

Office of the Public Advocate, South Australia

30th April 2015

Submission in response to the Consultation Paper

“Proposal for a National Disability Insurance Scheme

Quality and Safeguarding Framework.”

Introduction

The Office of the Public Advocate (OPA) is an independent statutory office that promotes the rights and interests of people who experience a disability that affects decision making most often due to an intellectual disability, brain injury, developmental disorder, mental illness, dementia or neurological disease.

OPA (SA) is a member of the Australian Guardianship and Administration Council. AGAC has made a submission on behalf of its members that we support.

This submission seeks to offer additional comment from our Office on conceptual and policy issues that we hope may assist the NDIS in its consultation.

The Universal Aspects of Quality and Safety

Safety and quality improvement principles are universal across industries. In this respect there is nothing special that separates disability services from other industries, and the same standards of quality control, and regulatory oversight should extend to disability services as applies to other critical areas. There is a risk if disability funded services see themselves as unique and separate and do not apply the same quality management techniques used elsewhere to benefit people in the community generally, that users of disability services will experience avoidable harm that could have been prevented. For this reason the National Disability Insurance Scheme (NDIS) will need to consider carefully any approach that departs from the existing approaches that has emerged from other industries, from overseas disability quality initiatives that are more advanced than Australia's, and the associated academic work in quality and safety.

The Health Care industry has been prepared to swallow its pride and learn from aviation and manufacturing sectors about how to improve quality. Health faced a safety crisis in the 1990s following the identification of significant numbers of preventable deaths and injury worldwide. Generic safety strategies have been used in health settings, including outcome measurement, reporting of consumer satisfaction, incident reporting (including near miss incident reporting) and organisational reform using that uses data to drive process improvement, and reduce unnecessary variation. Continuous improvement strategies such as “plan, do, study, act” and consumer participation at all levels of health care planning and operation are routine quality strategies. Concepts such as clinical governance drive the oversight of care by organisations. Practitioners and organisations are assessed and monitored by regulatory bodies, quality data is collected benchmarked and ideally shared with consumers to aid their decision making, and services must meet accreditation standards.

Therefore in assessing a framework we would suggest it is helpful to look at the elements of existing frameworks used not only disability services in Australia and overseas but also consider work in comparable human service industries such as health

and aged care that have implemented quality strategies to meet similar challenges, which in turn conform to generic universal quality principles.

Safety or Safeguarding

Key definitions provide the conceptual base for a framework. It is not just pedantry to get these right, as they determine the way work is undertaken in quality improvement for years to come.

For this reason we would suggest against developing a Quality and Safeguarding policy, but develop two separate policies that address on one hand “Quality and Safety”, and on the other a separate and distinct “Safeguarding” policy is needed. “Quality and Safety” and “Safeguarding” are two overlapping areas, but they are separate and there is a risk of giving each insufficient attention by merging the two.

The following table compares common definitions used either in Health or by Social Services, to the proposed NDIS definitions.

Term	Common definition	Proposed NDIS definition
Quality	At a broad level, quality reflects the extent to which a health care service or product produces a desired outcome ¹ . More specifically it refers to services that deliver effective interventions that achieve the desired outcome, provide continuity of care , are safe by avoiding harm caused by health care, responsive to clients, accessible , and are efficient and sustainable ² .	The extent to which a support is able to meet a participant’s requirements.
Safety	The avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered ³ .	No definition
Safeguarding	Safeguarding means protecting people’s health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect. It is	Actions designed to protect the rights of people to be safe from the risk of harm, abuse, and neglect while maximising the choice and control they have over their

¹ AIHW (2015) Definitions of Safety and Quality in Healthcare, <http://www.aihw.gov.au/sqhc-definitions/>
Definition based on B. Runciman, A. Merry and M. Walton, 2007, Safety and Ethics in Health Care, Ashgate, Burlington, VT, p. 297

² Health system performance from *National Health Information Standards and Statistics Committee (NHISSC) 2009. The National Health Performance Framework (2nd Edition)*

³ AIHW (2015) Definitions of Safety and Quality in Healthcare, <http://www.aihw.gov.au/sqhc-definitions/>

	<p>fundamental to creating high-quality health and social care. Those most in need of protection are: children, young people and adults whose circumstances make them vulnerable⁴</p>	<p>lives.</p>
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There is benefit in using a quality definition that is outcome based and refers to key performance criteria such as effectiveness, accessibility and responsiveness. Meeting participants' requirements alone, arguably, is not exacting and demanding enough. People vary in their expectations and requirements, and because of historical inadequacies in disability service provision, for some people, any improvement will be a positive experience, when in fact even better outcomes might be expected.

