

OCTOBER 2021

VICTORIAN DISABILITY ACT REVIEW

SUBMISSION FROM THE
MELBOURNE DISABILITY INSTITUTE



Melbourne
Disability
Institute

Executive Summary

Community Visitors play a vital role in the safeguarding and protection of the rights of people with disability and are an important part of a greater eco-system which, when functioning effectively, reduces the risk of abuse, neglect, violence and exploitation.

It is important to note that not all people with disability at risk of abuse, violence, neglect or exploitation are participants in and receive support from the National Disability Insurance Scheme (NDIS). In fact, it could be argued that some of the people who are at greatest risk sit just outside the scheme. But that raises a series of issues this submission will not address. We instead will focus on the important role Community Visitors could and should play with those who receive support from the NDIS.

The review of Community Visitors schemes conducted for the Commonwealth in 2018 concluded that Community Visitors were a valuable part of the safeguarding machine for NDIS participants – and that their role should be reflected in the NDIS Quality and Safeguard Framework.

However, we would like to suggest that in the future the role of Community Visitors in Victoria should be more individualised and nuanced based on:

- the risks that people with disability experience as a result of their disability, other personal factors and the environment
- the potential contributions of Community Visitors to the prevention of abuse, violence, neglect and exploitation of people with disability who are considered at risk, and
- a balancing of risks of abuse with privacy considerations and rights.

As part of a more individualised approach, there should be an assessment of personal and environmental factors that contribute to potential risks. This assessment of risk must also take into account the dignity of risk for people with disability, and their human rights respected, protected and upheld. Given the primacy of upholding human rights, and the significant consequences of failing to assess risk accurately, this risk and assessment framework must be co-designed by people with disability and their representative organisations.

Community Visitors should have rights of access to Core Visitable Sites. This is based on the fact that many of the people who live in these settings have complex needs. Environmental factors, including the setting itself, add to potential risks.

However, in order to individualise and tailor the role of Community Visitors and to carefully balance the protections provided by Visitors with the needs to protect privacy, there should also be provision to opt-in and opt-out of visits.

Opting-out will obviously need to have very significant built-in safeguards. Who makes the decision and how to prevent coercion should be key considerations in developing a framework that allows people to opt in and out.

There will therefore need to be extensive codesign of the legislation to ensure that the role of Community Visitors under new Disability Act in Victoria is sufficiently individualised and strikes the right balance between safeguarding and privacy rights.

There will also need to be much more effective coordination and greatly improved communication between the Office of the Public Advocate and the National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguards Commission (NQSC). In the absence of effective information sharing between these agencies, it will be impossible to establish and maintain an effective Community Visitors program.

Finally, the Office of the Public Advocate (OPA) must also be adequately resourced to ensure Community Visitor program operates effectively and as intended.

In summary, the Victorian Community Visitors program is a very important protective safeguard which needs to be strengthened and individualised as part of the new Disability Act in Victoria. Given the importance of this area, and the need to ensure the protection of rights as outlined by the UN Convention of Rights of Persons with Disabilities, the details of the legislation and the implementation of the program must be co-designed with people with disability, their families, their representative organisations and other key stakeholders.

Introduction

The Melbourne Disability Institute is an interdisciplinary research institute based at the University of Melbourne. We are pleased to provide this submission in response to the Victorian Government's Consultation Paper on the Review of the Disability Act 2006.

Community Visitors play an important role in safeguarding the rights of people with disability, particularly those who live in closed settings. While they play an important role for many people with disability, in this submission we have chosen to focus on the impact of the program on participants within in the National Disability Insurance Scheme (NDIS).

We have chosen to focus in particular to focus on the NDIS because while the role Community Visitors can and do play in the lives of many NDIS participants is important, it is also complicated and so a great deal of care needs to be taken in the design to get the balance right. There are, rightly, a wide variety of housing choices available under the NDIS, often individualised to meet the particular needs of participants. There is therefore a need for a flexible and responsive program which can take account of individual circumstances and balance both protection and privacy rights.

We make a number of recommendations in this submission.

But our strongest recommendation is this - any final decisions on the way to legislate for the Community Visitors program should be the subject of extensive co-design with people with disability, their families and their representative organisations.

Given what is at stake, is absolutely vital to bring together people with disability, their families, their representative organisations, the Office of the Public Advocate (OPA), the National Disability Insurance Agency (NDIA), the NDIS Quality and Safeguards Commission (NQSC), disability service providers and to work with the Victorian Government on the final details of the new legislation, and the implementation of the Community Visitors Program.

This submission also recommends that there needs to be much more effective communication channels and coordination between the OPA and the NDIA and NQSC - and vice versa. In the absence of effective information sharing between these agencies, it will be impossible to establish and maintain an effective Community Visitors program. This will require some negotiation and agreement between the Victorian and Commonwealth Governments, given that the NDIA and NQSC are Commonwealth agencies. The OPA must also be adequately resourced to ensure an effective Community Visitor program.

A Personalised Approach to Safeguards in the NDIS

The role of Community Visitors needs to be positioned within an overall framework for protecting people with disability against abuse, violence, neglect and exploitation.

In 2012 and 2013 I was Co-chair of the Quality and Safeguards Committee of the COAG NDIS Reform Council. I co-authored a paper entitled *A Personalised Approach to Safeguards in the NDIS* - a copy of that paper is at Attachment A. It proposed a three-tier safeguarding framework consisting of:

- Developmental safeguards
- Protective safeguards
- Corrective safeguards

Developmental safeguards start with the person, their capacity and their circumstances. Most importantly they seek to strengthen all of the elements that citizens need to build good and safe lives. It uses a capitals framework and recommends building the personal, knowledge, material and social capital of NDIS participants.

Preventative safeguards are focused on service design and the development of cultures to prevent abuse and neglect. They include measures which actively address risks for individuals. Community Visitors are a good example of a protective safeguard.

Corrective safeguards offer redress and trauma support in the unfortunate event that abuse, neglect, violence or exploitation of people with disability has occurred.

It was envisaged that developmental safeguards would be identified and then built on as part of NDIS capacity building supports. Unfortunately, this has **not** occurred as part of the implementation of the NDIS. Further, the risks for some people with disability have increased through a number of factors including the introduction of unregistered providers, a lack of effective stewardship of the NDIS market, the risks of exploitation and abuse of NDIS participants with large funding packages and a striking lack of investment in informal supports and supported decision making for NDIS participants. The NDIS has not driven innovation in service design and delivery at the scale hoped for by people with disability and their families. While there are certainly pockets of innovation and change, it has not driven a reduction in the use of closed settings at a scale imagined at the time of the introduction of the NDIS. What is worse, the NDIS planning process and pricing structure has produced some perverse and unintended consequences.

In this context it is even more important that the Community Visitor program is not only maintained but strengthened and personalised as much as possible to form a crucial part of protective safeguards framework in Victoria.

