

Protecting the privacy of people with a decision-making disability *by Lucy Blamey, Legal & Policy Officer, Privacy NSW*

The right to freedom from arbitrary or unlawful interference with one's privacy is enshrined in international law (International Covenant on Civil and Political Rights). Since the late 1980s, Australia has followed the lead of European countries and adopted laws that require government agencies and private organisations to be fair and accountable when they handle personal information. These laws are more important than ever given developments in technology that increase the capacity of governments and organisations to collect, store and use personal information.

Personal information privacy allows us to choose who has access to our personal information and how others use our information. In this sense, privacy is about being able to control our identity, by choosing how we see ourselves and how others see us. When our personal information is treated ethically and we are informed about how it will be handled, we experience a range of benefits, from the ability to form intimate social bonds with family and friends to receiving essential services by professionals, government agencies and other organisations.

Privacy is also critical to relationships of trust, whether between family members, friends, health workers and patients, or government agencies and members of the public. If we can't rely on others to protect our personal information and handle it responsibly, we can easily lose trust in that person or organisation. A loss of trust may have devastating consequences, especially if it involves someone that we rely upon in a personal or professional capacity.

While most people expect to compromise a reasonable level of their information privacy in order to live in society, people with disabilities are often expected to make more compromises in this regard than is expected of others. Some compromises are reasonable to the extent that a person can receive adequate services to meet their personal, health, financial or other needs. At the same time, people with disabilities are entitled to the same privacy rights as anyone else – including collection of personal information only by lawful means, the right to access and correct personal information held by agencies, restrictions on disclosure of personal information without consent unless lawfully authorised, and the right to hold organisations accountable when privacy is breached.

People with decision-making disabilities face especially great challenges when exercising their rights to personal information privacy. A person's ability to make decisions may be affected by such things as a mental illness, dementia, brain injury or intellectual disability. Depending on the stage or nature of their disability, a person may not have the capacity to understand the general nature or effect of a particular decision about how their personal information is handled. Privacy laws generally assume that all adults have the capacity to understand and make decisions about what happens to their personal information by giving or withholding their consent. This raises the practical question of how a person can exercise their privacy rights when they have a decision-making disability.

Privacy NSW, the Office of the Privacy Commissioner, has recently developed a Best Practice Guide on Privacy and People with Decision-Making Disabilities. The Guide was developed in consultation with public sector agencies, non-government organisations and advocates for people with disabilities. It aims to assist NSW government agencies to apply the principles in the Privacy and Personal Information Protection Act 1998 (PPIP Act), in a way that protects and promotes the privacy of people with decision-making disabilities to the greatest extent possible.

Privacy NSW's Guide cautions against making assumptions about a person's capacity and stresses that capacity is unique to each individual and is influenced by their social and physiological circumstances and their emotional and intellectual abilities. A person's capacity to make decisions also depends on other variables such as the type of decision or complexity of the information involved, the nature or severity of a person's disability at a particular point in time, and whether appropriate support is provided to assist the person to make a decision (for example by communicating information in a way that is appropriate to the person's

abilities and linguistic and cultural background).

People with a decision-making disability have the right to participate in decisions that affect how their personal information is handled to the greatest possible extent. Even if a person cannot understand the general nature and effect of a particular decision or action, they may still have strong opinions or preferences about who has access to their personal information and how it is handled. These views should be respected and properly considered by agencies when making decisions about what happens to a person's information.

If a person does not have capacity to give or withhold consent to what happens to their information, an alternative decision-making process is needed. Sometimes another person who has a close relationship of trust with the person, or who has lawful authority to make decisions on behalf of the person (such as a guardian), is able to make a substitute decision on the person's behalf. As well as making decisions about the collection, use and disclosure of information, a substitute decision-maker should also be able to exercise other information privacy rights such as the right to access and correct the person's information held by an agency.

The Guide recommends a flexible approach to choosing a substitute decision-maker, depending on the type of information at issue. For example, while it may be appropriate for a person's financial manager to make decisions about a person's financial information, their close friend may be a more appropriate person to make decisions involving information about their health or other personal matters.

Sometimes a person does not have anyone who can make decisions on their behalf. Even if a substitute decision-maker is available, Privacy NSW recommends that agencies consider the views of the substitute decision-maker alongside a range of other criteria before making a decision that is in the person's best interests. For example, what will be the consequences for the person if their information is/is not collected, used or disclosed; what are the views of the person about what might happen to their information; has the person (and/or their representative) been notified of their right to access and correct the information? A combination of substitute decision-making (if it is possible) and a procedural assessment of consistent and objective criteria, is more likely to properly address the person's privacy interests than either approach alone. It allows the unique needs of a person with a decision-making disability to be considered while also promoting transparent and accountable information handling by agencies. The alternative decision-making model should also ensure that aggrieved individuals can exercise their rights to have a suspected breach of privacy reviewed and remedied where appropriate. This is simply the same right that we are all entitled to if our information is handled unfairly or misused by those whom we trust.

The Best Practice Guide on Privacy and People with Decision-Making Disabilities can be ordered from Privacy NSW on (02) 9268 5588 and is available on their website: www.lawlink.nsw.gov.au/privacynsw