



Privacy Commissioner's Speech at:

National Disability Services Regional Support Workers Conference

Understanding Boundaries and Privacy

9 April, 2013

Goulburn NSW

Thank you. Before I begin, I'd just like to acknowledge the traditional owners of the land on which we're gathered today.

I'm delighted to be speaking with you at this regional conference.

As support workers, you touch the lives of so many people throughout the community.

The work you do and the services you provide are of such great benefit to people with disability across New South Wales.

While I don't pretend to have an in-depth understanding of the professional challenges you face in your field of expertise, I do know that we all share a belief in the importance of privacy, both in our personal and professional lives.

When I was invited to speak to you on the topic of privacy and social networking and the implications for your profession, I was impressed with this proactive approach to considering privacy in this professional context.

For many professions, this is still quite unchartered territory.

I applaud National Disability Services for taking a lead in what is clearly a "hot topic" in the current privacy landscape and one that will continue to present challenges for some time come.

It is vital and timely to consider ethical and professional boundaries in the context of social networking, in order to ensure that the ethical responsibilities of community support work in the "real" world remain the same in the "virtual" world.

The nature of your role in providing individualised support for people with disability, with its "person-centred" focus, presents many challenges.

In terms of maintaining the boundaries between your personal and professional lives, the advent of social media presents perhaps the greatest challenge when we consider the concepts of communication, friendships and networking.

From my perspective, it is the concept of privacy which is at the heart of this debate.

General rights to privacy

As New South Wales' Privacy Commissioner, I always like to begin any discussion about privacy by talking about our rights. Privacy – and our right to privacy – touches the very core of our expectations of in-alienable human rights.

Our ability to exert our right to privacy speaks to our position of control and selfdetermination – the respect we feel for ourselves, the respect we receive from others and, importantly, the respect we give to others.

Because of the significance of privacy to our ability to function as respected members of society, we find it enshrined in some of the most powerful international conventions.

Among the most profound is the *Universal Declaration of Human Rights*. (Did you know that an Australian, William Hodgson was one of the nine people who drafted the declaration?).

Right at the front of the declaration, the third article states that everyone has the right to life, liberty and security of person.

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But more specifically in Article 12, it says that:

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.ⁱ

And, to reinforce this message in the context of people with disabilities, the United Nations' *Convention on the Rights of Persons with Disabilities* includes Article 22 on Respect for Privacy.

It says:

No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

And, importantly, "States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others."ⁱⁱⁱ

Here we have not just the use of the broad term "privacy", but a very specific reference to the protection of information – personal information, health information and rehabilitation information.

The Australian Government signed the *Convention on the Rights of Persons with Disabilities* at the United Nations on 30 March 2007.

As you know, these principles are reflected in supporting legislation at the State and Commonwealth levels. And in a number of instruments that regulate and guide service provision to people with disabilities.

But before I go on to those points, let me just say a few words about my role.

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As Privacy Commissioner of NSW, I have responsibility for two Acts. The first is the:

• NSW Privacy and Personal Information Protection Act 1998 (PPIP Act)

The PPIP Act covers NSW public sector agencies that is, NSW Government agencies, local councils and universities. The Act also provides reserve power for the Privacy Commissioner to research and make public statements about any matter relating to the privacy of individuals generally. And, to make such inquiries and investigations into privacy related matters as appropriate.

The second Act, is the:

• NSW Health Records and Information Privacy Act 2002 (HRIP Act)

The HRIP Act covers NSW organisations both public and private that deal with healthrelated information.

In service delivery, privacy is a critical, but frequently taken for granted aspect of service delivery.

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In relation to that earlier point about the right to privacy being reflected in legislation and other instruments, Standard 10 concerning "Rights" produced by the NSW Department of

Ageing, Disability, Home Care requires service providers to be aware of the United Nations Convention on the Rights of Persons with Disabilities and, to apply its guiding principles...in all aspects of service delivery.ⁱⁱⁱ

The significance of privacy to the maintenance of dignity and control over all aspects of one's life makes it absolutely fundamental to people living with disabilities.

I am sure you will agree that it is your aim to ensure clients are given the opportunity to achieve a quality lifestyle by ensuring their privacy, dignity and confidentiality, and enabling them to participate and be involved in the life of the community.

Role of support workers

As support workers, your role is both rewarding and challenging.