There is additional value in the volunteer workforce which makes up the Victorian Community Visitors program. The volunteers are deeply embedded in local communities. This contributes to building social capital and is an important additional strength to the program which should be recognised.

These strengths were noted by the Commonwealth *Community Visitor Schemes Review* conducted in 2018. The review found that Community Visitors are a valuable part of the safeguarding machine for NDIS participants who are considered at risk, and that their critical role should be reflected in the new NDIS Quality and Safeguard Framework. At the same time the Commonwealth review noted that the power of Community Visitors to enter homes without invitation and to access all areas,

including personal files and records, could be seen to run counter to a contemporary understanding of disability equality, underpinned by the UN Convention on the Rights of Persons with Disability¹.

Principles

Against this background, it is important that a principles-based approach should be applied to setting the scope and role of Community Visitors in the future.

Prior to the introduction of the NDIS, the Disability Act allowed Community Visitors to have a mandatory right of access to visit the homes of people with disability who were living in shared supported accommodation. This included accommodation provided directly by the Victorian Government or accommodation provided by registered disability service providers but funded by the Victorian Government. The funding source, funding type and provider registration determined the scope of the role of Community Visitors. Consequently, eligibility for access to Community Visitors was derived from these criteria, rather than based on individual assessment and need.

One of the strengths of the Community Visitors program is that it provides for mandatory rights of entry. This is essential from the perspective of safeguards because unannounced visits ensure that it is not possible to organise any “cover-up” prior to a visit and allows visitors to see the genuine day-to-day operation of the residence. On the other hand, unannounced visits also represent a significant invasion of privacy of residents.

Going forward under the NDIS, it is recommended that the scope of the role of Community Visitors is operationalised in a more individualised and nuanced way based upon:

- the risks that people with disability experience as a result of their disability, personal factors and the environment
- the potential contributions of Community Visitors to the prevention of abuse, violence, neglect and exploitation of people with disability, and
- a balancing of risks of abuse with privacy considerations and rights as outlined under the UNCRPD.

The future operation of the program also needs to recognise that under the NDIS and its principles of control and choice, participants are choosing to live in many different forms of accommodation. They can also choose a wide range of support services from many sources, some of which are regulated and some of which are not. They may also be supported by workers who are not registered under the Victorian Disability Worker Exclusion Scheme.

It is an important principle that people with disability are not considered inherently vulnerable. Risk of abuse, violence, neglect or exploitation is often a combination of particular support needs and environmental factors. The nature and complexity of support needs, communication skills, and behaviours which may be a risk to the person or others sometimes place individuals at greater risk. Personal factors such as age, education and gender may also contribute. Environmental factors including strength of informal supports (including family, friends and support structures such as circles of support); whether or not the person with disability has chosen with whom they are living; compatibility of co-residents within settings; the number, quality and turnover of support staff; access to specialised supports/advice when needed; whether or not the person is subject to

¹ Department of Social Services for the Disability Reform Council, Council of Australian Governments, *Community Visitor Schemes Review* (2018)

restrictive practice orders; and, the suitability of building design and assistive technology all have an impact on the risk of abuse or neglect.

Any approach taken to the assessment of risk must therefore be a matrix and take into account all of these factors - rather than any assumptions around “inherent” vulnerability. The development of an agreed risk matrix should be an important priority and outcome from the co-design process.

The proposed approach must also recognise dignity of risk and the right of people with disability to take risks as part of ordinary life. This is something which has not been a feature of previous systems but which must be going forward. There is therefore a need for greater investment and support for supported decision making to allow people to make informed decisions about risk.

All of this suggests that the key guiding principles which should frame the role of Community Visitors is that Community Visitors should have access rights when the combination of personal and environmental factors of NDIS participants places them at greater risk and it is judged that access rights for Community Visitors could reasonably make a significant difference to protect them from unwanted risks. Finally, visitation rights by Community Visitors must respect the privacy of NDIS participants.

Core Visitable Sites

The starting point for the Community Visitors program should be “Core Visitable Sites” on the basis that many of the people who live either permanently or on a temporary basis in these forms of accommodation are at greater risk. The list of Core Visitable Sites should include:

- a) Specialist Disability Accommodation
- b) Medium Term Accommodation
- c) Short Term Accommodation
- d) Forensic Disability Services
- e) Mental health services, where NDIS participants are resident
- f) Supported Residential Services, where NDIS participants are resident
- g) Boarding houses, where NDIS participants are resident.

In addition, any adult affected by a restrictive practice order should be automatically included under the Community Visitor program irrespective of where they are living².

The recommendation that Medium Term Accommodation, Short Term Accommodation, Supported Residential Services and Boarding houses should be Core Visitable Sites recognises the significant risk that environmental factors in these settings can make them unsafe for people with disability. For example, this could be due to compatibility issues between residents, poor building design or insufficient or insufficiently trained staff or all of these factors. In addition, the ability of self-

² This will require significant consultation and co-design in relation to adults still residing in their family home, including to avoid unintended consequences.

managed or plan managed NDIS participants to choose unregistered providers means some of the standards expected as part of registration may not be present in all of these settings.

Regrettably, there is another still significant setting where many vulnerable NDIS reside and that is residential aged care facilities. There should therefore be a discussion with this group and their principal representative organisation, Young People in Nursing Homes, to determine whether these settings should also be in scope for Community Visitors or whether the aged care safeguards are adequate³.

Individualisation through Opt-in and Opt-out provisions

In order to individualise and tailor the role of Community Visitors and, especially, balance the protections provided by Community Visitors with the needs for privacy, there should be provision to opt in and out of visits.

Opting-in should be available to any NDIS participant. It will therefore be important to make sure that information about the Community Visitors program is available to NDIS participants and that the information is both sufficient and accessible so an informed choice can be made.

One of the groups who may consider opting in are people with intellectual disability. Prior to the NDIS, people with an intellectual disability who moved out of the family home were most likely to move into a shared supported accommodation, or group homes. These settings were included in the Community Visitors scheme.

In the future, people with an intellectual disability are likely to live in a wide range of places, including in private homes or rental properties. However, it would clearly be inappropriate to start from a position in private homes or rental properties are regarded as a Core Viable Sites. Therefore, an opt in model, and using a matrix which considered the full range of risk factors for any particular individual, would be more appropriate. This would allow identification of individuals who have risk factors concern, not simply individuals who are looking to make a community connection.

There would also need to be careful consideration of operational factors to ensure sufficient community visitors are available as part of the proposed opt-in arrangements.

Opting out is a more complicated proposition and will need to have very significant safeguards built in. The key issue will be who makes this decision and ensuring that the person has not been pressured into opting out and therefore at risk of neglect, abuse or exploitation. For example, if a person chooses to opt out, it will be important to have confidence that they fully understand the implications of their decision.

There is also an important distinction between group homes and share houses, where individuals who have known each other for a long period of time choose to live together in accommodation which is registered for SDA and where there are strong informal supports. Those people living in share houses may also wish to exercise their rights and opt out of the Community Visitor program. Similarly, NDIS participants choosing Individualised Living Options may also choose to opt-out, in situations which are stable and where the live-in support person has been known for many years.

