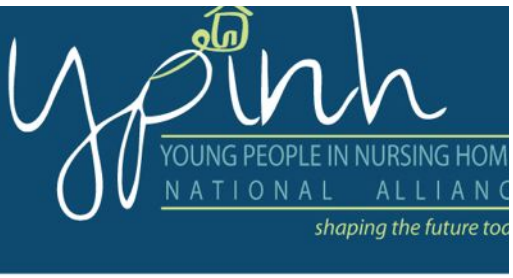

Response to the NDIS Quality & Safeguarding Framework Discussion Paper

Young People In Nursing Homes National Alliance

May 2015

Introduction

The Young People In Nursing Homes National Alliance welcomes the opportunity to respond to the *National Disability Insurance Scheme Quality and Safeguarding Framework Consultation Paper*.

The Alliance recognises the need for a Quality and Safeguarding Framework around the emerging NDIS that provides scheme participants and others with surety and confidence in their dealings with service providers and others who deliver care and support services under the NDIS' aegis.

While the Consultation Paper considers the impact of a Quality and Safeguarding Framework predominantly on service providers and future market capacities, the Alliance believes that the primary focus of any Framework of this kind must be the protection and ongoing capacity building of consumers of care and support services funded (among other programs) by the NDIS.

A robust Quality and Safeguarding Framework should thus ensure that consumers can have a minimum guarantee that standards and service provision of the highest quality is enshrined in the Framework; and that forceful penalties will apply wherever and whenever service delivery from providers falls short of consumer expectation and relevant state and federal legislation.

Fundamental aspects of a quality and safeguarding framework

The Alliance strongly believes that the following are fundamental principles of a successful and proactive NDIS *Quality and Safeguarding Framework*.

- Safety and competence is an essential expectation of any service or support funded by the NDIS (whether engaged through self management or external plan management).
- Safety and competence must be a foundational principle of an NDIS *Quality and Safeguarding Framework*.
- Providing safety and competence is not an issue of "choice". The only choice involved should be active choice of *competent* providers where competence is assured through a robust NDIS *Quality and Safeguarding Framework*.
- Any response must be systemic and universal and apply to everyone.

Natural supports, such as friendships or, indeed, existing informal supports, cannot be "roped into" a quality system or simply assumed to be part of the safeguarding arrangement. The safeguards framework needs to be designed to cover every circumstance and not assume short cuts can exist, individual by individual. Informal relationships that people have are just that and should not be corrupted or presumed by the scheme. These form the lives of people that NDIS supports should complement, not take over. A more deliberative approach is essential to ensure that all NDIS participants can have confidence in the quality and safety of the services and supports they receive.

Control and choice, quality and safeguarding

While choice and control sits at the heart of the NDIS reform, the supply of safe, high quality services should not be a subject of choice. Choice must exist around this fundamental baseline in the provider sector and be beyond negotiation. Choice must be monitored, measured and delivered in a variety of ways to suit the different approaches to the supply and management of support that will exist under the NDIS. There is a clear and implicit expectation that all services/providers and personnel providing support to people with disability are competent, operate safely and are subject to scrutiny.

In other words, service competence and safety cannot be seen as a choice but must be a fundamental element of the *system*, not just the market. As the UK's example shows, consumer choice alone will not lift safety across the provider sector. Deliberate intervention using a mix of regulation and existing community resources is required to guide the transition and ongoing operation of the market.

The Alliance is aware that this Quality and Safeguarding consultation will elicit many highly technical responses to the design questions posed in the consultation paper and we do not propose to further address these in this submission. Our contribution is based on our experience working with individuals and families in situations of service or systems failure (often across service sectors); working with service providers in health, aged care and disability services; and also with policy development.

The Alliance has worked closely with issues of poor service and system design, variable service delivery practice and the need to intervene to resolve difficulties that individuals and families have in accessing information, advocacy and certainty in their support. We see great opportunity in a new approach to quality and safeguarding, not only in managing areas of identified risk, but to raise the standards of service provision; in consumer interactions with service providers; and in the capacity to be an active provocateur in the transition of control and choice from providers to people with disability and their families.

The Alliance agrees that the four elements in Section 2 are important to include in the coverage of the Quality and Safeguarding system. But if this is all that the NDIS' Quality and Safeguarding Framework does, then these elements risk mimicking the worst features of our current one-dimensional, reactive and easily breached standards regime in disability services.

We believe the scheme's Quality and Safeguarding system would be most effective if it is mandated with a broader scope. Ideally, an independent body would be established that could assume responsibility for Quality and Safeguarding for NDIS and non-NDIS funded services. The type of activities the independent body would undertake include:

- Benchmark service provider quality and practice and actively engage service users (and their organisations) in the setting of benchmarks and audits of service providers
- Be a clearing house of evidence about service design and practice, consumer experience and outcomes and play a key role in requiring and incentivising translation of this evidence into service provision to
    - Ensure evidence is understandable and available in accessible formats to enable consumers, families and their advocates to use evidence in their planning and interaction with the scheme and providers
    - Commission research and evaluations that interrogate user led service design, quality assurance and safeguarding in the NDIS context
    - Engage with consumer protection systems in the jurisdictions to generate and disseminate real time information about questionable practices, provider comparisons and consumer experience.
- Regulate the provider market to:
    - Ensure registration of providers
    - Establish and monitor workforce standards
    - Monitor self managed service arrangements
    - Lead the reform of corporate governance requirements to include service quality as a positive obligation of boards of human service providers.
- Establish cross-program protocols with other safeguarding/regulatory regimes in programs used by people with disability (such as health, education, aged care et al), so that there are clear expectations set in these other programs regarding service delivery standards to people with disability; and practical – and agreed – applications of the NDIS Quality and Safeguarding benchmarks in those service sectors.

