Submission No 45

INQUIRY INTO SERVICE COORDINATION IN COMMUNITIES WITH HIGH SOCIAL NEEDS

Organisation: Information and Privacy Commission

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The Hon Bronnie Taylor MLC Committee Chair Standing Committee on Social Issues Parliament House Macquarie Street SYDNEY NSW 2000

Attention: The Director, Standing Committee on Social Issues

By email: socialissues@parliament.nsw.gov.au

Dear Ms Taylor,

Inquiry into service coordination in communities with high social needs

Thank you for your letter of 7 July 2015 inviting me to make a submission on the inquiry into service coordination in communities with high social needs.

My submission addresses the following issues:

- the importance of improving service coordination in communities with high social needs
- an overview of the privacy regime in NSW and recent activities relevant to improved service coordination
- discussion of the privacy regime's flexibility and opportunities
- privacy as an enabler of service coordination, and
- directions for the future.

It is based on experience with members of the public, our statutory advisory committee, the public sector and non-government organisations, academics and public officials.

1 The importance of improving service coordination in high social need communities

The Standing Committee's focus on this topic is timely and is commended. As highlighted in the East Dubbo Minister's Action Group Discussion Paper Report (July 2013) there can be pockets of intense social, economic and cultural disadvantage where communities have severe and complex needs that extend across employment, education, parenting support, domestic violence, accommodation and housing and health services.

One of the challenges of high-need communities is that addressing those needs effectively (through, for example case coordination or case management) can require the collection, sharing and consideration of greater amounts of more sensitive personal and health information than for clients

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with simpler needs. The complexity and interrelationship between the social needs and service use of individuals in communities with high social needs is elevated.

Achieving a flow of accurate, relevant and appropriate information can be particularly challenging for the delivery of services in rural areas where interaction is required with non-government and other private providers and agencies, which can be based in metropolitan areas. I am confident that service coordination and delivery of services to high social need communities can be performed in a privacy respectful way and discuss further below how this can be done.

2 Overview of the privacy regime in NSW

NSW has a proud history in privacy protection. It was the second international jurisdiction to legislate in 1975 to protect the privacy of citizens. More detail on the history of privacy legislation is contained in my 2015 report to Parliament titled 'Report of the Privacy Commissioner under Section 61B of the Privacy and Personal Information Protection Act'.

The NSW privacy regime now consists of two primary pieces of legislation. These set out the NSW privacy framework and my role as Privacy Commissioner.

The objective of the NSW privacy regime is to give citizens confidence that NSW public sector agencies and agencies handling health information, manage their personal information (including health information) appropriately in all circumstances. The structure and approach of this regime is broadly similar to that in other jurisdictions, including the Commonwealth privacy regime.

2.1 Privacy legislation

As Privacy Commissioner, I oversee two pieces of legislation that protect the privacy rights of citizens of NSW. These are the *Privacy and Personal Information Protection Act 2002* (PPIP Act) and the *Health Records and Information Privacy Act 2002* (HRIP Act). These Acts set out the obligations of NSW public sector agencies and other organisations to protect and manage personal and health information in accordance with the regime.

The PPIP Act regulates the way in which all NSW public sector agencies (NSW government departments and agencies, statutory authorities, universities, local councils and other bodies whose accounts are subject to the Auditor General) collect, use, access, store, dispose of, and discloses personal information of members of the public. The PPIP Act expressly does not apply to NSW state owned corporations. These obligations are set out as Information Protection Principles (IPPs) in the PPIP Act. The PPIP Act can also apply to private sector or non-government organisations (NGOs) if they are contractually required to comply with the privacy regime by a NSW public sector agency. As the Standing Committee is no doubt aware, there is a growing role for NGO providers in the provision of human services.

The HRIP Act regulates NSW public sector agencies, health service providers and certain organisations that collect, hold or use health information of members of the public. Similar to the IPPs, the Health Privacy Principles (HPPs) within the HRIP Act set out how health information must be collected, used, accessed, stored, disposed of and disclosed.

