access to comprehensive and reliable data. Other jurisdictions, particularly New South Wales, South Australia, Western Australia, and New Zealand have established various systems to gather data across government and to verify its accuracy. However, while there have been recommendations to develop a database in Queensland, the Government continues to drag the chain.

The Fitzgerald Report observed that the former government's departments, particularly the Police Service, were able to mislead the public on crime and policing issues because of the absence of a publicly verifiable criminological database. For information to be usable by government and the public, a database must be properly designed, have uniform standards across agencies, must have reliable data collection processes, and must be publicly accessible so that it can be publicly accountable.

Commissioner Fitzgerald noted:

> A review of the criminal laws, particularly those affecting prostitution and SP bookmaking, needs more information if it is to make decisions with reasonable confidence that it is not simply creating more problems. At present, that information is not available to this enforcement body, Commission or Government in the country.

> Later in this report, recommendations are made for the setting up of a body which can carry out the necessary considered review of the criminal law, informed by research and investigations. That is vital. Only then can decisions be made confidently. [Fitzgerald Report, 1989:190]

A Research and Coordination Division was established as part of the Criminal Justice Commission (CJC) in the wake of the Fitzgerald Inquiry. While this unit of the CJC has conducted research with the cooperation of government departments, it has not had access to government data in any coordinated way, nor has it been able to review the information-gathering procedures of government, other than the Police Service.

A scan of recent annual reports of the Corrective Services Commission, Justice and Attorney-General, Family Services and Police Departments reveals that comprehensive data is still not provided to the public of Queensland, and therefore presumably is unavailable to policy makers.

In its Report No. 13 tabled in Parliament in December 1991, the Parliamentary Criminal Justice Committee recommended that a criminal justice database be established and managed by the Criminal Justice Commission (Recommendation 37:180). A committee, set up by the CJC but independent of it, supported this recommendation (Report of the Committee to Review the Queensland Police Service Information Bureau, 1992:42).

The Office of the Cabinet has taken responsibility for the coordination of criminal justice policy across agencies of the government (this is also a statutory function of the CJC under s2.45(1)(b) *Criminal Justice Act 1989* (Qld)). The Cabinet Office has also taken a leading role in policy development, reducing the role of the Departments of Attorney-General and Police.

What form should a database take?

In 1990, the Inter-Agency Forum on Law Reform (comprised of representatives of the Cabinet Office, relevant government departments and the CJC) was set up to facilitate the exchange of information within government. It was asked to consider what form a criminal justice database should take and who should have responsibility for it. Advice was also sought from the Information Policy Board of the Premier's Department. These bodies have been unable to resolve the competing claims of the various departments and agencies to establish, maintain and control the database, or to decide what form the database should take.

New Zealand, South Australia and Western Australia have integrated systems which permit the linking of records between agencies. The New Zealand and South Australian models use a single mainframe computer to achieve integration. This model is out of favour because of the expense and the perceived threat to agency independence. Some Queensland agencies have already argued fallaciously that confidentiality would be sacrificed by an integrated scheme.

Linked databases permit agencies to control their own data but transfer it to another system. This is cheaper so long as there are common data standards and definitions and compatible software and hardware. This is the NSW model. The linked model is as effective as the integrated one so long as data transfer is not impeded.

The NSW Bureau of Crime Statistics and Research, located in the NSW Attorney-General's Department, collects data from other departments for its analysis and research. With the consent of other departments, it can gain access to data for use in its Computer Simulated Modelling Program. This program enables government to estimate the effects of proposed policy options on other agencies and programs. Like the CJC's Research and Coordination Division, the Bureau is specialised and expert in criminological research. Unlike the CJC, the Bureau is not independent of government.

There have already been suggestions that the CJC's research division be transferred to the control of the Queensland Law Reform Commission (QLRC). However, the QLRC is funded by the Attorney-General's Department, acts only on reference from the Attorney-General, and is dominated by the legal profession.

Who should be responsible?

While it is necessary to ascertain the best database model for Queensland, the first question to be answered is – who should have responsibility for the database? Once this issue is resolved then the nature of the database – linked, integrated or otherwise – can be resolved.

The CJC is the ideal body to maintain and control the database. It was established on the recommendation of the Fitzgerald Inquiry as a body independent of the Executive and accountable directly to the Parliament. There were good reasons for this recommendation and those reasons remain. It is important that the CJC be able to operate free from government interference so that it can place before the public of Queensland a thorough, informed and reliable assessment of the criminal justice system.

The CJC is in most respects an open and accountable body, particularly in the activities of the Research Division. Its recommendations and processes are scrutinised by government, the media, community organisations, individuals, and the parliamentary committee to which it is formally accountable. It has responded publicly to most of the criticisms of it. It is subject to FoI and judicial review. The CJC is not perfect, but it has a better record for openness than any government department. This firmly establishes it as the appropriate body in Queensland to be responsible for the database.

It is regrettable that the Cabinet Office, which appears to have the running on criminal justice policy has not consulted the community on criminal justice matters, unlike the CJC which consults widely on major research issues. The Cabinet Office should be careful not to emulate a body established in Bjelke-Petersen's Department of Attorney-General to coordinate several departments involved in criminal justice. This inter-departmental committee operated in secret and made fundamental decisions without consultation. It ignored requests by community groups to participate in its deliberations.