Conception of the NDIS in the Consultation Paper

The structure of the NDIS that the *Quality and Safeguards Framework Consultation Paper* is working to, is predicated on support being planned and packaged "up front". In other words, calculating or funding a participant's package of funding is done in advance, rather than as a 'pay as you go' method that sees payment for services made after services are received.

The Alliance believes this 'up front' approach warps the way a safeguards system should work. It reduces the effectiveness of a typical centralized system; and obviates the need for meso-level safeguarding in addition to the more traditional model of a sole government regulator overseeing a sector or industry. Further detail about how this needs to be incorporated is presented in the section on Community Living Organisations in this submission. (See pages 15 ff).

Rather than ongoing oversight and proactive engagement with providers that a Quality and Safeguards system should deliver, the devolved purchasing arrangements the scheme currently utilises mean that, because the scheme's engagement is all 'after the fact' or after the money has been allocated, the NDIS has additional challenges to ensure safety and compliance with its expectations – and those of its participants – around service quality and safeguard.

To give this effect and to do so without undermining the tenets of the NDIS is the obvious goal of a workable Quality and Safeguards Framework. Ultimately, however, this must be a non-market solution. Even in supposedly mature markets, consistent levels of failure can occur where the interests or behaviour of suppliers override those of customers.

One such Australian market is in telecommunications, where high levels of vigilance are required to ensure consumer protection and an independent Telecommunication Ombudsman's office has been created to handle complaints. In 2013, the Telecommunication Ombudsman had over 138,000 complaints lodged, demonstrating the need for an independent body in this market for consumers. As this example, demonstrates, no market can be expected to work perfectly on its own undertaking.

The market driven approach being relied upon to guide the scheme's evolution has no intrinsic tension in the system around safety or quality other than consumer choice, which is indirect and barely distinguishable in disability services. A *Quality and Safeguarding Framework* depends on the existence of tension in the system to prevent complacency. Previous expectation that service providers would successfully manage their own Quality and Safeguarding responses has been a comprehensive failure, as ABC TV's *4 Corners* expose of Yooralla's failures in this regard demonstrated.[1]

Expecting new or existing markets to deliver quality, confidence and surety of service provision is foolhardy and risks repeating the mistakes of the past. It has been noted repeatedly that the existing disability provider sector needs major reform to adapt to the new NDIS system. The Alliance contends that this 'reform' to a consumer directed fee-for-service system will not, on its own, change the fundamental culture of providers in regard to quality and safety.

Simply relying on consumer "control and choice" to ensure service quality and safeguards are upheld, is similarly naïve. It presumes strong consumer knowledge and understanding, input and oversight that cannot be generated through market activity alone. In this regard, the privatisation of Swedish welfare services in the 1990s and more recent moves in the United Kingdom to embrace a 'market

[1] See "In Our Care", ABC TV's *4 Corners,* aired 27 November 2014. See http://www.abc.net.au/4corners/stories/2014/11/24/4132812.htm accessed 22 May 2015.

approach' are instructive about the risks of reliance on a market economy to deliver safe, effective and quality services with limited external protections.

In the Swedish context, moves to a market economy through privatisation of services led to social stratification and demand for ever more exclusive and culturally "distinct" service alternatives. As well as offering providers an economic incentive to develop more 'exclusive' services, this also encouraged adoption of a more selective approach to users of these new services by providers. Not long after moves to privatisation of welfare services began in Sweden, there were already signs that, in a time of economic restraint, pressure was growing to privatise the financing of services as well as the services themselves.[2]

Blomqvist notes that should 'privatisation of financing' continue, privatisation will assume an "ever more detrimental form".

> *If a commercial market for high quality private social services develops, the better off might be inclined to pay for these services privately, rather than wait for public authorities to "purchase" them on their behalf. This will, by definition, undermine political attempts to maintain a universal, egalitarian welfare services sector.*[3]

Blomqvist concludes by saying

> *Increased private financing and the resulting diminishment of the redistributive character of the system, is especially likely under conditions of financial restraint, which seems to be the condition under which most policy makers will be operating in years to come.*[4]

In a similar vein, the wide take up of virtual or e-marketplaces under UK reforms to that country's care system, have relevance for the NDIS regarding development and delivery of the scheme's Quality and Safeguarding framework.

Designed to assist self-funded adult social care users and holders of personal budgets (including direct payment recipients) use Amazon or eBay-style digital platforms to search for and purchase products and services in line with their personal care plans, e-marketplaces were seen to have benefits that included

- Improving access to the market for new and small providers
- Enabling user-commissioning and
- Integrating networks of informal and formal care. [5]

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[2] Blomqvist, P. "The Choice Revolution: Privatisation of Swedish Welfare Services in the 1990s" in *Social Policy & Administration*, Vol. 38, No. 2, April 2004: 152.
[3] Ibid.
[4] Ibid.
[5] Roberts, C. *Next Generation Social Care. The role of e-marketplaces in empowering care users and transforming services*, Institute for Public Policy Research, London, May 2015: 2. Emphasis added.