However, it is very notable that in many cases in which NDIS participants employ disability support workers who are employed by organisations which are not registered NDIS Service Providers or who are not registered and so are not subject to the Victorian Disability Worker Exclusion Scheme, the

³ See Co-design section below.

NDIS participants are requiring their support workers to register with the Victorian Disability Worker Exclusion Scheme.

Again, opting in or out, particularly for people with an intellectual disability, should also allow for the provision of decision-making support to allow people the opportunity to make an informed decision.

Given the consequences, the circumstances in which people would be able to opt in or out must be the subject of careful and considered co-design with people with disability, their families and their representative organisations.

Co-design

There will need to be extensive codesign of the legislation to ensure that the role of Community Visitors under new Disability Act in Victoria is sufficiently individualised and strikes the right balance between safeguarding and privacy rights. This is especially complicated by the myriad of living arrangements that have begun to emerge and are likely to continue to flourish under the NDIS.

The co-design process should be extensive and bring together people with disability, their families, their representative organisations, the Office of the Public Advocate (OPA), National Disability Insurance Agency (NDIA), NDIS Quality and Safeguards Commission (NQSC), disability service providers and local area coordinators to advise the Victorian Government on the final details of the new legislation.

The aspects of the legislation which are likely to require particularly close co-design are the definition of a Core Visitable Site and the conditions for people with disability to either opt in or out, so that vulnerable people who would benefit from community visits are not excluded by service providers or individuals in their life who are not acting in their best interests.

The co-designing should also reach agreement on who would be responsible for any decision to either opt in or out. It should also include provision for more decision-making support to ensure people have the appropriate support to make their own decision.

Another important consideration as part of the co-design process is arrangements in the event that a person living in, for example, a group home chooses to opt-out. In that situation, it would seem appropriate that visitation rights of other residents should be retained but that the individual's file should not be reviewable by the Community Visitor and that Community Visitors could not enter the bedroom of any person who has opted out.

Effective Coordination of Safeguards with the NDIA and NQSC

For Community Visitors to effectively fulfil their roles it will be essential to have effective communication channels and coordination between the OPA and the NDIA and the NQSC - and vice versa. There are a number of considerations:

1. The OPA will be reliant on information from the NDIA, through the registration of dwellings for SDA, and its Local Area Coordination Community Partners to be informed about the living arrangements for NDIS participants.
2. The OPA will be reliant on information from the NQSC in relation to restrictive practices.
3. In order to give practical effect to the recommended opt in and opt out provisions to individualise the Community Visitor program, there will need to be protocols and key questions introduced into the NDIS planning process.

4. There must be much more effective information sharing between the OPA and the NDIA and the NQSC.

In July 2021 the Public Advocate made a very important submission to the Senate Committee Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Amendment (Improving Supports for At Risk Participants) Bill 2021. A copy of this submission is at Attachment B.

In this submission, the Public Advocate, Dr Colleen Pearce, states:


“The death of Ms Smith was a tragedy, and one that I feel will repeat itself with the current barriers that exist to information sharing which hinder the ability of my office to undertake its legislated safeguarding role...”

The NDIA and commission [NQSC] provisions need to change and ensure that there can be exchanges of information to facilitate follow-up of participants and their circumstances to ensure that beneficial outcomes have resulted.”

OPA Resourcing

The OPA should be sufficiently resourced for its Community Visitors to be able to visit all eligible NDIS participants. Given that the number of NDIS participants eligible for Specialist Disability Accommodation is expected to double and settings will have fewer residents than historically, there is likely to be a need for very significant increases in the number of Community Visitors.

Current and future Community Visitors will need to be trained and coordinated. There should be sufficient OPA paid staff available to become directly involved in advising on and resolving the more complex situations which Community Visitors may discover from time to time.



Professor Bruce Bonyhady AM
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Melbourne Disability Institute

29 October 2021

A Personalised Approach to Safeguards in the NDIS

Executive Summary

This discussion paper is the result of work led by the Safeguards and Quality Assurance Expert Group as part of the NDIS implementation groups.

It draws together current thinking around capital building for all citizens and empowering safeguarding in the context of the emerging NDIS.

The paper offers an outline of a Safeguarding Framework that enables citizens to be safe, well and included. The Framework is person centred and starts from the premise of building citizens capital through developmental investments. The approach is fundamentally steeped in the notion of citizens having an active role in safeguarding themselves.

Key Findings

Citizen Capital is the foundation of understanding people, their resources and their context and is a valuable way to develop a good plan that incorporates effective safeguards.

The assessment process and determining reasonable and necessary supports should have a focus on and preference for developmental investments. Investing in citizens and families to further develop the notion of capital and developmental investments, will also lead to people having higher expectations of the planning and supports they receive.

Further exploration is needed to develop ways in which the broad range of potential providers can be encouraged and incentivised to offer high quality, inclusive products and services.

The proposed framework seeks to acknowledge the individuals assessment of their own vulnerability and build on their capital and encourage expectations for high quality supports.

This paper provides a new conceptual framework and opportunity to develop new thinking and behaviours from the start of the NDIS.

Marita Walker, Kate Fulton and Bruce Bonyhady

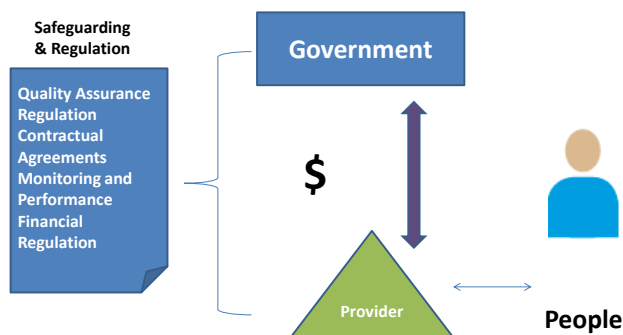
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Context

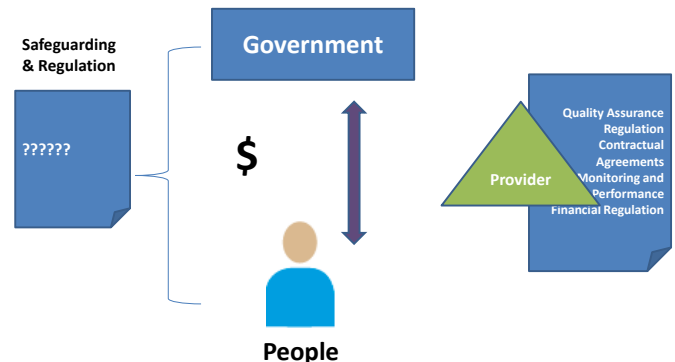
As the development of the NDIS progresses, resources, decision making and accountability will sit closer to people and their families, more so than ever before. The need for a balanced, proportionate safeguarding process is being explored to offer clarity, protection and safety to people, families and workers. The current Safeguarding mechanisms and regulatory frameworks in place across Australia, are largely focused on the relationship between the Government and the Support Organisations. As part of this, governments in the past have set quality standards and other requirements as part of their service funding agreements with Support Organisations and which have been applied at the service provider and service levels.

