

Confidentiality and Privacy¹

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As service providers we are often placed in situations which call on us to exercise judgment. As we all know often the answer is not clear cut, there is no black and white recipe book which gives us the right outcome or answer when we are presented with certain facts or situations.

What is generally required is a willingness to discuss the issues, consider the principles involved and, together with the consumer, work out a way forward.

The following comments are from the perspective of a service provider. I am not a lawyer². Think of them more as my own musings and perspective on the issues as you think about and debate the issues with your colleagues. It is that dialogue working out what the most appropriate approach is given the individual circumstances you are faced with that is the most important.

Confidentiality

During our professional training we have the issue of confidentiality drummed into us. But why is confidentiality important? To put it concisely, the whole basis of the helping professions, for the want of a better term, is the ability for someone to share information with us and by doing so engage our help and support to address the issues of concern.

For our purposes we will expand that to non health related services as well, as the principle is the same. Consumers provide us with information to enable us to provide them with a service. When this information involves the way they see or interact with the world, or the relationships they have with others and the difficulties they encounter there, we are provided with very personal information, maybe things which the person has never told anyone else. The information is generally provided on the basis that it will not be shared with anyone else. On the basis that it remain confidential.

It all comes down to trust. We endeavour to establish a professional relationship with our consumers which is based on trust. Given their experience of the service system trust is often something which for many of them has been breached over the years. If we are committed to working with consumers, assisting them to develop skills and become independent, showing them that they can trust people we should build and seek to maintain that trust.

To recognise the importance of confidentiality the law has established a Duty of Confidence. That is there is a legal requirement as service providers for us to keep the information our clients give to us confidential.

What does that mean? Basically the information consumers provide us is only is provided for our use. If we wish to share the information with someone else we generally need to get the consumer's permission.

¹ The comments in this paper are personal and do not necessarily reflect the views of the Office of the Protective Commissioner

² This paper is not intended to provide legal advice. Any issues in relation to the relevant law covered by this article should be discussed with an appropriately qualified legal practitioner

However, like everything, is not so cut and dry. The Duty of Confidentiality is not an absolute.

There are certain times when one can over-ride a Duty of Confidentiality, but these should be very rare occasions, for example:

1. When required to by law - e.g court order, a major crime
2. When it is in the 'public interest' – e.g. public health issue
3. When the person consents
4. When its as part of a “treatment”/”support” team, and then only on a needs to know basis and discussing that need to share information with the person

A breach of the Duty of Confidentiality is a breach of the law and can lead to very serious consequences, so we should be very careful about the decision making process when contemplating such a step. Documentation of our reasons for releasing information is very important so that if we or our agency are challenged at some stage there is a good record to rely on. The worse outcome is that there is no information there to back up the release of information and so some legal sanction imposed upon us.

In short we should refrain from giving information to anyone and if we have to only give the minimum amount of information necessary.

In the forums associated with the Inquiry in Mental Health Services, the report of which was handed down just under twelve months ago a number of people and groups commented how frustrating it was that they often carried the heavy responsibility of care and support, taking the person to the doctors, helping them in whatever ways imaginable to live in society, and yet when the person was unwell they could gain little or no access to information. The reason why? Professionals quote their duty of confidentiality or the person's right to privacy. Both are often reasonable responses, but clearly very frustrating for family members and carers.

However, a spouse, a partner, a family member or general carer has no legal entitlement to receive confidential information about a consumer without their consent (or the consent of an appropriately legally empowered person such as a guardian or person responsible).

Privacy

The *Universal Declaration on Human Rights* (United Nations, 1948) states

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Privacy is one of the buzz words right now – though it has taken a little while to get to the front page. Every day you open the paper there seems to be yet another issue related to privacy there staring out at you.

Many organizations are now claiming privacy as the reason they can not discuss any matter with others. A little bit of an over reaction, in my view.

NSW has its own privacy legislation, in fact two different Acts – the *Privacy and Personal Information Protection Act 1998* (PPIPA) and *Health Records and Information Privacy Act 2002* (HRIPA). Indeed the *Mental Health Act 1990* also has a protection for information prohibiting disclosure of information in connection with the administration of execution of the Mental Health Act. I will not go into the details of any of those very important pieces of legislation right now. Fact Sheets summarising privacy issues are available from Privacy NSW.

Federal privacy legislation, the *Privacy Act 1988* may also apply to private sector organisations and General Practitioners.

The important thing to note is that the law now clearly states what we can do with information that is collected and held in relation to someone.

So, what is privacy?

Privacy NSW has used the following definition

The right to be let alone, the right to personal space or autonomy, the right of people to exercise control over their personal information or the degree of interference with their personal life

I think we would all agree that is a reasonable definition and indeed outlines some rights that are very important to us all.