Despite this positive anticipation, take up of e-marketplaces in the UK has been fragmentary, with inconsistent commitment to using them as tools for empowerment, integration and personalised care. For example, some authorities saw e-marketplaces as a means of radically transforming care services, while others saw them mainly as drivers of cost-savings.

Other issues related to IT infrastructures that were difficult to adapt or change after set up. This risked poorly designed and managed e-marketplaces simply entrenching the weaknesses of the current system including "…unresponsiveness to user needs and demands, and competition that is too focussed on price – rather than support[ing] transformational change."[6]

Despite this, Roberts argues that government, local authorities and coordinating bodies have seminal roles to play in ensuring that e-marketplaces are successful in their aim of delivering personalised and integrated care and not entrenching "…the worst aspects of the current system."[7]

To build "next generation social care", Roberts concludes that three key actions must be embedded in the UK's evolving system. These are

- *Digital services **designed around the user experience and journey** rather than business' needs.*
  Users need to be directly involved in the design of the system, through feedback or iterative design. Current IT procurement practices in the UK were seen to encourage one-off purchases and not encourage user involvement in service design or prototyping digital products.
- ***Proactive offline activity** needed for an e-marketplace to succeed and **develop relational rather than transactional services**.*
  To achieve this, small and innovative providers must be encouraged and supported; barriers to entry need to be lowered for smaller scale and more informal types of service provision; and users must be actively supported to jointly commission services. Roberts cautions that, while "Market-based approaches do not necessarily result in services being run by large, impersonal providers…without active cultivation this can be the default."[8]
- ***Cultural changes**, particularly around trusting users and adopting appropriate attitudes to risk, are **prerequisites for success**.*
  Simply making services available online will not be enough to deliver diverse and integrated service offerings. Instead, advisors are required who trust service users' decisions while being aware of the risks in doing so; and are willing to recommend services users may be unfamiliar with.[9]

[6] Ibid.
[7] Op.Cit: 3.
[8] Ibid.
[9] Ibid.

These examples from both the Swedish and UK literature reiterate that providing information to consumers about what they might expect from service providers; monitoring the service responses providers deliver to consumers; supporting consumers in their interactions with providers and offering supportive recourse for consumers unhappy with the service they are receiving, are critical components of a robust Quality and Safeguarding Framework. The UK example also illustrates that consumer choice, market regulation and reform cannot be delivered solely via the Internet and IT infrastructure. Consumers and families still need capable organisations and trusted people to help inform their choice making.

As outlined later in this submission, the Alliance believes the Community Living Organisation (CLO) model described on pages 15 ff of this submission, can address these concerns and ensure a multi-pronged Quality and Safeguards system for NDIS scheme participants and providers alike.

Risk management

The Alliance agrees with the point in the consultation paper that the fundamental task of the proposed Quality and Safeguarding Framework is about managing risk. However, the Alliance sees risk management not only being concerned with the risks providers face from poor quality service delivery and practice. As end users of NDIS funded services, the possibility of abuse and neglect for people with disability is an area of risk that a robust NDIS Quality and Safeguarding Framework must also address.

In designing a Quality and Safeguarding system, it is important that the system has a mandate for education, information provision and active prevention activity, as well as the more traditional regulative, audit and punitive roles. Including a public health approach to addressing the key areas of risk in the design and delivery of services to people with disability (as well as managing the usual regulatory functions of a Quality and Safeguarding regime) would mean resources could be devoted to prevention of abuse and neglect; and promotion of good user directed service practice.

The structure of State and Territory workers compensation schemes could be a very useful model for the NDIS Framework to consider for their end-to-end approach and highly effective communications. These schemes undertake injury prevention activity (campaigns, production of guidelines, research); compliance (inspections); and sanctions and multi level communications with stakeholders. Brought together, these functions make for a robust approach to workplace safety.

It may be that the communications and inspection infrastructure of workers compensation schemes could be utilised by the NDIS to deliver part of the Quality and Safeguarding framework. Every disability provider and NDIS participant self managing their package, will have a relationship with their jurisdictional workers

compensation scheme, so some efficiencies already exist in this space for communications and compliance.

Adopting such approaches would also have the effect of providing a monitoring facility for non-registered providers.

Addressing multi program risks for participants

The Young People In Nursing Homes cohort (YPINH) is comprised of individuals with complex health and functional disability support needs. Satisfying the intensity and complexity of their care and support needs means that service input may be required from multiple human services programs simultaneously.

Because YPINH 'straddle' multiple programs and require simultaneous input from these programs to satisfy their complexity of need, a competent quality and safeguards system must not only ensure that a robust Quality and Safeguarding Framework delivering confidence and competence in the disability supports and services funded by the scheme, exists for NDIS scheme participants. A competent Quality and Safeguarding system but must also address the risks that may exist for scheme participants, like YPINH, drawing on services and support from other human services programs as well.

YPINH are particularly likely to require input from health and disability services concurrently. But they may also require concurrent input from aged care, education, employment or housing services at various times; and require this complete service input to be delivered in a competent, safe and integrated manner. However, the coordinated delivery of all these required services is all too rare.

The systemic neglect involved in denial of proper support to YPINH, is largely to do with the lack of a coherent pathway of rehabilitation, health and community support and funding to deliver these integrated trajectories. The gaps in heath service provision in delivering recommended services to YPINH can lead to major complications and the preventable exacerbation of disability through the person's life.