Providing such valuable support in people's lives can sometimes involve you in situations with clients and their friends and families where you may have access to private or confidential information.

You might also encounter situations where you are confronted with needs, requests or demands for services or support that are not in your role as a support worker.

As you are aware, setting ethical and professional boundaries is vital in providing the most effective support to your clients.

Rather than acting as barrier between yourselves and your clients, these boundaries contribute to the effectiveness of your role as support workers.

Among the many attributes required in your field, outstanding communication skills are perhaps the key to successful interaction between you and your clients.

Clearly, one of the most dramatic influences on the way we communicate in today's society is social media.

In recent years, the social networking phenomenon has become firmly entrenched in our society.

Sites such as Facebook, Twitter and LinkedIn have hundreds of millions of users worldwide, and have transformed the way many of us communicate and socialise with one another.

With the capacity on certain social media sites, such as Facebook, to search for and invite other users to be "friends", comes potential implications for professional relationships between support workers and clients, particularly with regard to privacy.

It would be unreasonable to expect support professionals not to engage in social networking sites outside of work. It is wise however to consider the ethical implications presented by social networking, particularly in a professional context.

Being aware of the boundary between your private and professional lives, with its direct impact on privacy, is extremely important for support workers as our everyday communications occur more and more in an online environment.

It is extremely simple for clients to perform searches on support workers, and other professionals in their lives, using social media websites.

Depending on privacy settings, clients and others may be able to view comments and photos and discover information about support professionals' lives – meaning the boundary between the professional and the personal can be easily blurred. And you may not even be aware it has occurred.

In the majority of cases, this is prompted by a desire on the part of clients to communicate or interact on a social level with their support professionals.

On one hand it can be seen as a reflection of the close and positive nature of your relationship with your clients. But on the other hand it is a strong signal to consider the boundary between the personal and the professional with regard to relationships with your clients.

As in all forms of communication, it is you as support workers, and not your clients or former clients, who are responsible for setting clear and appropriate professional boundaries.

You should consider this in all online communications, such as social networking, email communication, blogging or instant messaging.

From the perspective of privacy, your boundaries should reflect the approach you would already take in your face-to-face contact and written communication with clients.

There are many potential privacy risks you should consider when participating in social media.

Personal online postings that clients or others can inadvertently gain access to, could influence professional relationships and client expectations.

A client could learn something about their support worker via a social media site that may be at odds with their perception of the support worker in a professional capacity. Similarly, if a colleague or employer views something they perceive as inappropriate for a support worker's professional identity, or something derogatory relating to a client, colleague or work situation, it could be seen as compromising the professional reputation of the service.

It also pays to be aware that if you post a comment on another person's social media site, if this person posts a photo of you on their site, or if this person refers to you being present in a particular location (known as "checking in" on Facebook), you have no control over their privacy settings. Potentially, their comment, photograph or location information could be accessible to anyone, without your consent.

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When engaging with social media, it is wise to consider the following points:

- Ensure that all personal social media websites are set up with as many privacy settings as are available by the site so clients and other members of the public cannot gain access to information, photos, comments etc
- Sites where total privacy cannot be guaranteed might be avoided
- Read the privacy policy of the social networking site, and ensure you understand the limitations to privacy and how privacy can be best protected if engaging in a particular site
- Every time you post something on a social networking site, consider whether you would be happy for a stranger to see this information, or whether it would be appropriate for a client to see this information
- Check whether 'friends of their friends' can access your online profile. There could be a case where a 'friend of a friend' is a client or a colleague
- Social media sites sometimes change privacy settings options without users being aware. Regularly check your privacy settings and the site's privacy policy to ensure that there have not been any changes made which could compromise your privacy or allow unwanted access to your profile.