The criminal justice database must be established without further delay in spite of the territorial imperatives of departments which want to remain closed. If there is going to be a database, the body responsible for it must be appointed without further delay. Otherwise, Queensland will lose the opportunity to gain the information that government needs to properly develop and target its policies. The cycles of crime and the justice system and its absorption of vast public resources will continue to spiral upwards, and policy will

continue to be sidetracked by emotive and uninformed arguments, unless government can develop rational and just policies based on reliable information.

Tony Woodyatt is a lawyer at Caxton Legal Centre Inc., Brisbane.

Acknowledgment: The author gratefully acknowledges the advice of Dr David Brereton, Director of the Research and Coordination Division, Queensland Criminal Justice Commission.

IVF

The egg bank

KATHY MUNRO reports that new techniques allowing the mass production of mature, unfertilised eggs raise important ethical and legal questions.

Numerous legal, ethical and public policy concerns have arisen since the first *in vitro* fertilisation (IVF) baby was born 16 years ago. In 1982 the National Health and Medical Research Council (NH&MRC) issued guidelines and more recently Victoria, Western Australia and South Australia, have enacted legislation to guide and control clinical research in this field. Since then there has been a recognition that existing provisions require revision to reflect the current state of IVF and embryo transfer (ET) research in Australia.

All existing guidelines and legislation focus primarily on the ethics of storage and disposition of and experimentation on embryos or fertilised gametes after fertilisation. It has been assumed that there are few ethical concerns surrounding gametes prior to fertilisation and so the current system does not ascribe comparable importance to the recording and monitoring of research using unfertilised gametes, particularly ova.

There is now a need for these guidelines and regulatory frameworks to address the manipulation, storage and disposition of ova, through a new technique, known as *in vitro* maturation (IVM). This technique allows scientists to take unripe eggs from women's ovaries and artificially mature and fertilise them in a laboratory. Usually only one egg ripens in the ovary every month. Using IVM it is now possible to collect large numbers of mature eggs.[1] Current frameworks are ill-equipped to accommodate the important ethical and regulatory questions which IVM raises.

The creation of ova as experimental material

The development of IVM technology is significant because for many years research scientists in the field of reproductive technology were frustrated about the lack of ova available as experimental material.[2] Prior to this development the only sources of donated ova were from women who underwent hysterectomies, women who were superovulated for the specific purpose of ova donation, and women on IVF programs. The increased availability of ova is likely to expand the demand and hence the commodification of ova, potentially leading to further fragmentation of women's reproductive capacities.

Ditta Bartels observed that in spite of the current shortage of ova, considerable advances have been made in the genetic testing of embryos and suggests that technologies such as IVM move the research beyond the context of infertility and into that of genetic engineering by providing a greater pool of embryos for experimentation.[3]

The spirit of existing regulatory frameworks (e.g. *Infertility Medical Procedures Act 1984* (Vic.) and the *Human Reproductive Technology Act 1991* (WA) is premised on the undesirability of deliberately creating embryos as research material. However, with IVM it is now possible to obtain an unlimited supply of research ova without interfering with existing regulations on embryos.

Ova banking

The development of IVM and US research into the freezing of unfertilised eggs means that ova banks, run like sperm banks, will soon be possible.[4] Legal reform addressing the consequences will be essential. Ova banking will be fraught with many of the difficulties currently confronting sperm banks, such as awareness of and adherence to professional guidelines, record keeping practices, donor recruitment, limitations on the number of donations and payment to donors.

Like most other forms of ova donation, ova banking requires that women must undergo invasive surgical procedures in order to donate their reproductive material. These procedures are vastly more hazardous than the act of masturbation required to obtain gametes from men.

Given the ethical concerns previously expressed by the NH&MRC about the safety of using frozen-thawed human ova,[5] there should be specific requirements for IVF units to report use of this new technique to the National Perinatal Statistics Unit. Similar information to that currently required by the regulations of ss.29(6) and 29(9) of the *Infertility Medical Procedures Act 1984* (Vic.) could be provided, with some modification to reflect the recent developments in gamete retrieval and donation.

Ova from cadavers and aborted foetuses

In 1993 a scientist in Scotland disclosed to the media that he had approached the British Human Fertilisation and Embryology Authority for permission to use the eggs of aborted foetuses as a source of donated eggs in IVF programs.[6] In the same report other researchers stated their belief that transplanting the ovaries from young healthy women who have died suddenly, may be a preferable option to using eggs from aborted foetuses.

In an interview early this year, Professor Carl Wood of Monash IVF remarked: 'It needs to be debated but I think it's a possible source for women who otherwise can't get donor eggs'.[7] Such comments are of concern because they suggest the demand for donor ova is generated by infertile women, despite considerable evidence that this demand for eggs is actually driven by researchers.

The use of ova from aborted foetuses raises complex ethical and legal questions relating to dispositional authority and consent. Under the existing NH&MRC guidelines on ovum donation, consent is required from the ova donor. Clearly when the existing guidelines were developed no one had entertained the possibility of obtaining ova from aborted foetuses. It is therefore critical that dispositional authority for