Equally, the lack of adequate aged care services capacity to support YPINH is linked with the design of the Aged Care Funding Instrument (ACFI). The ACFI was expressly designed to fund support for frail older people and can lead to the perverse situation where poor individual outcomes for YPINH are delivered while these services remain fully compliant with the Residential Aged Care Accreditation Standards described in the Quality of Care Principles.[10]

The only avenue individuals currently have to seek redress for poor treatment or to resolve this system failure is with common law, as complaints systems cannot deliver binding judgments or deliver funding increases where they are needed. The

[10] See https://www.aacqa.gov.au/for-providers/accreditation-standards

costs and degree of difficulty in putting cases together is a barrier to people taking this option and current Quality and Safeguarding systems in health, disability and aged care cannot facilitate these actions effectively. A further disincentive is that a case can only be prosecuted after the fact, meaning that any action taken in this way cannot retrieve the situation and fill service gaps when people need them.

We acknowledge that reform of safeguarding systems in other service sectors is not the primary role of an NDIS Quality and Safeguarding framework. In the NDIS context, however, the Quality and Safeguarding framework does have a role to play in redefining service systems and their quality provisions, particularly since NDIS participants will routinely be accessing these systems as part of their plans.

The enduring problems created by the lack of service program integration for YPINH; the unique set of circumstances that exist with the establishment of the NDIS as a social insurance model; and the scheme's legislative and financial responsibility to deliver individual and social outcomes, means that a quality and safeguarding approach that can intervene *across* service systems, is much needed to shine an 'official' light on systemic neglect of YPINH and others.

Establishing such a robust system may require the creation of a National Disability Services Commissioner with a brief to investigate and resolve quality and safeguarding matters in a range of sectors. Such an office could be co-located with the independent Quality and Safeguarding body, or be one and the same. (See pages 12 ff.)

An essential feature of such a body would be to have power to make binding rulings on providers where consumer complaints are found to be valid and resolvable. These rulings could be reviewable at the Administrative Appeals Tribunal (AAT) in the same way that NDIS decisions are deliberated in front of the AAT.

In contrast, existing complaints bodies such as the Disability Services Commissioner in Victoria, cannot make binding rulings. The Alliance has been involved with members in bringing complaints about provider practice to the Victorian Commissioner and there has been no resolution, leaving the members and their families exasperated and fearful of ongoing bad practice in their care situations.

In regard to provider registration, the Alliance believes there should be a hybrid of the options presented in the consultation paper. There clearly needs to be a high degree of choice in provider selection, but safety and quality need to be non-negotiable. Accountability can be direct or indirect and mechanisms (such as governance requirements, OHS, industrial relations agreements, worker checks, consumer satisfaction reporting, standards monitoring etc) need to be developed as part of the framework to ensure that every type of support arrangement can be transparent and accountable.

There should also be opportunity for alternative support arrangements through the NDIS' Quality and Safeguarding framework, such as user and worker owned support cooperatives, individual and direct employment arrangements and micro boards. As these models are developed in the NDIS context, the Quality and Safeguarding implications could be designed in tandem, with specific requirements for the different models. This would require investment in some research, evaluation and co-design.

Training and certification of support workers a must

As this submission has already indicated, the YPINH cohort commonly presents with complex health and functional disability support needs that can include tracheostomy care and management, PEG feeding care and management and indwelling catheter care and management as well as pressure care and skin integrity management. Improperly managed, any one of these complex health areas can cause significant deterioration in health and even result in premature death.

The four options outlined in the Quality and Safeguarding Framework paper are concerned with the need for training and qualification of support workers as part of the provider registration process. Other than observance of such state and/or federal legislation as the National Standards for Disability Services, these options are concerned with registration of providers and have little to do with qualification or certification of workers employed by providers.

Developed to address the level of risk providers may face, these options do nothing to address the level of risk service users may face when untrained or poorly trained and monitored workers are used to provide support to vulnerable individuals.

The Younger People In Residential Aged Care initiative (YPIRAC) delivered significant learnings – and warnings – about the folly of expecting support workers untrained in the care and management of complex health needs, to support these needs via conventional disability support services. The Alliance is aware of instances in which poor understanding of PEG feed delivery and management has, for example, led to recurrent aspiration pneumonias, infections and preventable hospitalisations for YPINH.

The Alliance believes dedicated education, training and qualification in the care and management of these areas of complex health need must be developed to ensure the safety of the young people who require this intensive health service input.

Developing a workforce with this level of training will not only ensure improved health and well being for those younger people with this level of health support need. Undertaken in partnership with health networks and accreditation agencies, these additional qualifications can form new career pathways for workers seeking to specialise in particular areas of need; or to undertake training in specialist health areas such as nursing or medicine.

Service Provider Reform: an Independent Q&S Authority

The Alliance believes that an independent body is required to oversee a national Quality and Safeguarding system. The Alliance also believes that needed reform in service provision must be driven from within service providing organisations as much as from a large government body. The variable quality of disability services and the weakness in the current standards regimes in Australia indicates that major transformation is required in the regulatory environment and in the culture of service provision.