It should also be noted that exemptions from the NSW privacy regime may exist for NSW public sector agencies and organisations in specific circumstances. These circumstances include people who have been reported as missing and for public health and safety. The government can also amend legislation to allow non-compliance with the privacy legislation for a particular purpose. In the child health and welfare context, Chapter 16A of the *Children and Young Persons (Care and Protection) Act 1998* expressly notes that the safety, welfare and well-being of children and young persons takes precedence over the protection of confidentiality or privacy of the individual. In that special circumstance, information may be provided to or requested by prescribed bodies for investigative or service provision purposes relating to the safety and wellbeing of a child or young person.

As beneficial legislation, the NSW privacy regime places NSW citizens at the centre to ensure that NSW public sector agencies and organisations act lawfully and protect citizen privacy. This legislation can be complemented by other instruments such as Codes of Practice and Public Interest Directions to enable a flexible, context specific response to the needs of agencies, communities and individuals. Section 4 'Flexibility of the privacy regime' in this submission outlines the current codes of practice and public interest directions in operation.

2.2 The role of the Privacy Commissioner

The role of the Privacy Commissioner recognises the importance of the privacy rights of the people of NSW with respect to both their personal and health information. It is an acknowledgement that NSW citizens need an independent voice to oversee the protection of their privacy.

A particular concern of mine is that all NSW citizens have their privacy rights respected whatever their location or circumstances.

Section 36 of the PPIP Act enables me to, for example, promote privacy, publish guidelines, conduct research or inquiries, receive, investigate and conciliate complaints, provide advice on any privacy matters generally, and prepare reports recommending legislative, administrative or other action in the interests of privacy. This section also allows me to take up broader privacy issues which may arise in the community outside of the NSW public sector, for example, to examine the issue of drone surveillance.

I report to the NSW Parliament and am oversighted by the Parliamentary Committee on the Ombudsman, the Police Integrity Commission and the Crime Commission.

3 Relevant recent activities

In recent years I have advised the NSW Government on significant strategic initiatives that seek to improve privacy-respectful information sharing between public sector agencies and with other organisations. Such information sharing is often needed for good local planning.

3.1 Supporting public sector interagency initiatives

I and staff of my office have been or are currently involved in whole of government initiatives such as:

- Data Analytics Centre Steering Committee to establish the whole of government data analytics centre to share agency information and enable the delivery of better services and evidence-based policy development.
- Enabling Information Sharing Working Group reviewed the legislative, cultural and policy landscape to facilitate government's secure sharing of information for better service delivery and decision making required by the ICT Strategy while protecting individual privacy.
- NSW Legislative and Policy Framework for Government Records Management
 Steering Committee examined the effectiveness and gaps in the current legislative
 and policy framework (including the privacy regime) in a changing digital environment
 and new ICT sourcing models such as cloud based services and digital records
 management.
- Digital Licence Steering Committee to advise on the transition to digital licencing to address the number of physical licences currently issued to and required to be carried by NSW citizens.

3.2 Working with the non-government sector

I have undertaken training across NSW with National Disability Services to prepare such services for change in funding and organisation. The ability to meet the needs of such organisations is severely restricted by lack of a privacy budget and education officers.

3.3 Working with individual public sector agencies

My functions under the PPIP Act and HRIP Act require me as Privacy Commissioner to promote the adoption of the privacy regime and to provide assistance to agencies in adopting and complying with the IPPs and HPPs. The outcomes sought are good privacy practices in client service provision, particularly to high social need families and individuals. Managing privacy for these clients can be challenging in getting the appropriate balance between respecting the trust that people place in an organisation when providing their personal information and the perceived need to share this information.

To do this I regularly meet with agency heads and stakeholders to emphasise the importance of privacy in agency governance arrangements.

In 2014-15, I responded to 103 requests for policy advice on privacy by NSW public sector agencies and other organisations or individuals. These matters focused in particular on technological hub platforms, data sharing policies and programs across NSW public sector agencies and crime prevention. Many of these initiatives impact upon communities with high social needs. I was consulted on proposed legislation, reviews of Acts, program development, discussion papers, guidelines and protocols, for example, concerning the implementation of the Government's 2013 reforms of domestic violence arrangements.

