



**Australian
Privacy
Foundation**

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11 March 2013

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National Disability Insurance Scheme Launch Transition Agency
Department of Families, Housing, Community Services and Indigenous Affairs

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Dear Mr Sassella

Re: NDIS Consultation Paper

Thank you for your invitation to comment on the proposed design and operation of the National Disability Insurance Scheme (NDIS).

We attach our Submission.

We look forward to hearing from you about the ongoing consultative processes.

Thank you for your consideration.

Yours sincerely

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Australian Privacy Foundation
Submission re the National Disability Insurance Scheme (NDIS)

11 March 2013

INTRODUCTION

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. A brief backgrounder is attached.

APF thanks the Agency for its invitation to comment on the proposed design and operation of the National Disability Insurance Scheme (NDIS).

APF claims no special competence in the disability arena. Its function is to advocate for the privacy interests of the public, both generically and in relation to particular population segments, including those with disabilities.

APF recognises the significance of the NDIS.

APF welcomes the conduct of a privacy impact assessment (PIA). In an emergent initiative of this nature, a rolling PIA is appropriate, cumulative through the various phases.

Given the stage of development of the initiative, and the limited and provisional information that is currently available, the APF's comments are at an abstract level, based primarily on the Consultation Paper.

We make comments below about the nature of the initiative, about aspects that we perceive to be positive and important, and about a number of major privacy risk areas.

We conclude with some Recommendations that are intended to ensure that the privacy aspects are developed in concert with the primary focus, such that they enhance and support NDIS, rather than conflicting with and undermining this valuable initiative.

OUR UNDERSTANDING OF THE NDIS

The National Disability Insurance Scheme Launch Transition Agency's functions are stated to include developing the community sector, building disability awareness, and undertaking research. Legislation was tabled in late 2012, with the intention of commencement of 5 pilot sites in July 2013.

The description provided is abstract. It does not include a model of the current arrangements for disability support, and contains little indication of how the new scheme will complement, mesh with, and enhance existing arrangements. Two exceptions to this are the exclusion of people over 65 because they are covered by other schemes (p. 7), and the provisions relating to compensation from other sources (p. 27).

It is clear that the Agency will need to have policy and governance functions, and to act as a funding channel. **There would be concern if the Agency's functions were to drift into service-provision.**

Temporary residents and illegal residents appear to be excluded. If so, this would mean that **the initiative is not the comprehensive, no-fault scheme that many people had expected.** NDIS would accordingly itself need to be complemented by other schemes that address the remaining gaps.

IMPORTANT POSITIVE ASPECTS

Human dignity, including privacy, is critical to everyone, but is particularly at risk for people with disabilities. The APF accordingly stresses the importance of the following aspects that are evident in the Consultation Paper:

- **Self-determination, self-management, choice and control** are declared to be fundamental to the initiative
- The scheme recognises **the role of individuals' family, supporters, carers, and agents / nominees / guardians** (although there is little mention of advocates)
- The document acknowledges the **great care that is needed in relation to the overriding of individual self-determination and self-management**
- A commitment is made to compliance with obligations arising from the **Convention on the Rights of Persons with Disabilities**
- **Early engagement** has been undertaken with APF, and we understand, with other privacy and human rights and consumer rights organisations

PRIVACY RISK FACTORS

Unfair Discrimination and Data Intensity

The initiative adopts an insurance-based approach, without a directly-linked commitment that the insurance-load be shared across the entire population. During the last 50 years, the insurance industry has been permitted to cherry-pick its customers, and charge differential rates and/or offer differential benefits on the basis of individuals' characteristics. This has resulted in a highly discriminatory approach to insurance.

As a by-product of this approach, business processes have emerged that are highly information-intensive. Health insurance in particular has been permitted to traffic unnecessarily in highly sensitive personal data. **An insurance approach to disability creates a high likelihood** not only of discrimination instead of inclusiveness, but also **of unnecessary intrusiveness**.

Unnecessary Data Collection

The risk exists that personal data collection may be voluminous, may be subject to slim justification, and may be standardised across all forms of disability, such that **every applicant may have to disclose a wide range of data, much of which is irrelevant to their own condition(s), and hence whose collection is unjustified**.

Data Collection for Administrative Purposes

A further serious concern is the strong tendency of schemes such as this to be subjected to enormous bureaucratic loads. **Policy staff, auditors, statisticians and layers of managers provide no services to people with disabilities, but eat up resources and demand large quantities of data, a considerable proportion of which is personal data, much of it sensitive**.

An example of this arises on p. 20, where it appears that the Agency may intend to duplicate work already performed by other agencies. It is vital that administrative duplication be avoided, both because of the waste of resources it entails and the unjustified proliferation of copies of sensitive personal data.

The Privacy of Service-Providers and Carers

There are serious concerns also about the privacy of service-providers and carers. Recent decades have seen a manic scramble to 'save the kiddies', by imposing highly intrusive criminal records checks on individuals offering assistance in a vast array of voluntary capacities.

There is a substantial risk that highly intrusive checking processes will be imposed on service-providers and carers, without the application of key evaluation principles. A likely driver of this is lack of clarity concerning, and nervousness about, liability for incidents in which a carer takes financial or sexual advantage of a person with a disability.

A particular concern is the vagueness of pp. 25-27. Working With Vulnerable People schemes exist. They need to be incorporated into the process, and balances found that reflect the needs of carers as well as the needs of people with disabilities.

Privacy Beyond Data Privacy

There are multiple dimensions of privacy. At particular risk in this context is the privacy of personal behaviour and of the physical person.

