

Commissioner Initiated Inquiry under section 13 of the Privacy Act 1993

PUBLICATION OF PHOTOGRAPHS OF ELDERLY PEOPLE AND THEIR CARERS

BACKGROUND OF INQUIRY

In May 2006 "*Kai Tiaki* Nursing New Zealand", the New Zealand Nurses' Organisation's journal published a photographic essay "Who Cares". The five-page essay encompassed 39 images. The images portrayed the daily routine of carers looking after the elderly in an institutional setting and depicted both carers and residents, along with quotations from the subjects in the photographs. Some photographs showed carers, and apparently vulnerable residents who were near naked and engaged in intimate daily routines such as showering and toileting. The purpose of the essay was to highlight the work of the carers and the people for whom they care in an effort to improve work conditions.

Kai Tiaki received many letters from its readers employed in nursing and elder care. Strong views and emotions were expressed. On the one hand many felt that the photographs were "demeaning", "lacking in dignity" and an "exploitation" of vulnerable people for industrial relations purposes. These people questioned whether "a captive population in a residential care setting" should have even been asked to take part in the photo essay.^[1] Ethical issues and the role of the nursing profession and elder care workers were also raised.

On the other hand, some health care professionals described the photographs as "professional, touching" and one said "if the people who had their photographs taken were of sound mind and freely gave consent, then why ... deny them the right to tell their story?"^[2] Other letters in the same issue added:

^[1] Letter in *Kai Tiaki* June 2006

^[2] Letter in *Kai Tiaki* July 2006

This was the reality those residents faced, that they were old and infirm, and had the courage to bare their souls for all to see.

There seems to be the widely spread assumption that when people are old, wrinkly and possibly incontinent they can't make well informed decisions ... Is it possible we are trying to protect people who don't need to be protected?

I think a lot of the outcry can be put down to readers confusing dignity with respect. Life is not always dignified... The absence of dignity does not equal a lack of respect.

The publication of the essay resulted in a public and media furore and five complaints were made to the Office of the Privacy Commissioner. The complaints centred mainly on what the complainants perceived was exploitation of the residents. The complainants wanted to know whether informed consent had been obtained from the subjects and whether or not the privacy principles had been adhered to. Ethical issues were raised, in particular the role of the Nurses Organisation and the institutions involved in the care of the elderly. These latter issues are beyond the jurisdiction of the Office of the Privacy Commissioner.

The key parties involved in the publication were the New Zealand Nurses Organisation (NZNO), *Kai Tiaki* Nursing New Zealand, Woburn Elderly Care, Lower Hutt; St James Rest Home, Christchurch; Presbyterian Support Central (PSC) and freelance photographer Alan Knowles.

INVOLVEMENT OF THE PRIVACY COMMISSIONER'S OFFICE

The complainants

The complainants all addressed their complaints directly to this Office believing that, on the face of the publication, there were serious privacy issues involved. I shared that concern. Many of the complaints focused on the issue of consent. Complainants questioned how people, possibly with dementia, could consent, and queried how the photographic exercise was put to the residents. Some asked whether the photographs had been shown to the subjects before publication. One

complainant alleged that consent had not been obtained from a resident. There were also allegations that the photographs were misused as propaganda material for workers' unions involved in pay claims.

Wider issues were raised about the ethical judgment of all those involved in the project. Complainants saw the photographs as undignified, demeaning and exploitative of the residents. Some were sure that the rest homes must have allowed photographs to be taken in the dementia unit, and that the rest homes had failed in their duty of care to the residents. Lastly there were allegations that the editors of *Kai Tiaki* published intimate photographs in disregard of the Health and Disability Commissioner's Code of Rights and the feelings of the families of those residents portrayed in the essay.

Both the complaints and the wider public debate raised concerns that can be grouped broadly into privacy issues and non-privacy issues.

The privacy issues centred mainly on the process leading up to the photographs being taken and their subsequent use. For example, was consent sought, and to what extent was informed consent possible? Were residents and their families given full information about *Kai Tiaki* and were they shown copies of the photographs before publication? Were the photographs misused to support a pay claim for care givers?