This primary relationship between the Government and the Support Organisations is currently supported by a developed regulatory framework and has recently been extended through the National Quality Framework. However as the NDIS develops, the primary relationship will change focus to that between the Government and the Person and their families.

Current Relationship – Government and Support Organisation



New Relationship – Government and People / Families



The changing nature of this relationship requires a radical re think in the way that all mechanisms designed to support people's safety and wellbeing will operate. Whatever is designed needs to be mindful and helpful to both relationships with people and Support Organisations– which may require different elements.

Safeguarding is more than child and adult protection, its primary function is concerned with the promotion of the welfare of the person - supporting them to have a good quality of life, to be an active and equal citizen, to reach their potential AND to promote their safety.

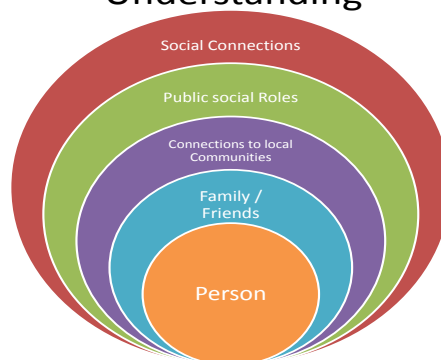
Questions

Is it possible to design a framework whose primary aim is to promote people's **wellbeing** and safety and maximise their opportunity to have a good life? Is it possible to capture the learning to date from people, families and workers and give some indication of what helps to keep all citizens safe, including a mixture of local informal supports such as family, friends, neighbours, community connections and formal Statutory Supports such as regulation, police checks and registers? What other processes are in place in today's society that promote wellbeing balancing informal and formal supports? Is it possible to develop a Framework that benefits all citizens not just those identified as vulnerable? What should be the potential national role of mechanisms that exist in some jurisdictions but not others, (e.g. Care Concerns Units and Community Visitor Programs), under a NDIS?

Potential Framework

This paper explores the potential design of a safeguarding framework that starts with the person, their capacity, their circumstances and crucially the elements that all citizens need to have in place to build good and safe lives. If we began from this position, could we work alongside people and families to explore their personal resources, identifying strengths and gaps and then best use public resources and safeguarding supports to fill and develop the gaps for each person within their own local communities and resources? We would like to use a frame of reference that refers to all citizens.

Potential Starting point for Understanding



The Fact Sheet on Safeguards for the NDIS outlines initial thinking. The inter-governmental agreements which govern launch sites, specify that the quality and safeguarding framework should be based on current regulations and requirements in each jurisdiction. This reflects the

practical reality that there is not time before 1 July to develop a new framework and ensure that service providers are ready for it.

This underlies that there is still a lot of thinking and work to be done. There is also the potential to influence outcomes during launch through the emerging values and behaviours of the National Disability Insurance Agency and amongst service providers.

The challenge is to focus on the individual, first, starting with the fact that they are citizens and understanding the range of factors that may increase their vulnerability.

An early question is, ‘vulnerable to what?’ In this context, it is the entire spectrum from death or serious personal harm to sub optimum or ineffective formal supports that reduce achievement of desired outcomes.

Participants in the NDIS will also potentially be vulnerable to not receiving the package of supports they need. Those who are most vulnerable to this are also likely to be vulnerable to other risks too. However, the vulnerability to not receiving “reasonable and necessary” benefits is not the subject of this paper, as it is better addressed as part of eligibility and assessment.

One of the principles in the NDIS Fact Sheet states that safeguards should be “risk based and person centred”. The parameters on which risk may vary are much more complex than those listed i.e. “functional capacity, natural support and services available”. There are a whole host of potential factors that are likely to impact on increased vulnerability which we have begun to explore. For each of the factors there is a spectrum of risk from low to high. An example of the extremes of the possible combinations is described below.

Risk Low	Risk High
<p>Eg: Adult</p> <p>Good communication & self advocacy skills. Not requiring intimate personal care. High socio-economic standing.</p> <p>Multiple relationships – family, friends, community who are close by and possess system advocacy skills.</p> <p>Living in a supportive and involved neighbourhood and community</p>	<p>Eg: Adult</p> <p>Reduced cognitive capacity. Use behaviours to communicate.</p> <p>Poor communication and social skills, vulnerable to suggestion and exploitation.</p> <p>Family not involved. No close friends.</p> <p>Homeless or living in housing with potential exposure to people who are likely to exploit.</p>

The presence of formal services cannot of itself be seen as a safeguard because as we can see above, the presence of a service does not simply eradicate the range of risks.

Quality assurance of government funded disability services has been a main focus of our current system. The capacity to maintain an effective quality assurance system in an environment where there is no direct relationship between government and the providers, has been a focus of discussion to date. However this should not be seen as the only, or main way to ensure adequate safeguards for individuals.

A better starting point would be to begin with the individual and explore how it might be possible to reduce their vulnerabilities in one or more of the areas where they are vulnerable. Then explore what could be put in place within the context of an NDIS and current safeguarding mechanisms.

Michael Kendrick's¹ approach of developmental, preventative and corrective approaches would be a useful starting point in this regard.

A framework that builds and invest in citizen's capital

Working from a strength and asset based approach a helpful and universal economic term and analogy to understand resources is that of citizen's capital as explored by Roland & Landua 2011² and Duffy & Murray 2010³. We understand that all citizens have capital in all aspects of their lives. How much capital and what investment is needed is different for everyone, depending upon their social and economic lifestyle and circumstances. Our starting point to explore capital in this context is the categories of the four areas of capital developed by Robbi Williams 2013⁴. As the authors of this paper we expand upon this initial work to describe the four categories of capital and examine the implications for safeguarding vulnerable citizens.