While the NDIS is driving reform in funding systems, reliance on market developments to 'pick up the slack' on quality and choice will leave far too much to chance and will also be too slow. Recent high profile abuse cases have shown that we must act with urgency on quality and safeguarding. A key part of this action is to locate the responsibility for quality and safety with boards and senior officers of providing organisations. Trying to drive reform through compliance with an externally imposed system and/or through immature markets, will only lead to a focus on compliance methods and financial issues rather than on quality – and safety – of care.

A case in point is that where feedback about the aged care sector's accreditation/quality assurance process leads to overt priority placed on accreditation visits, rather than the overriding attention to quality that should be in place at all times.

Some submissions to the 2004/5 *Senate Inquiry into Aged Care* argued that accreditation processes encouraged some residential care homes to employ additional staff and generally 'tidy up' the facility prior to the arrival of assessors, creating a false impression of the true nature of the facility and the services provided.

Representing individuals who work in residential aged care services, the Health Service Union noted that

> *Scheduled accreditation gives management the opportunity to roster extra staff on, adjust menus and activities, and generally have everything looking ship shape for the accreditors. However, members argue that the standards shown off at accreditation are rarely maintained outside of accreditation periods. The NSW Nurses' Association also noted that members routinely reported that 'the accreditation process is a farce as everything is set up for the day and then disappears'. The Nurses Board of WA* similarly commented that: *Arriving as anyone would arrive to an institution, you do get a feel of what normally happens. With the provision of notice, there is opportunity for preparation that may not normally be done.*[11]

[11] Parliament of Australia, Senate Community Affairs Committee: *Quality and Equity in Aged Care* Inquiry Report, Canberra, 2004: 38.

While the debate about the real impact of the aged care accreditation system and its impact on service quality is still open, it is clear that it has created its own 'marketplace' to manage accreditation visits.

In the same way that Aged Care providers sometimes employ external consultants to prepare for compliance audits,[12] the Alliance is aware that disability providers engage in the same practice, though these 'quality' consultants are not generally visible at other, non-audit times.

Reform of the governance requirements for human service organisations

In order to reform the culture of service organisations to make them focus more on quality and consumer needs, changes in the expectations and responsibilities of boards are needed.

In light of the recent high profile abuse cases at Yooralla and in Department of Human Services residential services in Victoria, it is telling that there is no positive obligation in legislation or in the corporate code for service provider board members or senior officers to ensure safety and quality services, despite this being their core business. No set of penalties or sanctions for boards exists under the current arrangements. This has meant that the Victorian Government has not withdrawn any of the affected services and Yooralla's contracts and the provider's funding have both remained intact.

To seek any kind of redress, abuse victims must pursue actions at common law. Service users who have been provided with substandard services have no useful recourse other than complaints processes. Despite having contracts that specify requirements to meet standards, weak contract management by government funders, weak standards regimes, provider self regulation and a lack of articulated liability for service failure, all mean that boards and senior officers of service providing organisations are not personally or corporately held to account.

Compare this with the legislated safeguards and sanctions in our occupational health and safety system (OHS). The national model OHS legislation contains civil and criminal sanctions of up to $600,000 in fines or five years' jail for individuals for serious breaches.

These obligations and sanctions in the OHS legislation have changed the behaviour of directors and companies over time. It would be unusual to see a board or senior management meeting agenda without an item on OHS because it matters personally to individual members. By locating the ultimate responsibility at the top of the organisation, it follows that action will be taken to manage the risks operationally. Significant contingencies and sanctions are in place to address failure to act.

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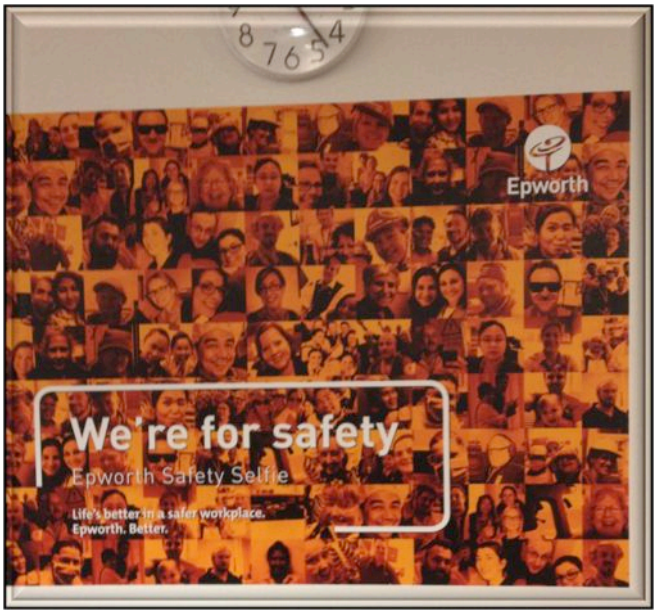
[12] Wynne M., *The Accreditation and Complaint Processes – Australian Nursing homes,* at http://www.agedcarecrisis.com/accreditation Accessed 10 May 2015.

The changes we have seen in corporate attention to Occupational Health and Safety in the last 15 years, have been brought about through placing a high value on the importance of safety at work; enacting legislation; and locating key responsibility and liability with boards and senior officers.

Having the same level of intrinsic focus on quality of support services as we do about worker safety, would be a marker of success for the NDIS reforms that are being implemented. Establishing additional positive obligations for boards of care organisations is a necessary reform in its own right and while it is not the sole job of the NDIS, the scheme could take a leadership role in pursuing this with key community organisations.