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- Be aware that you have little control over others' privacy settings when engaging on your friends' social networking sites. Therefore, even if your profile is private, information and photographs may still be accessible through another person's site if they don't have robust privacy settings in place, or who may be "friends" with a client or colleague
- Be mindful of who you "friend" on social networking sites. It is worth considering that in some instances, it may be inappropriate or a blurring of professional boundaries to include colleagues/managers/employees as "friends" on a social media site
- If you have a work-related social media website for posting blogs or sharing
 resources etc, it is important to clearly differentiate between this and a personal
 social networking site. It is a good idea to name the blog according to the area of
 discussion or use the business name rather than your personal name, and to clearly
 explain the nature and purpose of the site (if appropriate). Also, consider restricting
 access to the site through invitations rather than running a public forum
- Consider establishing an agreement with clients where you both agree not search for or engage with each other via social media sites so this boundary is mutually agreed
- When engaging with social media forums such as Twitter, consider that people can create ambiguous names and request to "follow" another user. Be aware that you could inadvertently accept someone as a "follower" who is a client. You may also wish to consider employing a username that makes you harder to identify on Twitter
- Also remember that people have the ability to "check in" to actual geographic locations through sites such as Facebook, which may present privacy implications for both yourselves and clients.

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Possible scenario

A former client has invited you to be friends on Facebook. Is it appropriate for you to accept?

(Audience participation through general discussion and ideas from audience)

If faced with such a situation, it is best to weigh up the ethical and organisational considerations for both options and decide to accept the friend request or not. Your

organisation may have a policy that indicates this is not to occur, or to occur in limited circumstances. You need to check.

You might also consider the context of the friend request. There may be some circumstances where connecting with clients via social media might be acceptable, especially as communication through social media is becoming increasingly common, and it's a convenient and reliable way to manage changes in services for example.

Some examples may be:

- If you have a 'work' profile page which does not disclose any information about your personal life
- If you work in youth services and have a professional profile for the purposes with connecting and communicating with younger clients.

But generally, if the social networking site is your personal, non-work related site, it's not recommended as there are further things you should consider.

Think about your own privacy, the boundary between your professional and personal life, and recognise the fact that your relationship with your former client was of a professional nature.

Accepting your former client's request may signal a change in the nature of your original relationship.

If you don't accept the "friend" request, the issue of the client experiencing rejection from their former support worker could be a concern.

In accepting, or not accepting, a "friend" request you must consider the implications this could also have for the former client and manage these.

You should also consider what benefit accepting the friendship request would have for the client. Perhaps you could ask yourself: why are they requesting your friendship, did they depend on the previous support relationship, and are they looking for a way to continue this relationship?

If faced with such a scenario, consulting your supervisor or a senior member of the agency would be the first step I'd advise.

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Scenario 2

A family member of your current client has started following you on Twitter. Should you remove them from your "followers"?

(General discussion, ideas from audience)

Again, in this situation it is important to weigh up the ethical considerations when deciding whether or not to allow the family member to continue following your "tweets".

If your Twitter profile is of a personal nature and unrelated to your professional role, consider the boundaries you have established to keep personal and professional interactions separate.

Ask yourself: is the family member of a client part of my personal or professional life?

The answer should then be fairly straightforward.

In cases such as this, it is often difficult to reject an invitation or "follower" because of the nature of your relationship with your clients and their families.

An idea is to establish an agreement, as I mentioned earlier, about interacting on social media sites.

If you, your clients and, when appropriate, their friends and family members, make an initial agreement not to search for, follow, or make friend requests using social media networks, the boundaries are clear from the outset.

The ethical and organisational issues we identified earlier in our discussion are relevant here.

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Conclusion

As I said at the opening of my presentation today, I am impressed by how proactively NDS has approached the subject of privacy, both in its own practices and by presenting opportunities for support professionals such as yourselves to consider privacy in your work.

I thank you for your participation in this conference today and urge you to spread the word about the importance of privacy protection to your colleagues and friends. Particularly with Privacy Awareness Week coming up later this month.

And most importantly, as you continue your vital work with people with disability, I encourage you to embed at the foundation of your professional work a recognition of the fundamental right to privacy we all share.

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(IPC contact details – displayed on screen during questions)

ⁱUnited Nations, *Universal Declaration of Human Rights*. The Declaration is the basic international pronouncement of the inalienable and inviolable rights of all members of the human family. The Declaration was proclaimed in a resolution of the General Assembly on 10 December 1948 as the "common standard of achievement for all peoples and all nations" in respect for human rights.

ⁱⁱUnited Nations, *Convention of the Rights of Persons with Disabilities*.

ⁱⁱⁱAgeing, Disability and Home Care, Department of Family and Community Services Fact Sheet #3, April 2012. "Working Together to Improve Outcomes: Updating Standards in Action – Rights".