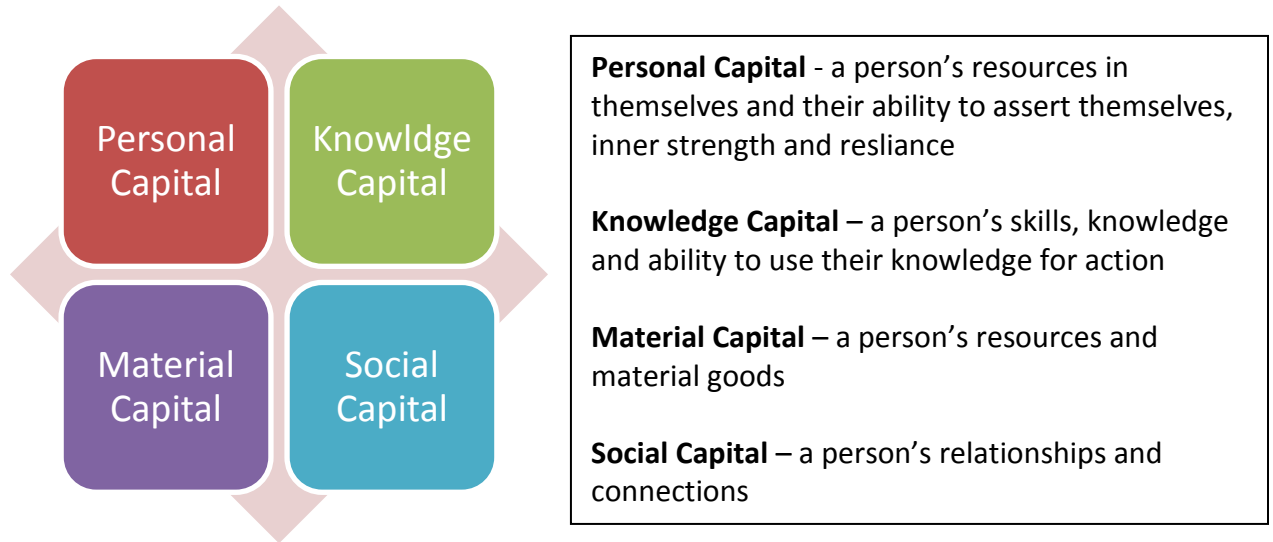
¹ Kendrick 2005 Self Direction in Services and The Emerging Safeguarding and Advocacy Challenges that may Arise.

² Roland and Landua, 2011, <http://appleseedpermaculture.com/8-forms-of-capital/>

³ Duffy & Murray, The Centre for Welfare Reform, 2010.

⁴ Williams, Purple Orange, Personal Communication 7.2.13

The aspects of Capital for all Citizens are:



These various aspects of capital are one way of seeing and understanding the range of resources that all citizens need in their lives to enable them to live safely and well, in their local communities. It helps to think about resources in a way that best reflects real lives for all citizens – resources that are way beyond purely monetary and material resources.

Although not exhaustive they may include:

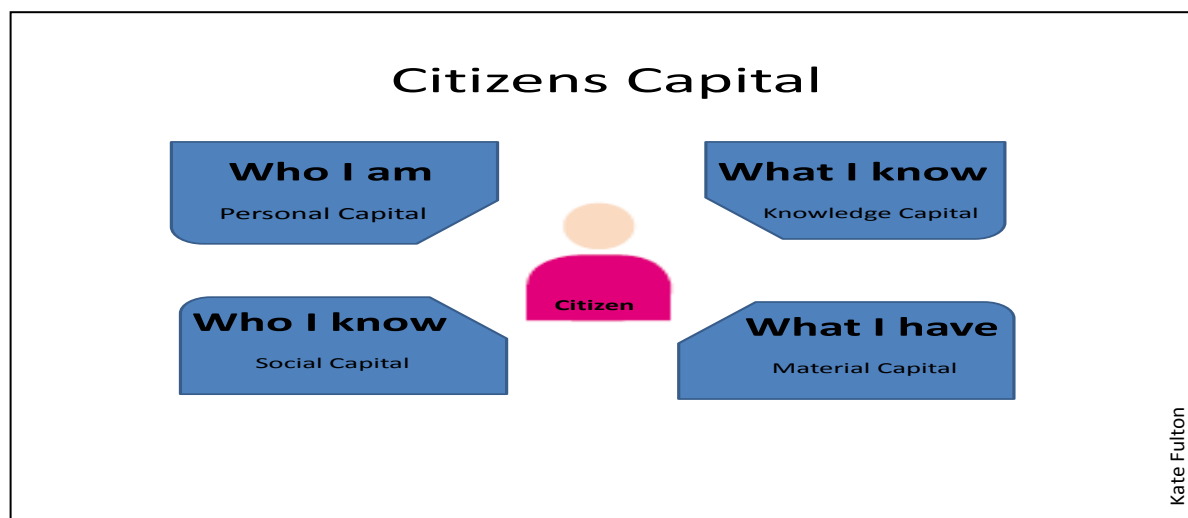
Personal Capital including self-esteem, confidence, cognitive and intuitive capacity, ability to self-advocate and be present and their inner strength and resilience

Knowledge Capital including skills, and general / specialist knowledge and the ability to access information from people, the internet and the community and to act on this information

Social Capital including relationships, family support, friends and community connections.

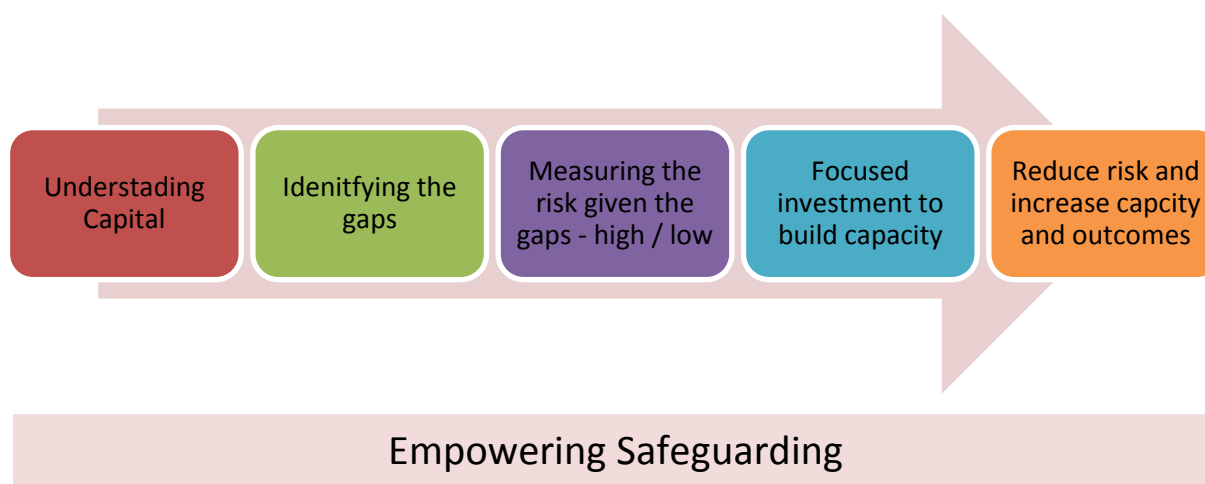
Material Capital including income, material goods, own home and community resources e.g. library, beaches, parks, which vary depending on location.

This perspective of capacity makes it possible to learn what it takes for all citizens to live well and have safe lives. Viewing resources and wealth in this way enables people and families themselves to measure their own wealth and resources, for example a person can be materially poor and relationship wealthy.



The measurement of capital across all domains is challenging, but we are keen to explore the possibilities of determining a base line of capital that all citizens require to be well and safe. The majority of citizens will have a range of resources in each area of their capital.