3.4 Improving agency understanding and application of the NSW privacy regime

I am committed to promoting the importance of privacy and the NSW privacy regime so that agencies continue to build trust with the community when handling their personal information and to place privacy respectful practices at the heart of service delivery. This is particularly important in communities with high social needs where public sector agencies and non-government organisations foster positive relationships, and to work effectively and build trust with its members in order to achieve good social outcomes.

I have developed the Privacy Governance Framework for agencies to support their responsibilities under the NSW privacy regime and to embed good privacy practices in their business processes. The Privacy Governance Framework is an online privacy tool developed to assist agencies to understand the NSW privacy and personal information protection framework, to identify how the NSW privacy regime can be effectively implemented, and to help agencies identify, measure and resolve privacy risks to comply with NSW privacy legislation. It is aimed at Chief Executive Officers and senior executives while emphasising the need to be privacy aware at all organisational levels and at all points of service provision or project planning. The Framework is available on the Information and Privacy Commission (IPC) website here: http://www.ipc.nsw.gov.au/privacy-governance-framework.

4 Flexibility of the privacy regime

One of the benefits of a principle-based and technological neutral privacy regime is that it can be flexibly adapted to circumstances. This is particularly important given the rapid change in technology which allows the collection, analysis and sharing of information in ways previously unimaginable. The privacy principles (and privacy modifications and exemptions allowed in the legislation) can provide a robust privacy framework in which an agency initiative, program or project can operate within.

The application of the privacy regime can be modified in two main ways:

- making of 'Public Interest Directions' (directions) for short-term modifications (such as for program pilots or temporary changes in information flows) or
- Privacy Codes of Practice for longer-term modifications.

Legislation amendment is also always an option.

Directions and codes are forms of subordinate legislation and can be made under both the PPIP Act and the HRIP Act. They are made in different ways but both are ultimately approved by the Attorney General (and, where relevant, the Minster for Health) and do not require Parliamentary approval. Both

directions and codes require an assessment of the public interest in varying the application of the legislation.

Some privacy codes of practice of relevance include:

- Privacy Code of Practice (General) 2003 modifies the application of the IPPs and public register provisions of the PPIP Act. Particularly, Part 4 of the Code permits human services agencies to collect, use and disclose personal information to allied agencies or other agencies to develop or give effect to a case management plan or service delivery plan for an individual. Part 6 of the Code varies the collection, access, alteration, accuracy, use and disclosure principles for ageing, disability and home care agencies so that appropriate services are delivered to the individual; priority and placement of individuals to services can take place; and harm is prevented and ensures compliance with occupational health and safety laws by the agency
- Health Records and Information Privacy Code of Practice 2005 modifies the
 application of the HPPs for specific purposes or programs. Part 2 of the Code permits
 human services agencies to collect, use and disclose health information to another
 health service agency or allied agency to develop or give effect to a case
 management plan or service delivery plan for an individual
- Privacy Code of Practice for NSW Health (signed 28 June 2000) permits, for example, a health public sector agency as defined in the Code to disclose health information for the purposes of care or treatment (Clause 3)

Similarly, operative public interest directions under the PPIP Act that enable the collection, use and/or disclosure of personal information relevant to service delivery include:

- Direction on Information Transfers between Public Sector Agencies authorising exchanges of information that are reasonably necessary to allow NSW public sector agencies:
 - to deal with or respond to correspondence from Ministers or Members of Parliament
 - o to refer enquiries between agencies
 - to audit the accounts or performance of an agency
 - for law enforcement purposes not covered by an exemption in Part 2 Division 3 of the PPIP Act (this part outlines specific exemptions relating to law enforcement matters)
 - to enable the performance of agreements (whether formal or informal) between agencies which operated in the 12 month period prior to 1 July 2000 and have continued to operate under the Data Protection Principles (in the PPIP Act)
- Direction on the Collection of Personal Information about Third Parties by NSW Public Sector (Human Services) Agencies from their Clients – authorising the collection of personal information of a third party from a client, where this is reasonably relevant and necessary for the purpose of the public sector agency providing services, diagnosis, treatment or care to the client
- Direction for the Department of Families and Community Services and Associated Agencies – authorising agencies to collect or disclose personal information to an organisation for appropriate planning of a service delivered to an individual; enables the involvement of guardians or next of kin for situations where individuals do not have capacity to consent to collection, use an disclosure of their personal information