Privacy has become a hot topic of late for a number of reasons. I think one very important reason is that there is so much information held about us by other people/organisations to which historically we have had no access and over which we have had no control. I think this is starkly obvious if you think of the mental health system.

People are also more aware and it is becoming technologically easier and cheaper to share, search, manipulate and combine this data.

The rise of the consumer movement has meant that people have become more educated about what happens with information, and how misleading it can be if used out of context. It is not uncommon for us to see in a consumer's records some very interesting comments or notes, or even hypotheses about behaviour which end up being used as labels and used against them.

Privacy legislation generally requires us to inform consumers of

- What information we will collect about them
- How that information will be used
- How it will be stored
- Who it will be shared with (if anyone)

It emphasises the need to gain the person's consent to the collection, storage and release of information.

I do not think any of us would argue with that approach. It respects consumers' rights to independence, self determination, decision making and choice – some of the key stones of service provision.

A significant challenge for those interested in privacy is how do we make the law work with reality as we see it day to day? Working with consumers with disabilities which affect their decision making makes both confidentiality and privacy interesting challenges.

One of the challenges is how do we protect people's fundamental rights to confidentiality and privacy whilst providing a service to them?

What happens if someone refuses to give us permission to share information with someone else, such as a spouse or partner or carer? What can we do? Well, generally our course of action is limited.

I note that National Privacy Principles (contained in the Federal Privacy Act) say that if the person lacks capacity personal information can be disclosed under the National Privacy Principles for care and treatment or on compassionate grounds to a parent, sibling or spouse. However as noted before these arrangements only apply to private sector organisations and General Practitioners.

The complexity of this specific area of privacy law is reflected in the best practice guide recently released by Privacy NSW, *Privacy and People with Decision Making Disabilities*. In short the guide tries to provide assistance to individuals and agencies in working through consent to collect, store, use and most importantly, release information in relation to consumers with a disability.

The guide provides a model of decision making for those times when someone is judged incapable of making decisions. It emphasizes that just because you can not make a decision does not mean you might not have a view about what information is collected, used, stored or given to someone else. It is an attempt to enshrine the person's right to participate in decision making to the extent their abilities allow and to maintain their independence and self determination.

One of the major challenges for agencies is communicating with people in ways which are meaningful and enables them to participate in decision making.

It may also require agencies to seek a substitute consent from another person, if the person is totally incapable of participating in decision making – what HRIPA calls an 'authorised person'.

I encourage you to access a copy of the best practice guide and start thinking about how your agency will need to use them.³

You should also be mindful of the provisions of the *Guardianship Act 1987* under which guardians are appointed for people with decision making disabilities. If a guardian is appointed with a health care, medical and dental consent or services function it would be appropriate for you to discuss issues in those areas with the guardian. Indeed, depending on the powers of the guardian, it may be mandatory that you seek the guardian's consent prior to carrying out a treatment or providing a service. Discussing matters fitting within the guardian's powers, as outlined in the Guardianship Order, would not be considered a breach of the law.

The Guardianship Act also provides for 'persons responsible' who may not be formally appointed guardians to provide consent to medical and dental treatment. In a similar way providing relevant

³ Available on the Internet (www.lawlink.nsw.gov.au/pc.nsf/pages/guidelines) or phone Privacy NSW on (02) 9268 5588

information to a person responsible would also not be a breach of the law. Information about persons responsible can be obtained from the Office of the Public Guardian or Guardianship Tribunal.

Generally our clients will be able to interact with us and discuss the issues required. Most importantly they will be able to provide a view about who they wish information to be shared with, or, more notably, who they do not wish information shared with. That becomes most problematic if we are faced with a consumer who does not wish us to discuss information with a family member or carer, particularly if they are the only ongoing support the consumer might have.

What do you do?

I think the only answer is to use your best endeavours to explain to the consumer the importance of sharing information with the other person - the pros and cons of doing so. It may be that you have to negotiate exactly what can be said and what can not be said. In the end the consumer's decision stands. That is, unless they are deemed incapable of making decisions, at which time a guardian might be appointed to make decisions on their behalf.

No matter what approach is taken it is still extremely important that the consumer is involved in the decision making process to the extent their disability allows.

Interestingly in Victoria this problem has been overcome at least in law. Recent amendments to *Mental Health Act 1986* (Vic) allow for information to be disclosed

to guardians, family and primary carers if the information is reasonably required for the ongoing care of a client and the person who is receiving the information will be involved in providing the care

Such a provision provides surer footing for professionals in disclosing information, but once more requires us to make a judgement about what is "reasonably required". I would argue that relates to the need to know test mentioned earlier. What does the person need to know – it is not an open book where the person gets to learn about everything to do with the consumer just what is necessary to do the job. That would seem to be a sensible way ahead.