This base line measure would enable **all citizens** to determine themselves via a self or shared assessment / wellbeing check where there may be gaps in their own capital resources and to consider what risks this may present to the person and their life. The level of risk associated with gaps in their own capital, will then enable them to consider the right investment to build and boost their capital in the immediate and long term. The aim with any investment is to increase areas of capital to ensure any investment is an activity that promotes growth of capital and prevents erosion of capital and that supports the person to be included and protected.



What could a measure look like?

One way of exploring capital is to provide an easy to use and robust measure in each area of capital - making it relatively simple for people, families and workers to explore.

The following provides a simple measure of capital in each area of people's lives – providing simple statements that the person and their family can relate to and determine which statement best represents their own life and circumstances.

The following is an example for Personal Capital

Level of capital	Levels of Personal Capital
Significant capital	Ability to be assertive, strong identity, ability to make decisions, confident in self-determination , control over physical environment
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction including wishes and needs
Low capital	Little personal capacity in making major decisions, limited communication, limited autonomy over physical space and limited ability to create direction

In using this simple measure we can explore all areas of capital across each of the four domains. The colours provide an easy and accessible measurement using a traffic light rating.

Understanding those most at risk

Level of capital	Level of Personal Capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination, autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person including family, friends, strong community presence and participation	Financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person's lifestyle. Limited access to info and can act on this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction in wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.
Low capital	Little personal capacity in making major decisions, limited communication, limited autonomy over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt

This potential measure needs to capture all four domains of capital helping to easily identify and understand those people most at risk. This requires all four areas being considered in a person's life.

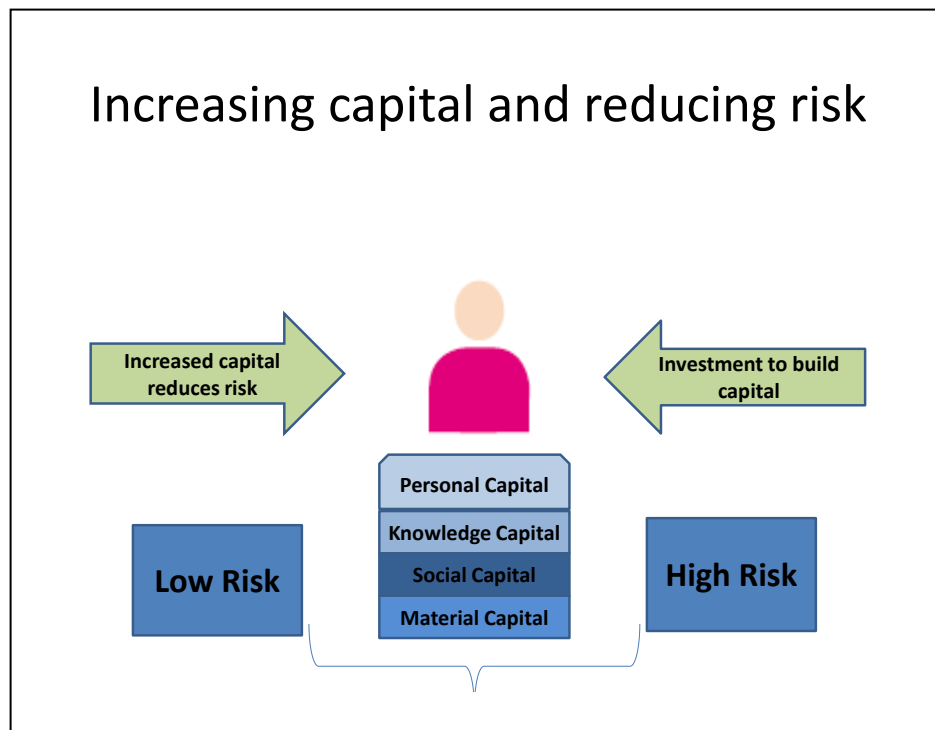
Across all areas there is some level of risk for all citizens; however measures enable us to consider given the person's capital, whether the risk low or high. Therefore we can add alongside the measure of capital an easy to use measure of risk;

- the more capital a person has, the lower the risk
- the less capital a person has, the higher the risk

Level of capital	Level of Personal capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital	Risk
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination , autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person inc family, friends, strong community presence and participation	I am financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.	Low risk
Reasonabl e capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person’s lifestyle. Limited access to info and can act of this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.	
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction inc wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.	
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt, living in a community with limited resources	
High Risk					

Minimising risk with developmental investments

This potential framework acknowledges the fact that for all citizens reduced capital increases risk and the sensible role for a safeguarding framework is to provide investment that builds capital in the short term as well as importantly, building capital for long term benefit. The framework would be based on current thinking in building all citizens capital for a good and safe life.



Developmental investments are investments that aim to grow areas of a person's capital, not simply adding a short term immediate solution, but developing and growing the person's capital and are proportionate to the risk posed.

Kendrick (2005)⁵ describes Developmental Safeguards as safeguards which aim to produce socially desirable conditions for the inclusion and protection of people with a disability, supporting their valued status in community and developing supports through family and intentional relationship building.

Examples of Developmental Investments may include things such as a peer supporter; someone who can provide an immediate connection but who can also connect the person to other locals based on shared interest and support the person to increase their social capital over time. Another example of a Developmental Investment is education, investing in a person's low knowledge capital enables the person to secure employment leading to the potential increase in both knowledge capital, social capital and material capital.

Developmental Investments are critical in any safeguarding framework and in any service delivery, to ensure the framework provides longevity and is investing in people to grow.

⁵ Ibid

The following provides an overview of how the kind of Developmental Investments may be used to support people in each domain whose capital is low and who are at potential high risk. The list is not exhaustive but provides an insight into typical developmental investments.

The right hand column shows some of the kinds of Developmental Investments that are likely to support a developmental approach and areas in italics depict areas that the NDIA are likely to influence and promote.

Level of capital	Level of Personal capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital	Risk	Developmental Investments to increase Capital and have a Safeguarding effect
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination , autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person inc family, friends, strong community presence and participation	I am financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.	Low risk	Self-directed support
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person’s lifestyle. Limited access to info and can act of this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.		Individualised funding
						Service models and approaches that support individualised supports
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction inc wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.		Individual & Family capacity building
						Organisational Capacity building to promote and encourage strategies that increase investment in capital
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt	Outcome Based Monitoring – that increases capital via Review - Reflection and refinement of the plan / outcomes	
High Risk						
Development Investments That develop each domain of capital	Investment to speak up for yourself, Lifelong learning and development Communication, Environmental controls, Assistance to control environment, Nominee for Supported Decision Making, Advocacy, Family Leadership, Family Investment	Initiating social contact, opportunities for leadership, the opportunity to speak for others, Family Advocacy Education, Access to info and IT	Lifelong learning and development, carer development Assistance to build circles of support, build community relationships support to develop friendships,, , Peer Support, assistance to achieve diverse experiences	Investment support, Disability Trust, Shared Housing Employment Support,		

* (inconsistent across jurisdictions / Italics – NDIA Role

Preventative and Corrective Safeguards

Alongside developmental investments we need to acknowledge the preventative and corrective safeguards that are currently in place that protect all citizens including those deemed as vulnerable and will be an integral part of any safeguarding framework that aims to enable the NDIS. Preventative and corrective safeguards work alongside developmental investments. Kendrick 2005⁶ describes them as follows:

- Preventative safeguard: which is focused on service design and cultures to prevent abuse and neglect and actively address risks for individuals
- Corrective safeguards: which offer redress and trauma support after incidents occur

The graph demonstrates the kind of preventive and corrective safeguards that are typically used as a response to low capital in each area. The right hand column depicts the typical safeguards open to all citizens.