The second category of concerns, non-privacy matters, included whether the care givers and other professionals involved had made an error in judgment in allowing the photographs to be taken and used, especially in an industrial context; that the project amounted to exploitation of residents; and concerns about welfare guardians consenting to photographs.

Our jurisdiction

The Privacy Commissioner has a role to protect and promote individual privacy and has various powers to investigate complaints and to inquire into privacy matters generally. Privacy issues dominated the debate about the publication of

these photographs and lie at the heart of the incident. The debate inevitably raised a number of other issues such as the ethics of caring professions and the use of the powers of the welfare guardians. These matters are beyond my jurisdiction. No doubt the debate about the wider ethical matters involved will continue.

Complaints to this Office are commonly dealt with under Part 8 of the Privacy Act. Part 8 complaints require an individual to have been subject to a breach of a privacy principle and in most cases to be able to point to some serious humiliation or other loss or damage. As it turned out, the complainants did not have a direct personal interest in the alleged privacy breaches and therefore dealing with complaints under Part 8 of the Privacy Act was inappropriate.

As a result, I chose to deal with all the complaints under my wider inquiry powers in section 13(1)(m) of the Privacy Act. Section 13 sets out the functions of the Privacy Commissioner, and provides that the Commissioner may inquire generally into any matter, practice or procedure if it appears to the Commissioner that the privacy of the individual is being infringed. The important issues raised, the very public nature of the project, the resultant complaints, and general public disquiet left me with little doubt that I should inquire into this incident.

There has been some public comment that this office is unable to inquire into the news activity of a news medium. The privacy principles are worded so as to place responsibilities and obligations on agencies. A news medium engaged in a news activity is not an agency under the Act and therefore is not subject to scrutiny by the Commissioner under the privacy principles. Industry magazines such as *Kai Tiaki* fall within the definition of news media exercising news activities. However, section 13 of the Act empowers me to inquire generally into any matter where it appears that the privacy of the individual is being, or may be, infringed. It is not restricted to situations where an agency may have breached a privacy principle. This was an incident where, on the face of it, there appeared to be just such an infringement of privacy in a wider sense.

Effects on residents, carers and families

It became apparent during the course of the inquiry that some of the carers and families of the residents were deeply affected by the national media exposure and public furore over the publication of the photographs. Some of the families have since lost relatives who were subjects of the photographs. Some families commented that they would not have become involved in the essay if they had anticipated the resultant public furore. The complaints and the focus on the photographic essay have had an impact on them all to a greater extent than they first envisaged. We owe a huge debt of gratitude to the families and carers who agreed to talk to us at a personally difficult time.

I believe that it is desirable that, as far as possible, this inquiry does not further expose the residents and their families to unwarranted intrusions. This report is therefore kept anonymous to protect the residents, carers and their families as far as possible from further media exposure. In releasing this report, I ask that we all respect the privacy of the photographed residents and their families and carers who became part of the public furore without any desire to do so.

OUR INQUIRIES

We conducted a large range of inquiries including face-to-face meetings and telephone conversations with a number of people and groups. We interviewed many people involved in the essay, including the author and publishers of the essay, the photographed carers and the families or representatives of the photographed residents. We also spoke to people who were able to give accounts of the process and events leading up to the publication, and we reviewed relevant documents.

At an early stage we decided not to re-engage the residents involved in the photographic essay unless we had no other option. Many had in fact died since the photographs were taken. In addition, three years had passed since the first photographs were taken. In the course of the inquiry it became apparent that we did not need to disturb the peace of the residents. Enough information was

available from other sources for us to form clear conclusions about what had occurred.

We were aware that other residents were photographed, beyond those who were selected for the published photographic essay. We decided that the residents and carers in the photographic essay provided a sufficient sample to test the integrity of the wider process. Additionally, the essay subjects are the only individuals who were potentially disadvantaged by any perceived breach of their privacy.