The lack of a safety definition, and the avoidance of this term in the policy, could lead to a lack of policy focus on the harm caused by services to clients, which is the focus of safety initiatives. Such harm whether it be due to error or system design failure, may not be particularly evident to either staff or service users, because the harm caused may not be readily apparent. Catastrophic events may have a low frequency, which is why a safety system relies on critical incident reporting (including near miss reporting) and rigorous root cause analyses following pre-designated incident types. Falls, injury, deaths and mental harm caused by trauma in care are examples of sentinel events in a disability setting.

It needs to be made very clear that safety in this context specifically refers to harm caused by services; it is not a reference to historical practices of keeping clients safe by denying rights, choice and denying "dignity of risk." This misguided past application of the word "safety" should not preclude its use now when applying generic quality and safety principles to a disability setting but the definition needs clear explanation. The substituting of the word 'safeguarding' for 'safety' could lead to a focus on other types of harm, and lessen the effort in preventing harm caused to people with disability by services.

Safeguarding has a different focus related to harm, abuse and neglect and is the basis of both child protection and 'at risk' adult protection responses. The UK definition refers to rights generally. The proposed Australian definition has a focus on choice and control. The UK definition is more encompassing and preferred because of its reference to the full range of human rights. The Australian definition may be seen to imply that safeguarding is in some ways balanced with a process of maximising the level of choice and control a person has. However applying the UNCRPD it should be possible to maximise all rights, including freedom from abuse and exploitation, as well as autonomy in decision making. Once again the more general UK definition has strengths

We believe that a safeguarding policy needs to be separate from a Quality and Safety Policy. The international evidence of best safeguarding practice is that safeguarding cannot be accomplished by organisations acting alone, and requires effective collaboration between health and social service providers, police and other parts of the justice system, as well as a range of community agencies and adult protection services.

⁴ Care, Quality, Commission, United Kingdom. The independent regulator of health and social care. <http://www.cqc.org.uk/content/safeguarding-people>

Key examples of international practice includes England's "No Secrets: guidance on protecting vulnerable adults in care"⁵ and the implementation of the Scotland's Adult Support and Protection Act (2007)⁶. All organisations have a duty to prevent and respond to abuse. This can need resources, and a mechanism is required to ensure that if extra time is needed to talk with a service user to prevent and respond to abuse, that this is available, and such a response is expected. In an Australian context this will require effective collaboration between Commonwealth funded Disability services, with a range of State Government agencies, and local government.

Safeguarding strategies need to be rights based. Article 16 of the UNCRPD, Freedom from exploitation, violence and abuse, provides excellent guidance for the development of legislation, policies and strategies within organisation and across the community.

It is also relevant to note that internationally, safeguarding legislation and policies apply to all at risk adults regardless of age. There is not a policy and practice separation between protecting younger adults at risk, and elder abuse prevention and response. A single strategy can prevent unnecessary duplication by agencies across the community that work with all groups (eg police, health, local government.) and more effectively interface with child protection, and domestic violence initiatives.

The Office of the Public Advocate (SA) in conjunction with the University of South Australia completed a project defining the elements of a rights based adult protection response for vulnerable adults, entitled "Closing the Gaps."⁷ While this was funded through the aged care sector and therefore focuses on elder abuse, the principles and strategies apply to all adults.

Information Systems

The discussion paper asks questions about information for participants.

We wish to flag a related issue, that is basic, and prosaic, but a key component of a quality and safety system.

That issue is how service provider store and share information about participants. Questions to be resolved include who owns the information, how it is accessed and the means of sharing information between multiple providers.

In the current system a disability service user may have information about them stored by a State Government provider. Usually a Government's Chief Information Officer carefully assesses the security of that storage, including the location of cloud based electronic records, usually kept in Australia, but sometimes backed up overseas. These arrangements are subject to both technical scrutiny by IT experts and legal scrutiny by Government lawyers. Information is exchanged between practitioners by e-mail behind government firewalls, and although this e-mail traffic is unencrypted it cannot be intercepted by other parties as it does not travel on the internet.

⁵ Department of Health (UK) 2000. No Secrets: guidance on protecting vulnerable adults in care, <https://www.gov.uk/government/publications/no-secrets-guidance-on-protecting-vulnerable-adults-in-care>

⁶ Scottish Government, 2007. Adult Support and Protection (Scotland) Act 2007, <http://www.legislation.gov.uk/asp/2007/10/contents>

⁷ Office of the Public Advocate and University of South Australia (2012) Closing the Gaps, Enhancing South Australia's Response to the Abuse of Vulnerable Older People." http://www.opa.sa.gov.au/files/187_closing_the_gaps_final_report_proposed_policy_complete_document.pdf

Records are subject to Freedom of Information laws, giving the service user access to what is stored about them.

In the future it is possible that multiple providers with their own record systems might deliver a similar range of services which formally came from one department, and will need to communicate and share information between themselves to provide a properly coordinated service. These providers, who may be small organisations, may not have access to the same technical and legal backup to plan and operate a client information system, as does Government.