Unless it articulates the points of responsibility and liability for service failure under the NDIS and changes the imperatives for providers, the Quality and Safeguarding system will be largely reactive in this area. This should not diminish the focus on OHS, but complement it.

Many businesses, such as providers in health, aged care and other human services, have posters like the one Epworth Hospital uses (right) to demonstrate that hospital's commitment to worker safety. Without the OHS legislative obligations, the need for this display would be voluntary and less likely. Similar displays about safe and quality service delivery to individuals are much rarer, despite it being the (presumed) *raison d'etre* of providers.



Until there is a separate legislative framework that reforms the corporate code to mandate positive obligations for safety and quality for officers of human services organisations, the Alliance recommends that the NDIS Quality and Safeguarding framework include capacity to take civil and criminal action against providers (as well as cessation of funding) for breaches of the NDIS *Quality and Safeguarding Framework* by their organisations, should such breaches occur.[13]

[13] See Appendix A in this regard.

Community Living Organisations (CLO) as front line agencies
At present, the NDIS has assumed a highly centralized and controlling presence. While this early position is understandable as the scheme transitions away from the block funded service provisions of the past, the Alliance believes the NDIS should develop a much smaller footprint and have greatly lessened visibility, both for scheme participants, providers and for the community at large.

At this stage in the scheme's development, the necessary cross-program connections with community services are immature at best, while the integration of disability supports with other areas of participants' lives in the community, are individually driven.

Retaining responsibility for all aspects of service planning, funding and coordination lessens the opportunity to leverage the contribution of existing personal and community structures to assist NDIS participants with their goals.

The current reliance solely on disability service providers to deliver reform also ignores the valuable contribution of non-provider organisations to the NDIS objectives, as well as the ambition of the Quality and Safeguards Framework.

Part of the scheme's challenge in integrating with the fabric of the community, lies with the trajectory of the trial sites and their difficulty in dealing with statewide programs. Rather than assuming this central role in the lives of participants as it presently does, the scheme will need to be less prominent and fit better with other parts of the community as it evolves and develops. The Quality and Safeguards Framework has a key role to play in integrating the NDIS with other programs used by participants and by using non-provider community organisations for such key roles as information provision and co-provider management.

Similarly, the scheme's large footprint and current focus on its own operations, severely limits its capacity to interact and develop valuable associations at a local or community level. Developing these community associations needs to be a priority not only for the Quality and Safeguards system, but also for the scheme's evolving design.

CLO Quality and Safeguards management integral to scheme design
A major Imperative in designing the scheme is to define and locate those non-providing organisations that can foster and support community inclusion and provide a range of advice, information and complementary supports to scheme participants. These supports include cross sector linking, supporting and extending informal support and provider management.

While community engagement achieved by scheme participants is a key objective of the NDIS, a funded support package clearly cannot deliver engagement in and with the community on its own. Assessing provider claims about their capacity to deliver sustainable social outcomes will need to be carefully undertaken.

As well as the more traditional forms of provider regulation, consumer advice and support is a must for the Quality and Safeguards framework in a market situation.

Also central to the success of the NDIS, is that people with disability remain connected with their family and friendship networks; not become defined by their disability; are not characterised primarily as a funded service user; or valued by the community by virtue of the size of a funding package.

The CLO role was expressed largely as that of a financial intermediary in the Productivity Commission report and has been further expressed as a peer support role since.[14] There are strong and compelling reasons to expand and strengthen the role of these Community Living Organisations to enable them to influence companion service programs and take a lead role with community engagement as well as undertaking a level of provider management within the specialist disability provider market.

The CLO's long term coordination and integration role will be critical to safeguarding a system that is structured primarily as a market. A key design step in developing the NDIS market is to define the character and requirements of the CLO and to facilitate the separation of organisations that fit these requirements, from service providing organisations.

This could be done on an opt-in basis, with the key organisational requirements being established by the NDIA. This new class of organisations needs to be established within the scheme's trial sites so they can be evaluated and refined for full scheme rollout

Structurally, CLO's create an alignment between the scheme and the community that is important in supporting long term scheme sustainability. The shared social objectives of the CLO sector are fundamentally different to the commercial relationship between disability providers and the NDIS.

In essence, the markets created by the NDIS cannot, on their own, deliver the social outcomes desired in the objects of the NDIS Legislation.

[14] The naming of these front line agencies continues to change. In the Alliance's 2010 submission to the Productivity Commission's Inquiry into Disability Care and Support, they were named Lifetime Support Agencies. In its final Inquiry Report, the PC used the term Disability Support Organisations to refer to these agencies as financial intermediaries. The NDIS legislation refers to plan management providers (PMP) that undertake this task. In order to clarify a specific role and purpose, the Alliance now refers to these front line agencies as Community Living Organisations (CLO) that have a mandate to work with scheme participants and others to access formal and informal supports and engage proactively with their local communities. This paper will use this latter term to refer to these front line agencies and their purpose.

With responsibility for the following functions, a CLO will be able to promote the achievement of plan outcomes and also monitor quality in real time with participants, doing so via

- Community connections and engagement
- Ensuring coordination and cohesion of NDIS package with other service and program areas including health, housing, education, transport, and aged care
- Mediating long term support delivery and real time quality assurance/safeguarding via the key role of provider management shared with the consumer and the scheme. This meso-level role would put mission driven and consumer focused tension into the provider market, as there would be community level 'eyes' on provider behaviour and performance.