SUMMARY OF FACTS

In 2002, the Service and Food Workers Union (SFWU) and NZNO first raised the prospect of a project to raise awareness of care for the elderly. They felt that work conditions had deteriorated, and that a campaign to improve conditions in the industry would benefit both carers and the elderly. A photographic essay was one of the tools seen as appropriate to highlight the issues. Publishing the essay in *Kai Tiaki* was one of the envisaged options. The project was not tied to any one specific industrial action, but was rather a general endeavour to highlight this sector of health care.

NZNO and SFWU provided funding for the project, and Alan Knowles, a professional freelance photographer, was engaged. The project started as a pilot in 2003 and focused on residents and carers at Woburn Elderly Care in Lower Hutt. This institution is part of the Presbyterian Support Services (PSC) network. In 2005, St James Rest Home in Christchurch also became part of the project.

Presbyterian Support Central, SFWU and NZNO met and established a number of protocols in order to support the project. A consent form was produced, along with a letter that outlined the scope and objectives of the project. The letter was intended as an introduction to both the photographer and the project, and was to be handed to all prospective participants. PSC and the Woburn staff ensured that there was wide knowledge of the project in the institutions concerned.

The photographer visited Woburn over a period of about three weeks. During that time, he established a rapport with carers and residents, and sought consent for the taking of photographs. Some people readily became involved. The wishes of those not wanting to be involved were respected. The photographer took photographs of only those carers and residents who verbally consented to having a photograph taken.

The photographs taken were later shown to all subjects, who were again given the opportunity to consent generally to being involved in the project and specifically to the use of individual photographs.

The photographer met the owners of St James in Christchurch. The photographer entered into an agreement with St James. The agreement covered expectations of respect for the wishes of the residents and carers, and respect for the individuals' right to privacy. The management at St James selected appropriate people to be involved, based on their ability to consent and understand the project. Those with dementia were excluded. At all steps in the project subjects were canvassed to ensure that their consent was still forthcoming.

The photographer then selected a series of shots for publication, and designed a layout. He revisited all subjects of the photographs and again sought either their consent or, if appropriate, the consent of family or suitable next of kin. The photographs were shown to carers and residents and anyone who asked was given copies. Consent was obtained in writing where appropriate or in a clear verbal manner from their families.

The NZNO finally decided to print the photo essay in the May 2006 issue of *Kai Tiaki*. Before publication, the photographer was asked to check with all subjects to ensure that consent was current and valid. By this time, some of the subject residents had died. In addition he was asked to check with representatives of those who were unable to consent or who were no longer alive to consent. I was assured that this was done.

INQUIRY CONCLUSIONS

Even though they are not directly applicable to a section 13 inquiry, the principles in the Privacy Act are an appropriate framework for examining responsibilities and obligations. On completion of the inquiry I am satisfied that there has been compliance with the principles of the Act. To quote one witness, "The whole project was undertaken within an environment of consent." Informed consent was critical, then, to the acceptability of the project at a wider level. The existence of informed consent also ensures that there is no breach of the relevant privacy principles on collection and disclosure.

I am satisfied that all subjects were clearly informed that personal information was being collected, that they authorised the collection, that they knew it was being collected for publication and that they were consulted before publication. Where a subject was not fit to understand the project or consent to it, I am satisfied that an appropriate representative was consulted to obtain the requisite consent. In addition, all subjects or their representatives were consulted immediately before publication to ensure consent was still forthcoming.

The ultimate purpose of the publication of the photographs, as the consent form states, was to "raise the profile of aged care workers in New Zealand". I am satisfied that all subjects were aware of this purpose, and that they or their representatives agreed to personal information being used in this way. They were also made aware specifically that the publication finally involved an essay in *Kai Tiaki*. Although *Kai Tiaki* is primarily a membership magazine and not for sale to the public, there was always a risk of wider publicity. The magazine readership is made up of mainly nurses and other health professionals. The essay was aimed at that specific audience.

There is no evidence of coercion, bad faith or compulsion in the collection of the information for the photographic essay. On the contrary, it appears clear from our inquiry that there was a willingness by all subjects or their representatives to be involved, and that they agreed with the aims of the project.

