

QUESTIONS ON NOTICE TO DR KATH MCFARLANE ON FRIDAY, 14th MAY 2021

Supplementary question

1. How can privacy or ethical considerations be appropriately managed, so that more data on prisoners' parents is shared between government agencies and made publicly available for researchers and service providers?

Response:

I do not have any direct experience with information sharing between government and its contracted non-government human service providers, but it is obvious that information sharing, often of very intimate details, must take place.

I am however, well aware of complaints from non-government agencies concerning the vast amount of data they must feed up to the departments that contract them concerning the clients they administer on behalf of the department concerned. I am aware that complaint has been made at numerous Parliamentary inquiries over the decades that this flow is a one-way street, and that the contracted agencies concerned rarely derive any benefit from this data flow.

I will therefore limit my answer to addressing your question as it relates to **research**. I suggest that for a full understanding of the complex issues involved with this question, the Committee speak with agencies with specific expertise on ethics and research issues, such as the National Health and Medical Research Council (the NHMRC), the 'key driver of health and medical research in Australia'.¹

I bring to the Committee's notice that NSW legislation recognises the importance of agencies being able to inform themselves so as to improve their service to the public. This responsibility to do so is implied in Section 27B of the *Privacy and Personal Information Protection Act*.

Exemption is made in the *Privacy and Personal Information Protection Act* for research - see below:

27B Exemptions relating to research

A public sector agency is not required to comply with the information protection principles with respect to the collection, use or disclosure of personal information if—

- (a) the collection, use or disclosure of the information is reasonably necessary for the purpose of research, or the compilation or analysis of statistics, in the public interest, and
- (b) in the case where the agency would otherwise contravene section 9 in respect of the collection of the information—it is unreasonable or impracticable for the information to be collected directly from the individual to whom the information relates, and
- (c) in the case of the use or disclosure of the information—either—
 - (i) the purpose referred to in paragraph (a) cannot be served by the use or disclosure of information that does not identify the individual or from which the individual's identity cannot reasonably be ascertained and it is impracticable for the agency to seek the consent of the individual for the use or disclosure, or

¹ <https://www.nhmrc.gov.au/research-policy>

- (ii) reasonable steps are taken to de-identify the information, and
- (d) in the case where the use or disclosure of the information could reasonably be expected to identify individuals—the information is not published in a publicly available publication, and
- (e) the collection, use or disclosure of the information is in accordance with guidelines, if any, issued by the Privacy Commissioner for the purposes of this paragraph.

Privacy Commission Guidelines

The Privacy Commissioner has issued statutory guidelines on section 27B research, most recently updated during September 2019².

Much of the Commissioner's guidance is a simple explanation of the section, however the guidance does add some additional safeguards that seem obvious. These include: the requirement to document the reason why a research exemption was considered to be in the public interest and why other preferred mechanisms in the Information Protection Principles issued by the Commission were not utilised for the purpose of research, such as deidentification of the data or the obtaining of consent from the individuals to whom the data relates.

The Commission has also introduced requirement that a Human Research Ethics Committee, a professional market or social research agency, or the Commission itself has considered the ethical and privacy implications of the research and agrees that the research is acceptable with the *National Health and Medical Research Councils National Statement on Ethical Conduct in Human Research*³ or other standards. The Commission sets out guidance for how these approvals need to be carried out, and the sort of information about the process that must be retained.

Agency responses

The Committee will understand that the importance of research was recognised by members of parliament at the time the Bill discussed above was introduced.

It is therefore quite odd that often when the matter of research, or access to data, is mentioned to government departments, the immediate response is invariably that the request would be impossible because of privacy implications.

In my view, the use of this excuse by agencies that not only hold the most sensitive and intrusive information of people - especially children - is also inconsistent with the reality that some of these agencies maintain children in situations of almost constant surveillance; that they intercept and read the communications of children, and even, at least until recently, regularly strip-searched children.

NSW Government departments should be making more data available. Child welfare and child protection departments in other countries for example, make data freely available to the public concerning such matters as the numbers and nature of adverse incident reports regarding children in statutory care.

² Information and Privacy Commission NSW. *Statutory Guidelines on Research- section 27B*

³ National Health and Medical Research Council. *The National Statement on Ethical Conduct in Human Research*; 2007. Available from: <http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e72.pdf>.

In the public hearing on Friday 14th May I referred to my frustration that agency interpretation and (mis)understanding of privacy and ethics requirements operated to restrict rather than facilitate information about, among other disadvantaged and vulnerable groups, children of imprisoned parents. In my experience, Government agencies collect myriads of data about people to whom they provide services, however, this information is infrequently provided to researchers, the general public or service providers such as to enable a deep understanding of the issues affecting and impacting those agencies purports to service or assist. Where data is collected, it is not consistently or readily extracted, analysed, or applied so as to inform policy and programs that would benefit the people directly affected. Barriers to assessing information have resulted in important information being excluded from policy development, to the detriment of people serviced by government agencies.