However it is important to note and further explore that for many people who are low in capital across all or many of the areas, their ability to fully access and utilise the preventative and corrective safeguards can be very reliant upon their current support strategy. An example may include a person with an intellectual disability who has been a victim of abuse who requires support and assistance to report the crime, to be understood, to benefit from criminal legal advice and to fully utilise the court system. We know that many people do not always gain access to these safeguards in the same way the majority of citizens do.

⁶ Ibid.

Level of capital	Level of Personal capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital	Risk	Developmental Investments to increase Capital and have a Safeguarding effect	Preventative Safeguards	Corrective Safeguards
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination , autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person inc family, friends, strong community presence and participation	I am financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.	Low risk	Self-directed support	Restrictive Practice Legislation & Guidelines * Community Visitor Schemes * Care Concerns Units Police Checks Acquittal Procedures Registration of Specialist Disability Providers - Developmental not compliance Based on National Disability Standards AND Accountability for individual outcomes that increase capital Outcome Based Monitoring – that increases capital via Review - Reflection and refinement of the plan / outcomes Independent Individual Advocacy / Systemic	Ombudsman *
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person's lifestyle. Limited access to info and can act of this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.		Individualised funding		Consumer Law
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction inc wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.		Service models and approaches that support individualised supports		Complaints Procedure*
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt		Individual & Family capacity building		Police Courts – Legal Litigation Child Protection
High Risk								HADSCO / Disability Commissioners * Antidiscrimination Laws

Dev Investments That develop each domain of capital	Investment to speak up for yourself, Lifelong learning and development	Initiating social contact, opportunities for leadership, the opportunity to speak for others, Family Advocacy	Lifelong learning and development, carer development	Investment support, Disability Trust, Shared Housing	Advocacy Agencies	Access and Inclusion Plans	
	Communication Technology, Environmental controls, Nominee for Supported Decision Making, Advocacy, Family Leadership, Family Investment	Assistance to build circles of support, build community relationships, support to develop friendships,	Education, Access to info and IT, Peer Support, assistance to achieve diverse experiences	Employment Support,			
Preventative Safeguards	Minimal Personal Care Support	Relationships with paid staff	Information, Advice and Guidance – Buyers guide	Income Support Housing Assistance, Medicare,			
Corrective Safeguards	Guardianship* Involuntary treatment orders *	False and misleading Advertising – Corrective action	Guardianship	Legal Aid Consumer redress processes			

* (inconsistent across jurisdictions)

Italics – NDIA Role

Developmental Investments and Service Delivery

In exploring a Safeguarding Framework it inevitably raises the issue of how any investment provided by Government either directly or indirectly works to either increase the person's capital or erode it. The NDIA will undoubtedly be concerned with this element of the NDIS in exploring the kind of approaches and models that the NDIS may promote as development investments to citizens directing their own supports.

Developmental approaches are more likely to build capital while congregated and segregated services responses cannot promote or sustain individualised and flexible responses. Within institutional settings developmental approaches are even more compromised and individuals, particularly those with labels of challenging behaviour can be housed in settings that are isolated, restrictive and punitive. Some people end up in the corrective services system as a result of inadequate support. Examples of developmental approaches and models that should be actively promoted by NDIA are shown below.

- Individualised Funding
- Individualised Supports
- Emotional support and decision making
- Individual Planning and Review
- Mentoring / Coaching
- Shared Management
- Shared Living
- Social networking/ social connecting/Circle of support
- Drop-in volunteer support/ natural support
- Independent living development and support
- Peer support
- Family Leadership\
- Positive Practice Support
- Preparation for leaving home
- Community Engagement / Connection
- Recreational Support
- Educational Options / Support
- Occupational Options
- Employment preparation
- Transport Training

Developmental Investments and Assessment

The focus of assessment could be made citizen centric by starting with the four areas of capital, relative to the person and their circumstance, rather than a more traditional focus on diagnosis and function. Often this approach leads the assessment into identifying 'needs', but doesn't help identify what will make the most difference to the person, in their life and context. Assessment should acknowledge and assist people to explore the nature of the support required, whilst recognising the depth and hugely individualised solutions, that what will actually move people towards social and economic participation. By building citizen capital into the heart of assessment it can focus on enabling people to think differently and explore more diverse solutions based upon their own resources and community capacity.

Whilst acknowledging that the development of an insurance system has a need for data for actuarial purposes, there are alternatives to collect this data. The need to gather data should not drive the assessment and planning processes, but could be addressed through a formal research approach, that initially used the standardised measures. However it would be logical in the future to look at measures of increases in capital and the correlation to social and economic participation.

Recognising and starting with the person, their contribution and their capital means that assessment is really about one person at a time.

Citizens Safeguarding Themselves

A new system should be intentional in how it actually builds awareness, ability, confidence and assertiveness for all citizens to actively safeguard themselves. Initiatives to consider are:

- Explore and better understand the current approaches that exist across Australia e.g. self advocacy, leadership training for disabled people
- Identify what could be shared and replicated across states and from international experience e.g. user lead organisations,
- Identify what would benefit from being harmonised across States e.g. Community Visitors
- Intentionally develop, resource and support peer support
- Further develop, resource and support family to family mechanisms of peer support

The new system needs to start from the premise that people and families can and should be able to navigate it with ease and for some with little or no assistance. However where people require assistance, there should be a range of options that are easily accessible to all.

Quality Assurance of All Suppliers

It is highly likely there will be a quality assurance mechanism based on the National Disability Service Standards for specialist disability service providers. What shape and form a national system will take is still to be negotiated by the jurisdictions. However as we develop the NDIS there will be an expanded and more diverse range of suppliers when people choose to use their resources in different ways. This will include suppliers beyond the traditional specialist services. We need to consider an approach that recognises and acknowledges all provision that citizen may use or purchase.

The possibilities might include;

- A feedback mechanism that is based on citizens experiences and suggestions for change e.g. Shop for Support
- Intentional awareness building of government and commercial enterprises e.g. Count Me In strategy in Western Australia
- Opportunities for businesses to commit to inclusive practices that create a point of difference with some objective measure e.g. Heart Tick.
- Structured assistance by people with lived experience to be more consumer focused e.g. Quality Checkers with lived experience in the UK Health service
- A legislative framework for Disability Access Improvement Plans e.g. Western Australia

This is an area of enormous potential and can affect the success of outcomes gained by those participating in the NDIS. It is important that we consider how we shape and influence suppliers now and in the future.