- Direction on Disclosures of Information by Public Sector Agencies for Research Purposes – authorising agencies to collect, use, disclose, access, alter and/or store personal information to conduct research generally, or when personal information in records is deposited with an agency, or where the collected personal information has historical or cultural significance.
- Direction relating to the Youth on Track program authorising participating agencies and NGOs to share personal information to identify individuals and offer them consent based case management and early intervention programs. There is a related direction made under section 62 of the HRIP Act relating to health information.
- Direction relating to the Life on Track program authorising the collection of personal information by the Department of Justice to enable case managers to identify individuals likely to re-offend and to provide consent based programs to them.

The Standing Committee may also be interested to know that I am currently advising NSW public sector agencies on how to enable privacy-respectful mechanisms for the collection, use, disclosure and/or access to personal and health information in the context of issues as diverse as improving the delivery of disability services, countering extremism in the community and facilitating the roll-out of the National Broadband Network in NSW.

The codes and directions are available on the IPC website at www.ipc.nsw.gov.au. A full list of codes and directions which are currently in operation is also attached at **Attachment A**.

5 Privacy as an enabler of effective service coordination

The Inquiry's terms of reference include that it will inquire into and report on:

"... barriers to the effective coordination of services, including lack of client awareness of services and any legislative provisions such as privacy law"

The flexibility of the privacy regime described above has, in my experience, allowed ample opportunity for agencies to respond to the needs of communities, families and individuals in a coordinated and effective way. As the list and scope of directions and codes show, there have been a number of quite substantial modifications to the privacy regime, and there can be further modifications where there is clear evidence of public benefit.

Nevertheless, there are undoubtedly misperceptions about privacy and considerable misunderstandings about what are barriers to effective service provision.

As evidence of this in 2014 the Department of Premier and Cabinet commissioned research into the exchange of personal information between agencies to examine, among other things:

"gaps, enablers and opportunities for improving the sharing of personal information...to support more effective service delivery".1

The research explored these issues through three detailed case studies. Key findings were that:

- "There did not appear to be significant legal impediments to information sharing in NSW."
- "...sharing information is often perceived to be complex by front line workers and agency managers. Many practitioners are reluctant to share information even when they have the legal authority to do so, and many agencies have a risk-averse attitude to information sharing even when this may be in the interests of clients. There is often a disparity between the actual legal and policy context and the perceptions of those involved."

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¹ Keeley, M., Bullen, J., Bates, S., Katz, I., Choi, A. (2015). Opportunities for information sharing: Case studies: Report to the NSW Department of Premier and Cabinet (SPRC Report 04/2015). Sydney: Social Policy Research Centre, UNSW Australia.

- "Organisational factors are the most significant barriers (and enablers) of information sharing."
- "Legislation and policy can also create significant barriers to information sharing. However, the research shows that the interpretation of these policies is more significant than policies themselves...."
- "Technological barriers to information sharing include different data storage and client record formats and privacy protection in storage of information. However, ... technological barriers can generally be overcome where necessary."

The report concluded that:

"In NSW, the two main reasons for the lack of information sharing were:

- · risk-averse organisations, and
- organisational or professional cultures which did not value holistic interventions.

The key gap in all three case studies was the lack of discussion about information sharing with the information subjects or their carers."

Similarly, a report prepared for the interagency Enabling Information Sharing Working Group found one enabler for sharing was:

"Robust legislation (Privacy and Personal Information Protection Act 1998, Health Records and Information Privacy Act 2002) which protects the privacy and confidentiality of personal information while allowing appropriate sharing and re-use."