This structure can also work to create greater rigour around community services as well as improve service expectation and delivery from other program areas; and proactively manage the risk that the NDIS will wear through the cost of failure by other service areas.

This is something that the UK's *Next Generation Social Care* paper sees as an important role for what it calls 'coordinating bodies'.[15]

Even with one funder for disability services, the service system for people with a disability will still be relatively complex, as people seek to access a range of health and community services, information and family support.

As well as systemic work to define and negotiate the service pathways, detailed work will need to be done at the individual level to design and coordinate services across program areas.

The UK Government's *Vision for Adult Social Care, Capable Communities and Active Citizens* paper describes a similar vision in establishing how that Government wants services delivered for people.

This policy paper provides a new direction for adult social care and puts personalised services and outcomes 'centre stage'.[16]

The British Government's vision for a modern system of social care is built on principles that the NIIS and NDIS could easily adopt via empowering CLOs to support individuals across the scheme and beyond.

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[15] Roberts, C. Op.Cit: 3.

[16] Social Care Policy Unit, UK Department of Health, *A Vision for Adult Social Care: Capable Communities and Active Citizens*, London, 2010. Accessed 22 May 201 at http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121971.pdf

These principles include:

Personalisation: individuals not institutions take control of their care. Personal budgets, preferably as direct payments, are provided to all eligible people. Information about care and support is available for all local people, regardless of whether or not they fund their own care.

Partnership: care and support delivered in a partnership between individuals, communities, the voluntary and private sectors, the NHS and councils including wider support services, such as housing.

Plurality: the variety of people's needs is matched by diverse service provision, with a broad market of high quality service providers.

Protection: there are sensible safeguards against the risk of abuse or neglect. Risk is no longer an excuse to limit people's freedom

Instead of waiting for service user complaints to reach the scheme as ultimate arbiter, the NDIS must invest in front line agencies that can

- Manage scheme participant expectation.
- Assist scheme participants with information and assistance in making informed decisions about choice of provider.
- Work with scheme participants to trial and assess new service providers.
- Work proactively with both providers and consumers to improve service certification, training and quality for individuals and for broader service delivery.
- Manage service provider expectation.
- Oversee provider training and compliance with declared standards, certification and quality assurance frameworks.
- Monitor service delivery with scheme participants and broker positive engagement between consumers and providers.
- Monitor and address established service delivery concerns or complaints from scheme participants early in the resolution process.
- Proactively manage the relationships between scheme participants and providers.
- Provide a timely intervention when issues of service Quality and safeguards are raised.
- Link scheme participants and service providers with local community resources and organisations able to work collaboratively with service providers and the NDIS to successfully deliver informal, community based supports in concert with paid service delivery.

As front line agencies of the scheme, non-service providing Community Living Organisations with a mandate to undertake these critical and necessary services and activities, can help proactively manage the relationships between scheme participants and providers across a range of areas and interventions. In these ways, CLOs can actively monitor quality and play a dynamic role in the NDIS' Quality and Safeguarding framework.

In undertaking this front line role, CLOs thus become the visible face of the NDIS with an imperative *and a capacity* to address participant and consumer concerns early and locally, thus preventing the more intense and complex interactions that are likely to arise should the NDIS itself remain as the only visible point of intersection for scheme participants.

The CLOs active oversight, interaction with and management of the scheme's Quality and Safeguarding Framework for scheme participants, will ensure that a community level safeguarding approach can complement the centralized approach of the NDIS and an independent quality assurance body. This multi-pronged approach we believe will be more effective than a single organisation oversight structure.

Further Information
For further contact regarding this submission or for further consultation on the Quality and Safeguards framework, please contact:

Dr Bronwyn Morkham
National Director
Bronwyn@ypinh.org.au
0437 178 078

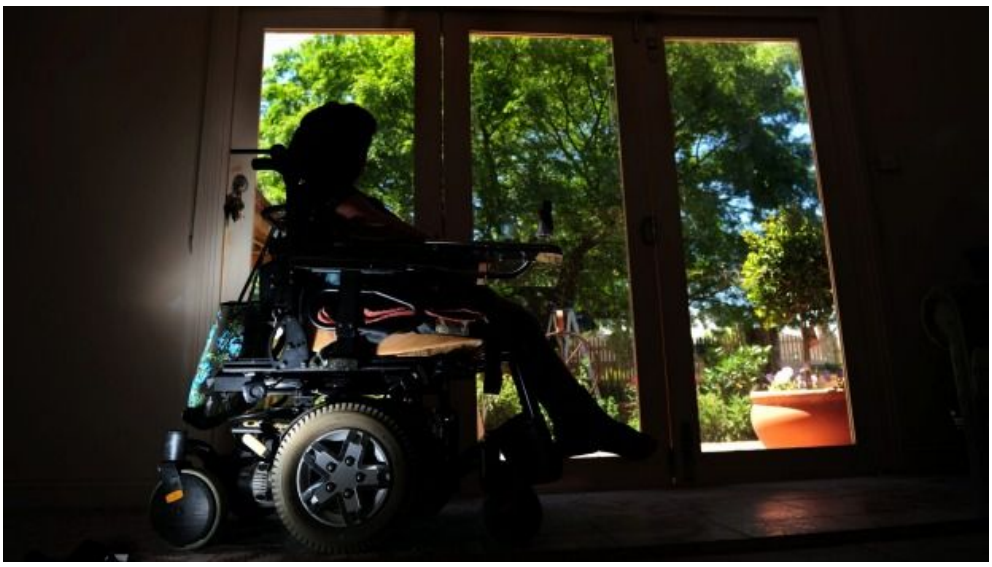
Appendix A

Yooralla failings: no more excuses

November 25, 2014

Alan Blackwood

Victorians with disabilities and their families should not have to rely on whistleblowers to keep them safe.