Conclusion

This paper attempts to

a) pull together current thinking around both capital building for all citizens and empowering safeguarding in the context of the emerging NDIS.

b) outline the possibilities of developing a Safeguarding Framework that enables citizens to be safe, well and included. It is person centred and starts with participants to build their personal, knowledge, social and material capital through developmental investments.

The proposed framework therefore contrasts with the current Quality and Safeguards framework, which starts with the primacy of the government/provider relationship and through funding agreements, seeks to set provider and service standards, without necessarily taking account of the people's or families own capacities to assess quality or risk.

The challenge and the opportunity is to develop new thinking and behaviours from the start of the NDIS, whilst also recognising the practical reality that the inter-governmental agreements for launch specify using existing quality and safeguard frameworks.

This paper provides an alternative conceptual framework for taking up this challenge and has the potential to be developed further, within the launch of the Scheme, in at least three key areas.

First, Developmental Investments should be made part of the assessment process and determining reasonable and necessary supports.

Second, investment in citizens and families to both understand and further develop the notion of capital and to explore how the NDIS can best support people in this, ensuring the messages are consistent in raising expectations, person centred supports and in a quality assurance mechanism. To ensure we begin from the premise of citizens having an active role in safeguarding themselves.

Thirdly, further thought is worthwhile to develop ways in which the broad range of potential providers can be encouraged and incentivised to offer high quality, inclusive products and services.

The initial draft of this paper was presented to the Safeguards and Quality Assurance Expert Group and further development and refinement has been undertaken as a result of their feedback and discussion at the meeting.

Marita Walker, Kate Fulton and Bruce Bonyhady

March 2013



12 July 2021

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
community.affairs.sen@aph.gov.au

Dear Committee Secretary,

Senate Community Affairs Legislation Committee Inquiry: National Disability Insurance Scheme Amendment (Improving Supports for At Risk Participants) Bill 2021

The Office of the Public Advocate (OPA) is a Victorian statutory office, independent of government and government services that works to safeguard the rights and interests of people with disability. The Public Advocate is appointed by the Governor in Council and is answerable and accountable to the Victorian Parliament. There are similar offices in each state and territory across Australia.

A key function of the Public Advocate is to protect persons with disability from abuse, neglect and exploitation; and to undertake advocacy for persons with a disability on a systemic or individual basis.¹ To undertake these functions, I have a range of powers, including to be a guardian where appointed by the Victorian Civil and Administrative Tribunal (VCAT) and I may investigate any complaint or allegation that a person is under inappropriate guardianship, is being exploited or abused or is in need of guardianship.²

My office plays a key safeguarding role for people with cognitive impairment and mental illness in Victoria. In 2019-20, OPA was involved in 1792 guardianship matters (950 of which were new), 430 investigations, and 284 individual advocacy matters. The majority (72 per cent) of eligible guardianship clients were National Disability Insurance Scheme (NDIS) participants, compared with 58 per cent in the previous year.

Community Visitors are Governor in Council appointed volunteers who visit closed environments, including specialist disability accommodation enrolled dwellings.³ The Commonwealth *Community Visitor Schemes Review* showed that Community Visitors are a valuable part of the safeguarding regimes for NDIS participants who experience vulnerability and that they should be reflected within the NDIS Quality and Safeguarding Framework.⁴

OPA coordinates the Community Visitors Program in Victoria and I am Chair of the Combined Board. I reported on 20 May 2021 to the Joint Standing Committee on the NDIS in its recent public hearing as part of its Inquiry into the NDIS Quality and Safeguards Commission. I advised the committee that, so far this year, Community Visitors had made 41

¹ *Guardianship and Administration Act 2019* (Vic) s 15(b)–(c).

² *Ibid* s 16(1)(a), (g).

³ *Disability Act 2006* (Vic) s 30A.

⁴ Department of Social Services for the Disability Reform Council, Council of Australian Governments, *Community Visitor Schemes Review* (2018) 9.

high-risk abuse referrals to it at that time. I had only received brief feedback about some of the action to be taken by the NDIS Commission (for example, referral to the reportable incident team). My office received further advice about the action on the remaining referrals one week after the hearing. However, I still do not know the outcomes of any of those referrals.

The Bill implements certain recommendations of the independent review of the adequacy of the regulation of the supports and services provided to Ms Ann-Marie Smith.

The death of Ms Smith was a tragedy, and one that I fear will repeat itself with the current barriers that exist to information sharing which hinder the ability of my office to undertake its legislated safeguarding role. As one example, OPA's Investigations Team is often unable to obtain information directly from the National Disability Insurance Agency (NDIA) regarding a person's engagement with the NDIS, unless the information is provided by another person involved in the matter, such as a family member or the person themselves. I note, OPA has its own confidentiality provisions which apply to the disclosure or communication of information relating to the affairs of an individual under the *Guardianship and Administration Act 2019*.

I wish to make the following key points in response to this inquiry:

- The NDIA should work collaboratively with state governments and state statutory bodies with safeguarding responsibilities as this facilitates the availability of the NDIS to participants and people with disability.
- The commission should work collaboratively with state governments and statutory bodies with safeguarding responsibilities to improve the quality of services and to protect participants from abuse, neglect and exploitation.
- My office has documented numerous examples of the failure of the commission to inform areas of my office, including the Adult Protection and Advocacy Program, Disability Act Officers and the Community Visitors Program, about the outcome of issued raised with them.

The commission's failure to communicate the outcomes of complaints or high-risk abuse referrals means that where poor, inadequate or unsafe service responses resulting in harm to participants are identified, my office often is unaware of what specific actions have been taken to address the concerns. As a consequence, my office is unable to reassure vulnerable participants that risks to their safety will be addressed and that they will be safe from harm.

This fails participants, leaving them feeling frustrated, disempowered and crucially, some at further risk of serious harm. For my office, this can mean a duplication of safeguarding efforts or a reduction in safeguarding support to individuals because the matter has been referred to the commission and the belief that it may do something, sometime in the future.

- Effective sharing of information, particularly timely advice on any action that will be or has been taken, will lead to pathways out of complex situations and ensure that adequate and appropriate safeguarding measures are in place to address harm.
- The NDIA and commission provisions need to change to ensure that there can be exchanges of information that facilitate follow up of participants and their circumstances to ensure that beneficial outcomes have resulted.

I am an independent statutory officer charged with responsibility to safeguard and promote the rights of people with disability, and to protect them from abuse, neglect and exploitation. Legislative and practice barriers must be addressed to improve collaboration and information sharing between offices such as mine and the NDIA and commission, to enable each body to fulfil its broad mission and statutory responsibilities to improve lives and outcomes for people with disability.

Yours sincerely,

A handwritten signature in cursive script that reads "Colleen Pearce".

Dr Colleen Pearce
Public Advocate