Some of the information held by disability providers can be highly personal, and great harm could be created to an individual if information security is breached.

For these reasons, NDIS funded providers should be required to maintain set information security standards using recognised software and physical storage protocols. When client information is shared between providers it should be via encrypted e-mail. Standard e-mail encryption is commonly used in health to share medical reports with practitioners and other organisations, but not routinely used in the disability sector at this time to share similarly sensitive information, for example between government and non-government providers.

The requirements should give as much choice and control to the service user to determine where information is shared, and what level of information different providers can access. The information should also be readily accessible to the service user.

It could be helpful for the NDIS to commission its own generic information system. Confidential web based systems already exists that provide cloud based storage of sensitive data. A participant may choose to have all of their information stored in a single system, that is Government endorsed, rather than have reports, progress notes and other information scattered in the computer systems of multiple providers large and small. Providers could then make notes and share information by accessing a single record rather than maintain multiple records and copying information sent by e-mail.

Natural safeguards

An example of a natural safeguard is the establishment of supported decision making arrangements, so that a person who might otherwise have had their personal decisions made by others, is empowered to make their own decisions, and connected with other people of their choice, who provide decision support. The South Australian Supported Decision Making trial is an example of an approach to supported decision making that enabled people to make a range of personal decisions, including those about services⁸. If the choice and control approach is to benefit as many people as possible, then the Australian Law Reform Commission recommendations pertaining to the NDIS in their Equality, Capacity and Disability in Commonwealth Laws Final Report⁹ need implementation.

Oversight Body, Quality Assurance and Complaints Mechanisms

The need for appropriate oversight bodies, accreditation mechanisms, provider registration and complaints systems is recognised.

⁸ Office of the Public Advocate (2012) SA Supported Decision Making Project, http://www.opa.sa.gov.au/resources/supported_decision_making

⁹ Australian Law Reform Commission (2014) Equality, Capacity and Disability in Commonwealth Laws, Final Report, <http://www.alrc.gov.au/inquiries/legal-barriers-people-disability>

We do not have a strong view of the exact make up of these agencies but would expect that the design of this system would be based on an analysis of similar social care systems for people with disability overseas, and systems used currently in Australia in health and aged care.

Given the universal nature of quality and safety activities across industries, serious thought should be given to merging existing quality commissions into a single organisation with different divisions for health care, disability services and aged care. This could concentrate quality improvement expertise in a National Organisation with state offices, and avoid duplication in administrative functions saving costs. A similar arrangement could apply to a disability specific complaint system, that rather being stand alone is established as part of a larger complaint mechanism for all social services (disability and aged care).

In most Australian states a Community Visitors function has assisted in upholding the rights residents of disability supported accommodation. A Commonwealth statutory scheme should be established with a similar rights protection role.

Screening of Employees

We support a central screening agency that could be established alongside a complaints agency. This agency should make a decision about safety of a person to work in a particular setting. This decision should not be left to providers or participants, given that it is desirable to have expertise in assessing risk.

Having said this, the participant and provider in some cases will need to be fully informed of any relevant information that emerges in screening, particularly if a person is accepted for employment, but still considered to represent a risk in some way, and conditions imposed on their role (for example to work under supervision.)

Restrictive Practices

The NDIS should implement the most rigorous and effective system for preventing and eliminating the use of restrictive practices.

Recognising the constitutional roles of the Commonwealth and the States, this would need a combined legislative approach between the Commonwealth who can exert leverage through funding, and the States who can regulate the use of detention and the use of force (implicit in physical and mechanical restraint).

Standards should focus on all forms of restraint (physical, mechanical and chemical), seclusion and detention in disability facilities.

NDIS legislation should provide definitions of restrictive practices, outline the rights of participants who may be subject to restrictive practices, and the requirements of providers to prevent their use, and report. States should align their own relevant acts (usually Guardianship and Administration legislation) to provide consistent protection by defining consent arrangements. People with disability should not be held in locked houses (ie detained) on the basis of a defence of necessity or "duty of care"; instead there should be clear statutory provisions in state law, that give the service user a right of appeal through relevant state law.

We suggest that there needs to be dual protections that provide for both best practice and independent consent. On one hand an appropriate mechanism is needed to ensure that restrictive practices are avoided where possible through effective behaviour support by services, which could be part of a Commonwealth funding requirement, and

also at the same time have a requirement for consent to the use of such practices through state legislation usually by an appropriately authorised substitute decision maker or guardian. These approaches are complementary, and should occur together; not have one at the expense of the other.

Given the success of Victoria in implementing positive behaviour support and reducing restrictive practices, we would suggest that a Senior Practitioner role be part of a national scheme, perhaps as an independent officer in a Care Quality Commission, with similar functions to the Victorian senior practitioner.

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