At risk: People with a disability are most likely to be abused in segregated service environments, where abusive practices go unrecognised and unreported and where client and family participation in services is devalued. *Photo: Penny Stephens*

Four Corners' and Fairfax Media's expose of the sickening sexual abuse, violence and exploitation of people with disability living in Yooralla's residential services, is the latest in a long line of reports of abuse and neglect experienced by Victorians with disability.

The full expose of Yooralla's failings is shocking enough. But what is equally shocking is that it took the courage of whistleblowers to raise the alarm and, despite multiple cases being proven, senior Yooralla officers have not faced any sanction for the abuse suffered by those in their care.

Yooralla's now former chief executive, Sanjib Roy, resigned voluntarily on Sunday and, in a stunning turn of events, did so with plaudits from the board. The denial of responsibility implicit in the chairman's statement farewelling Roy is difficult to fathom.

I worked at Yooralla in the early 1990s and it is sad indeed to reflect on what has become of a once-leading organisation. It is also distressing to see the prevalence of

abuse and neglect of people with disability is a "yet to be resolved" crisis in both government and non-government services across the sector.

World Health Organisation research shows that people with a cognitive impairment are three times more likely to be victims of sexual or physical abuse than other citizens, and children with a disability are nearly four times more likely to be victims of abuse.

Yet, despite evidence such as this being around for many years, we still don't have a vigilant safeguards system in place that offers the protection on which the individuals in Yooralla's care should have been able to rely.

With each case of abuse or neglect in care services reported by *The Age*, care providers have responded with the excuse of the "bad apple" worker to explain how such terrible abuse occurred.

Time and again, governments and service organisations have reassured us that steps have been taken to prevent future cases of abuse, guaranteeing that once rogue workers have been identified and removed, the problem will go away.

Well, it hasn't and it won't, unless we take strong and decisive action to safeguard individuals with disability.

A legislative framework that can drive a revolutionary shift in the culture of service providers is imperative, as are the sanctions and penalties needed to enforce compliance.

For too long, non-government disability providers have been allowed to self-regulate their way out of trouble by governments that have not intervened swiftly or decisively to force accountability and change when abuse cases surface. Cases such as those detailed in the *Four Corners* program show that the kind of soft regulation at the core of the disability sector's operation is devastatingly inadequate.

Ten months after Vinod Johnny Kumar was jailed for sexually abusing a number of Yooralla clients in 2013, the Victorian government's belated response was to introduce the Disability Worker Exclusion Scheme to identify people posing "a proven risk" to those living in group homes.

Care workers must be carefully vetted, but by focusing only on workers, the scheme is a piecemeal response that merely plays to the "bad apple" tune and does not fully address the larger issues that have allowed this crisis to fester. The scheme is also limited to disability residential services, meaning other types of services where the risk of abuse is just as real, such as community or aged care and those receiving care at school, are not covered.

People with a disability are most likely to be abused in segregated service environments, where abusive practices go unrecognised and unreported and where client and family participation in services is devalued. Delivering safe, open and

accountable services that respond to individuals with capable staff and comprehensive accountability must be the minimum expectation, not only in Victoria, but nationally.
It is unacceptable to rely on weak regulation, the occasional criminal convictions of carers or compensation claims by abuse victims to deliver the change individuals with disability and their families are seeking. Legislated obligations are needed to underpin this change, to both prevent abuse and neglect and to deal strongly with it when instances occur.

We already have a successful system of legislated safeguards and sanctions in our occupational health and safety system (OHS) that locates responsibility for workplace safety with boards and management. Legislated civil and criminal sanctions for breaches of OHS duty of up to $600,000 in fines or five years' jail for individuals for serious breaches have materially changed the behaviour of directors and companies.

The cultural change needed to incorporate the OHS framework in the life of organisations has taken time and hard work. This would never have occurred without legislation to drive the change and establish clear expectations, obligations and sanctions.

It is telling that, like all company directors in Australia, board directors and senior officers of disability organisations have legislated liability for breaches of financial, corporate and OHS regulations, but face no comparable liability or established sanctions for serious breaches in their duty of care to clients. This is what we need to fix.

We should be ashamed that we have had to rely on whistleblowers and investigative journalists to reveal the injustices done to Yooralla's clients and those in state-run homes. But unless a national system of safeguards is implemented that ensures transparency, accountability and consequence for failure across the board, an imperfect reliance on whistleblowers and the media will be all there is.

The guarantees of detailed inquiries into Yooralla and the wider disability sector are welcome, but long overdue. Now that the cover has been lifted, there are no more excuses for Yooralla or the state government.

Alan Blackwood has worked in the disability sector for more than 30 years. He is director of policy and innovation at the Young People In Nursing Homes National Alliance.

Available online at http://www.theage.com.au/comment/yooralla-failings-no-more-excuses-20141125-11t5cl.html

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