The report went on to identify five categories of barriers to improved information sharing:

- Process (including inexperience and gaps in resources or infrastructure)
- Technology (including poorly organised or inaccessible data)
- Culture (including agencies not viewing data as an asset to be shared)
- Legislation/regulation (including myths and misconceptions about what can be shared), and
- Policy (including lack of direction on what can be shared)

My own experience in advising agencies confirms that that there can be significant gaps in agency knowledge about the current operation of the privacy regime which can lead not only to missed opportunities for service improvement but the use of inappropriate work-arounds or delayed service provision. I also emphasise the need to ensure that in sharing personal information that there is not the unintended consequence of deterring those who need assistance from seeking it.

In summary my view, based on interactions with agencies and experience in implementing modifications is that the current privacy regime in NSW is broadly capable of adapting to changed needs and circumstances and is not a significant barrier to coordination of services.

6 Directions for the future

Notwithstanding the flexibility and adaptability of the privacy regime there are number of areas where it could be further enhanced, including giving greater support to service coordination. I list below some of the areas of possible change and, where relevant, recommendations from my Report to Parliament on the operation of the PPIP Act.

6.1 Educating and informing the community and agencies

As noted above concerns within agencies about privacy are often based on mis-perceptions of the regime. To address this issue more educative activities and tools are required. This is essential.

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One particularly important message is the need for agencies to plan ahead and to communicate their approach to privacy. Effective management of privacy is often helped by adopting a systematic and thorough approach early on in the process, and not leaving it as an 'add-on'. Agencies and nongovernment organisations seeking to coordinate services and engage with high social need communities are assisted by:

- adopting a 'privacy by design' approach to ensure that the coordination of services and exchange of personal information between the entities is respectful of the privacy rights of individuals and the community, and
- conducting a privacy impact assessment to identify the privacy risks of the proposed model and the options to mitigate the risks. This would assist in preventing any potential challenges and would be a useful tool to designing the overall privacy management framework and aid in the evaluation of the outcomes.

As noted in my Report to Parliament communicating and explaining the operations of the privacy regime to agencies is a key statutory role that requires significant resources. The loss of the IPC's training and education position in 2013 due to budgetary savings requirements has been sorely felt.

6.2 Transborder movement of information

One of the greatest challenges for agencies in coordinating services is where individuals or communities are located close to the borders of other jurisdictions. This is because effective coordination can involve giving and receiving information from agencies 'across the border'. A similar challenge can arise where information is desired to be shared with Commonwealth agencies.

Unfortunately the PPIP Act does not currently regulate the transborder disclosures of personal information. Under section 19(4) of the PPIP Act the Privacy Commissioner is required to prepare a code of practice relating to the disclosure of personal information. I prepared and submitted a draft code to the former Attorney General in May 2014 and following receipt of that draft code, the then Attorney General indicated that the regulation of transborder disclosures would be best addressed by a legislative amendment.

In my Report to Parliament I recommended that the movement of personal information outside of NSW or to Commonwealth agencies be protected by amendment to the PPIP Act in the manner of health privacy principle 14, Schedule 1, HRIP Act. (Recommendation14). Such protection would foster trust with members of the community.

6.3 Role of NGOs and private services

The growing role of NGO and other private providers requires that their role be better acknowledged in NSW's privacy regime. In my Report to Parliament I recommended that:

- The PPIP Act to be amended to clearly cover contracted service providers and contractors who may be involved in services other than 'data services'. (Recommendation 4)
- Privacy compliance obligations are specified in contractual terms for the outsourcing of the provision of government services by public sector agencies to non-government organisations. (Recommendation 5)

In my Report to Parliament I also identified that I would assist agencies to provide guidance and assistance to non-government organisations in meeting their obligations and to manage the implementation of contracts including measuring, monitoring, benchmarking and reporting on compliance. (Recommendation 6)

6.4 Mandatory notification of breaches

Furthermore, agencies have and must continue to act responsibly if breaches do occur so that systems and processes can be improved and that client trust is not eroded. This is particularly important as agencies collect more detailed, comprehensive and sensitive information in order to coordinate services.