Fiscal responsibility demands that reasonable care be undertaken to ensure that individuals actually have a disability, and to assess the degree of that disability. On the other hand, **the extent to which observation and tests are conducted, and the manner in which they are conducted, must be justified and proportionate, and mitigating measures must be incorporated in order to minimise the negative impacts on the individuals concerned.**

RECOMMENDATIONS

Meta-Principles

It is essential that a framework be established whereby the privacy aspects of the scheme's design can be managed. APF proposes the following as fundamentals:

Justification

All privacy-intrusive aspects must be demonstrated to be necessary pre-conditions for the achievement of specific positive outcomes.

Proportionality

The benefits arising from all privacy-intrusive aspects must be demonstrated to be commensurate with the disbenefits and risks.

Transparency

Sufficient information must be disclosed in advance to enable meaningful and consultative evaluation processes to take place.

Mitigation Measures

Where privacy-intrusiveness cannot be avoided, mitigating measures must be conceived, implemented and sustained, in order to minimise the harm caused.

Controls

All privacy-intrusive aspects must be subject to controls, to ensure that practices reflect policies and procedures. Breaches must be subject to sanctions, and the sanctions must be applied.

Audit

All privacy-intrusive aspects and their associated justification, proportionality, transparency, mitigation measures and controls must be subject to review, periodically and when warranted.

Data Disclosure Powers

The powers contemplated for the Agency CEO to disclose personal data (unnumbered p.19) must be tightly circumscribed, must be defined in primary legislation not in delegated legislation, and must under no circumstances be at the CEO's discretion.

We note in particular, and firmly oppose, the excessive s.60(3) relating to disclosure for purposes of research into matters relevant to the NDIS, actuarial analysis of matters relevant to the NDIS, and policy development.

Assignment of Guardian Powers

Where a person with a disability lacks the competence to appoint an agent, processes must exist whereby an appropriate person can be authorised on their behalf.

However, **the APF expresses serious concern about the proposal to vest these powers in the Agency CEO** (p. 24). This is an example of extension of the Agency's scope beyond its necessary and proper roles in policy, governance and funding, into the inappropriate area of service-provision. Existing arrangements exist, which have been carefully balanced and are court-supervised. Whereas the Agency has a role to play in the review and refinement of such processes, we submit that the Agency has no role to play in the processes themselves.

Data Breach Notification

Given the sensitive nature of personal data involved, **it is essential that all parties be subject to appropriately framed obligations to disclose material breaches of data protections.**

Continuity

The APF has had very bad experiences with agencies responsible for a range of initiatives as diverse as the Access Card, toll-roads and the PCEHR. It has been all-too-common for the agency that commences discussions to fail the following responsibilities:

- to assimilate the information provided to it
- to sustain corporate memory of the issues and the organisations that it has engaged with
- to document both the concerns expressed and the manner in which they are to be addressed
- to pass its memory and commitments on to subsequent agencies in the eternal re-organisational merry-go-round which is typical of such projects
- to fulfil the undertakings provided

APF understands that a considerable range of Working Groups exist, as per:
<http://www.ndis.gov.au/towards/expert-groups/>

APF submits that **it is critical that the Agency build a Reference Group that considers the privacy aspects across the full range of NDIS activities, supports it, and sustains it.** Because the existing Working Groups already have parts of the privacy area within their scope, coordination will be essential.

Australian Privacy Foundation

Background Information

The Australian Privacy Foundation (APF) is the primary national association dedicated to protecting the privacy rights of Australians. The Foundation aims to focus public attention on emerging issues that pose a threat to the freedom and privacy of Australians. The Foundation has led the fight to defend the right of individuals to control their personal information and to be free of excessive intrusions.

The APF's primary activity is analysis of the privacy impact of systems and proposals for new systems. It makes frequent submissions to parliamentary committees and government agencies. It publishes information on privacy laws and privacy issues. It provides continual background briefings to the media on privacy-related matters.

Where possible, the APF cooperates with and supports privacy oversight agencies, but it is entirely independent of the agencies that administer privacy legislation, and regrettably often finds it necessary to be critical of their performance.

When necessary, the APF conducts campaigns for or against specific proposals. It works with civil liberties councils, consumer organisations, professional associations and other community groups as appropriate to the circumstances. The Privacy Foundation is also an active participant in Privacy International, the world-wide privacy protection network.

The APF is open to membership by individuals and organisations who support the APF's Objects. Funding that is provided by members and donors is used to run the Foundation and to support its activities including research, campaigns and awards events.

The APF does not claim any right to formally represent the public as a whole, nor to formally represent any particular population segment, and it accordingly makes no public declarations about its membership-base. The APF's contributions to policy are based on the expertise of the members of its Board, SubCommittees and Reference Groups, and its impact reflects the quality of the evidence, analysis and arguments that its contributions contain.

The APF's Board, SubCommittees and Reference Groups comprise professionals who bring to their work deep experience in privacy, information technology and the law.

The Board is supported by Patrons The Hon Michael Kirby and Elizabeth Evatt, and an Advisory Panel of eminent citizens, including former judges, former Ministers of the Crown, and a former Prime Minister.

The following pages provide access to information about the APF:

- Policies <http://www.privacy.org.au/Papers/>
- Resources <http://www.privacy.org.au/Resources/>
- Media <http://www.privacy.org.au/Media/>
- Current Board Members <http://www.privacy.org.au/About/Contacts.html>
- Patron and Advisory Panel <http://www.privacy.org.au/About/AdvisoryPanel.html>

The following pages provide outlines of several campaigns the APF has conducted:

- The Australia Card (1985-87) <http://www.privacy.org.au/About/Formation.html>
- Credit Reporting (1988-90) <http://www.privacy.org.au/Campaigns/CreditRpting/>
- The Access Card (2006-07) http://www.privacy.org.au/Campaigns/ID_cards/HSAC.html
- The Media (2007-) <http://www.privacy.org.au/Campaigns/Media/>