The inquiry has satisfied me that given the thorough process followed, there has not been an infringement of the privacy of any of the individuals involved. I am also satisfied that the procedure used by those involved directly in the photographic essay was appropriate and complied with the general standards of the Privacy Act and its principles.

Lessons from the inquiry

The debate about the publication of these photographs has been a useful one. It has shown that the privacy and dignity of the individual are closely linked. Privacy is an important freedom: it includes freedom of the individual to maintain and protect identity, freedom from unwarranted intrusions into personal space, and freedom to make choices about how much we want other people to know. One of the characteristic features of privacy values is that sensitivities may vary widely from person to person, and that variation is not necessarily predictable.

In this case, one instinctive public reaction was that dignity had been denied and privacy invaded. The facts of the case show that the individual subjects of the photographs or their representatives chose to allow photography and publication for a cause they believed in. Our investigation shows that great care was taken over a period of time to ensure that the residents and carers involved were fully aware of what they were consenting to. Old people, just as much as younger ones, have the right to make these choices if they wish.

I remain concerned, however, about what might be described as the unintended consequences. The residents and their families temporarily became the eye of a storm of public attention. It is clear from our discussions with families and care givers that, in consenting to publication, they were unaware that significant media exposure could result. The 'environment of consent' within the rest home may have influenced some participants to agree, without a full appreciation of the possible consequences. Some commented that they would not have consented if they had anticipated the media debate.

Privacy is an ever-present and important feature in our daily lives. Those of us who are adult, healthy and autonomous generally have the ability to protect our privacy. However a significant number of people do not possess sufficient autonomy to protect their individual privacy because of their youth or age, ill health or incapacity. The public furore over the photographic essay is a reflection of how the community reacts when it perceives that the elderly have been disadvantaged. Where the privacy of the vulnerable is at risk extra care needs to be taken. Their best interests should be predominant in all decisions made about them. But it must also be noted that the mere fact that a person is old or ill does not automatically mean that he or she cannot make clear choices. Many of those photographed in this case, including residents in intimate situations, were able to make those choices.

During the course of the inquiry I have been made aware of a specific potential problem. The consent process included a form that contained inconsistent purposes. The form stated that the photographs were being taken solely for the purpose of highlighting the work of carers and the people they care for, including the potential of publication in *Kai Tiaki* or an SFWU publication. However, the form also purported to give the photographer and the unions wide ongoing rights to use the photographs. It has been clear to this office that the subjects were moved to take part in the project because they supported the exposure of the care of the elderly and the work of carers. While the consent form does contain a reference to wider anticipated use of the photographs, I believe the subjects who gave consent were motivated by a much narrower concern. As a result, any further use of the photographs might not meet privacy standards. I understand, however, that the photographer intends to seek further consent before any republication (for example for artistic purposes).

I understand the criticisms that have been made of the project. We ought all to ensure that, in circumstances where the integrity of personal information is at risk, consultation, knowledge sharing and consent are included in our interactions with the elderly and infirm, and their families or representatives.

The general debate about this issue has been healthy and timely. The facts of the investigation, however, show that care was taken to explain the purpose of the project and to obtain and confirm consent at every stage. Proper processes were followed, there was an environment of choice and consent, further consents were obtained before publication and all concerned appear to have treated the matter with great sensitivity.

No formal recommendation is therefore necessary from the broad scope of this inquiry. However, the level of public exposure of the individuals concerned was beyond what was anticipated. The lesson to be learned, especially for those caring for vulnerable people, is that wider consequences can unexpectedly flow from well-intentioned decisions made within a narrow context. The reality of the public and media environment today is that exposure of any private information can result in individuals being captured in the spotlight of public attention in a way that most people will find uncomfortable. Those of us who do not wish to occupy that spotlight, and who as private individuals have no reason to do so, need to be increasingly cautious about revealing our personal information.

Marie Shroff
Privacy Commissioner
March 2007