In my Report to Parliament I recommended that the PPIP Act should be amended to provide for mandatory notification of serious breaches of an individual's privacy by a NSW public sector agency similar to that proposed to be provided in the Commonwealth *Privacy Act 1998*. (Recommendation 10)

6.5 Supporting information sharing and service integration

The focus on integrated, coordinated 'place based' service delivery by agencies is fully supported. In my Report to Parliament I recommended:

- The alignment of the PPIP Act and emerging service provision models particularly of 'one government customer' be examined and a report prepared if amendment of the PPIP Act is indicated. (Recommendation 27)
- The appropriateness of a Code of Practice to enable information sharing for planning and policy analysis purposes between agencies be examined and developed if such a need is demonstrated. (Recommendation 30)
- The Departments of Family and Community Services and Education and Communities confer with each other and the Privacy Commissioner in relation to the development of a Code of Practice for the exchange of information in relation to the management of child protection issues. (Recommendation 31)

In that report I also undertook to establish a project, in conjunction with relevant agencies, to identify and investigate methodologies that enable the safe use of personal information in de-identified, aggregated and linked data sets so as to protect the privacy and personal information of individuals. (Recommendation 29)

7 Conclusion

I trust that the information provided assists to explain the NSW privacy legislation and clarify its application. I emphasise the applied research which shows that the failure to share personal information owes more to the lack of capability, culture and processes than privacy legislation.

I and IPC staff are committed to promoting the importance of privacy and NSW privacy regime so that agencies continue to build trust with the community when handling their personal information and to place privacy respectful practices at the heart of service delivery. This is particularly important in communities with high social needs where public sector agencies and non-government organisations seek to foster positive relationships, and to work effectively and build trust with its members.

I recognise that the legislation protecting personal information needs to reflect the changing nature of government's delivery of services and involvement of non-government organisations. I also see importance in continued engagement with such agencies to ensure that a clear and robust privacy management framework is implemented to aid efficient and effective information sharing.

I would be happy to assist the Standing Committee further if there were any questions about the NSW privacy regime in relation to coordinated service delivery in high social need communities.

I would particularly welcome discussing with the Standing Committee any issues or concerns raised by submissions or witnesses in regard to the operation of the regime.

Yours sincerely

Dr Elizabeth Coombs

NSW Privacy Commissioner

7.1.1 Privacy Codes of Practice

- 1. Privacy Code of Practice and Management Arrangements on the Government Employee Number
- 2. Privacy Code of Practice (General) 2003
- 3. Privacy Code of Practice for the Bureau of Crime Statistics and Research
- 4. Privacy Code of Practice: Department of Education and Training
- 5. Privacy Code of Practice for the Office of the Director of Public Prosecutions
- 6. Privacy Code of Practice: Department of Housing
- 7. Privacy Code of Practice for the Legal Aid Commission
- 8. Privacy Code of Practice: NSW Police Service
- 9. Privacy Code of Practice for the NSW Workforce Profile
- 10. Privacy Code of Practice for Local Government
- 11. Privacy Code of Practice for the Office of Fair Trading

7.1.2 Health Privacy Codes of Practice

- 1. Health Records and Information Privacy Code of Practice 2005
- 2. Privacy Code of Practice for NSW Health

7.1.3 PPIP Act directions currently in operation:

- 1. Direction relating to the Life on Track program
- Direction relating to the disclosure of information to credit reporting agencies
 Direction on the Collection of Personal Information about Third parties by NSW
 Public Sector (Human Services) Agencies from their clients
- Direction on Disclosures of Information by the New South Wales Public Sector to the National Coronial Information System
- 4. Direction on Disclosures of Information by Public Sector Agencies for Research Purposes
- Direction on the Disclosures of Information to Victims of Crime.
- Direction for the Department of Families and Community Services and Associated Agencies
- 7. Direction on Processing of Personal Information by Public Sector Agencies in relation to their Investigative Functions
- 8. Direction on Information Transfers between Public Sector Agencies Direction relating to Youth on Track
- Direction relating to the Disclosure of Personal Information by Councils to NBN Co Limited for the delivery of the National Broadband Network

7.1.4 HRIP Act directions

1. Direction relating to Youth on Track