To try give some guidance in this area the Inquiry in Mental Health recommended

That the Minister for Health seek to amend the NSW *Mental Health Act 1990* to allow limited disclosure of information about clients of mental health services without the consent of the client. These exceptions to confidentiality would allow information to be disclosed in the following circumstances:

- to guardians, family, and primary carers if the information is reasonably required for the ongoing care of a client and the person who is receiving the information will be involved in providing the care and
- where it is required in connection with the further treatment of a client

So we are still in a difficult situation if a consumer is capable of making decisions and refuses to let us provide information to others that might be providing support to them (other than the treatment team). We owe the consumer a duty of confidentiality. We must uphold their right to privacy. The law says those things very clearly.

Only in very limited circumstances can we over-ride those rights, and if we do it we should very clearly document why.

Work it out beforehand

For some people with an episodic mental health problem or one which might improve with medication (with potential to relapse if medication is stopped) it might be possible to work out with them who can be provided information if they are unwell. The Schizophrenia Fellowship called this 'secondary guardianship' in its response to the Inquiry into Mental Health Services. I think a similar scheme has been tried in North America under the title of a Ulysees Agreement. In these arrangements someone might be given the authority to make decisions or receive information about the consumer from a specific moment, e.g, when the treating psychiatrist determines they are incapable of making certain decisions. The arrangement ceases when certain things occur or milestones are achieved, e.g. the person becomes capable again.

This is a more flexible approach to traditional limited guardianship and a further development on enduring guardianship instruments which were introduced in NSW in 1998.

The whole idea in these matters is planning ahead. Providing people with information when they are more able to process it, providing information in accessible formats and giving people time to consider the issues fully.

Carers' Rights

So, as we can see the law at least at the state level does not help us much in relation to carers rights at this point in time, though the Inquiry into Mental Health has recommended some changes.

Generally, carers do not have a right at law to access information about a consumer, without the consumer's consent. With consent the carer can participate in planning meetings, meetings with doctors and be part of the team supporting the person as they live their life in the community, and during episodes of illness. Without consent it becomes very difficult to tell carers much at all, understandably leading to great levels of anxiety and frustration.

Sometimes health professionals breach consumers' rights to confidentiality and privacy in order to provide information which will help a carer participate as part of the "team". Whilst that may sometimes be justified, I think such a practice often walks a very thin line and great caution should be used – unless the person is at risk of serious and imminent harm (in which case privacy laws allow relevant personal information to be disclosed).

People providing professional support to consumers are legally required not to breach a consumer's confidentiality and privacy (subject to the relevant exceptions provided in the law) especially if the consumer is competent and has expressly told them they can not disclose information to any one else.

Depending on their relationship with the consumer a carer may be able to access information and participate in decision making, at least in some limited way, if the consumer is judged by the treating health care professionals to lack capacity to make decisions. I say depending on the relationship as mentioned earlier the Guardianship Act provides for persons responsible to provide substitute consent to medical and dental treatment if someone is not able to provide such consent, without the need for any order of a court or tribunal.

If a consumer is so unwell and is unable to make medical treatment decisions the person responsible should be consulted and consent gained from them. To gain that consent you would need to discuss the situation and the treatment proposed. That does not mean you tell them everything the consumer has shared with you, only those things that you think are relevant in assisting the person responsible make an informed decision.

That does not stop the carer being seen as part of the team in providing information about the consumer, a role and information which are undoubtedly very important in supporting the consumer in the community, which should be one of our fundamental goals.

If that is true carers are recognised as an important part of the service system, helping many consumers live productive and meaningful lives in the community. As service providers it is our job to assist carers as much as possible to undertake a role which is sometimes very taxing and goes on day in day out for many, many years.

Lastly I note a very positive development at the federal level specifically on this topic. Currently the National Mental Health Coalition made up of the Australian Medical Association, Royal Australian and New Zealand College of General Practitioners, Private Hospitals Association and the Mental Health Council of Australia) have been discussing the challenges of privacy and mental health in the context

of Federal law. It is hoped that the result of those discussions will be some guidelines for mental health professionals, carers and consumers.

Summary

Confidentiality and privacy are not concepts to fear. They are there to protect everyone's human rights. They remind us of the importance of being thoughtful when disclosing information about a consumer and releasing information, generally, only after obtaining appropriate consent.

This paper has not endeavoured to cover all the issues or provide a comprehensive guide to the law in these areas. It has simply been written to stimulate some further discussion and thinking.

The most important thing is that we continue think through these issues, debate them and develop policies and procedures about how we will deal with them when they arise.

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