Their Future Matters

In 2016-17 the Their Future Matters was established to ‘build an evidence base about ‘what works’, including piloting programs and creating a new dataset to identify risk factors for vulnerability and future costs to government’. Through the Human Services Data Set, de-identified data from 11 government agencies - spanning child protection, housing, justice, health, education, mental health, alcohol and other drugs, parental risk indicators and commonwealth services - were linked. This was a recommendation of the 2016 Tune Independent Review of Out of Home Care in New South Wales.

A 2020 report by the NSW Auditor General⁴ was positive in its assessment of the scope of this initiative, finding that ‘TFM partner agencies worked to share and link more than 60 frontline data sets containing de-identified data, to define key vulnerable groups of children and young people in NSW, identify risk factors contributing to the vulnerabilities of these groups, examine their service usage pathways and estimate future costs to government of providing related services’. The TFM Human Services Data Set was described as ‘unprecedented in scale in NSW, bringing together 27 years of data and over seven million individuals’ de-identified service records’.

Regrettably, these ‘important foundations...were not used to make key decisions on reprioritising funding or on scaling up promising or proven pilots before the end of the TFM reform period’.⁵ The resulting evidence base did ‘not yet comprehensively map how existing services meet needs, identify system duplications or gaps, nor demonstrate which government funded supports and interventions are most effective to make a difference to life outcomes for vulnerable children and families in NSW.’ The Auditor General concluded that failures in government and cross-agency partnership arrangements had meant the TFM program of reform ended without having achieved its aims.⁶

The Auditor General’s assessment outlined the reasons why the initiative had failed. It identified a lack of leadership of seniority sufficient to ensure the reforms were supported, lack of agency cross-agency collaboration and systems, among other concerns. Importantly, none of these issues are at all

⁴ Audit Office of NSW (2020) New South Wales Auditor Generals’ report: Performance Audit Their Futures Matter. <https://www.audit.nsw.gov.au/sites/default/files/documents/Their%20Futures%20Matter%20-%20PDF%20Report.pdf>

⁵ Audit Office of NSW (2020) New South Wales Auditor Generals’ report: Performance Audit Their Futures Matter. <https://www.audit.nsw.gov.au/sites/default/files/documents/Their%20Futures%20Matter%20-%20PDF%20Report.pdf> pg2

⁶ <https://www.governmentnews.com.au/nsw-child-protection-reforms-fail-to-deliver/>

the fault of the clients each agency services. It is not the responsibility of children of imprisoned parents, and it should not be the responsibility of their advocates or of researchers, to ensure that government and funded service-provider agencies, are able to do their job and generate meaningful, timely and insightful data that will assist children to navigate barriers and disadvantage - not of their fault or own actions - that arise simply because they are the unexpected and unanticipated face of parental incarceration.

EG: the lack of accessible information regarding NSW schools' suspension and expulsion rates¹ has contributed to the ongoing disproportionate impact of these policies on Indigenous children¹ and children in Out of Home Care¹. According to the Australian Human Rights Commission, almost 60% of children in OOHC were suspended in 2016, and these children lost, on average, 29 school days to suspensions.¹

Other key agencies have simply not collected information about children of prisoners. As I outline in my written submission, these include, among others: the NSW Department of Communities and Justice (whether the child welfare or the criminal justice, youth detention or adult corrections agencies); police; education; or the NSW Bureau of Crime Statistics and Research (BOCSAR).

In failing to do so, they have disregarded the recommendations of numerous parliamentary and independent inquiries. If information on even simple demographics of such groups is not collected, it is irrelevant that mechanisms for data sharing and dissemination, such as TFM, are celebrated. The information simply isn't there, and as such, any opportunities for policy development and assistance are advocated for in a data and research vacuum.

RECOMMENDATIONS

Access to deidentified data, and perhaps even in rare and exceptional circumstances, to identified data⁷, by external researchers and others independent of government departments, should be regarded as being in the public interest.

That the Committee make a recommendation to the Information and Privacy Commissioner and to the Attorney General, seeking a review of privacy restrictions around children in OOHC and the children of incarcerated parents, so as to enable the better treatment of these children, and whether they may benefit from exemptions in the Act being utilised, thus enabling access and exchange of information relating to them, and whether any additional safeguards need to be put into place to protect the information around those exchanges.

The Department of Communities and Justice, and other relevant agencies including the Bureau of Crime Statistics and Research:

- collect and publish information about children of incarcerated parents;

⁷ As is allowed by Section 27B the *Privacy and Personal Information Protection Act* in the term 'disclosure'.

- collect information on the OOHC status of prisoners in correctional facilities and information pertaining to their children;
- conduct research to aid in better understanding the needs of these cohorts;
- facilitate open access, minimal or low-cost access to government-generated datasets and information, so that independent and agency researchers and advocates can access information without requiring recourse to freedom of information requests; and
- tailor appropriately designed and effective programs to strengthen family and community ties and to reduce recidivism.

That government agencies assume responsibility for educating and advising community organisations about ethics and privacy aspects of research and facilitate processes that avoid individual community organisations having to develop and implement these themselves.

If funded to provide services to clients of government, community-based agencies should automatically be assisted to navigate the issues involved in producing, publishing and disseminating the outcomes of their research, advocacy and services.