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Final report of the consultation with stakeholders for the NDIS Quality and Safeguards Commission

*Reviewing the Regulatory Recommendation 2 in the Robertson Review in
response to the Ann-Marie Smith Case*

A. Introduction

1. Purpose

The purpose of the consultation is to gauge stakeholder views on the appropriate regulatory response to the issues raised by the Ann-Marie Smith case and the subsequent independent review into the circumstances relating to Ms Smith's death by Alan Robertson SC. Ms Smith died on 6 April 2020 after having been supported by a sole carer in her own home. She had no engaged family and no strong ties with the community.

Recommendation 2 of the Robertson Review was that, to safeguard against these events happening again:

"No vulnerable NDIS participant should have a sole carer providing services in the participant's own home. The relevant statutory instruments and guidelines should be amended to provide expressly for this."

2. Stakeholder profiles

- **Australians with disability** and organisations representing them are the primary stakeholders in the regulatory arrangements in the disability sector. The quality of care, choice, and control in the arrangement of care and other life decisions, as well as the provision of safe services and care is primarily a concern of people who live with disability. As the disability movement says, 'Nothing about us without us'.
- **Friends, family, and supporters** of people with disability are important stakeholders. The consultation has considered the opportunities for parents, siblings and friends of people living with disability to participate in the discussion. This is a numerous but more nebulous group of stakeholders. Several of our participants are in this stakeholder category while also having a role in another capacity, such as service provider or advocate.
- **Advocates** in the disability sector – particularly those who work for advocacy organisations and senior advocates – are visible and engaged with stakeholder participation. The consultants engaged with a significant number of advocates. Advocates are engaged in several ways with disability clients, but the preservation and advancement of the human and civil rights of Australians with disability is their primary stakeholder role.
- **Service providers** have an interest as stakeholders in regulatory arrangements from at least two perspectives: securing the safety of their own clients and people living with disability in

general; and the regulatory decisions that affect the management of their operations and personnel.

- **Academics** in disability-related disciplines have at least three levels of stakeholder interest. First, direct professional practice is affected by regulation. Second, most academics with an interest in disability are concerned with how regulation affects the social construct of disability. Like advocates, academic researchers are often concerned with the rights of people living with disability. Third, they have a humanistic concern with evidence-based improvement in supports for people living with disability.
- **The community** interest is served in an overall sense by having a safe and high-quality disability support sector. It has also been suggested that community engagement with safety issues in disability are part of an overall opportunity to reduce risk for clients.
- **Public interest** – there is a clear public interest when a fatality such as Ann-Marie Smith’s is reported. Such fatalities mean every aspect of practice must be considered.

B. Identification of stakeholders

The consultation undertook to organise discussions with all the major advocacy groups at a national level. Some preference was given to those organisations most likely to represent or have members in similar circumstances to those of Ann-Marie Smith. In addition, as set out above, we identified key persons from each of the other identified stakeholder categories.

It was a priority for the consultants and the NDIS Commission that a significant number of the participants in the review are people who live with disability.

Several additional stakeholders from the academic and industrial sectors were included. To ensure a comprehensive perspective, several service provider CEOs – whose organisations have diverse models of care and staff management – were approached and participated in the consultation.

In addition, the consultants exercised some discretion (with agreement of the NDIS Commission) to include in the discussion some individuals with knowledge of the NDIS and the policy considerations around its development.

A list of stakeholders interviewed is at [Annexure A](#).

C. Method of consultation

All stakeholders were contacted first by email from the NDIS Commission’s Registrar, Ms Samantha Taylor. The consultant then emailed or phoned each contact. (For a small number of stakeholders there was no known phone number.)

Each stakeholder was given the option of a Zoom interview or an in-person interview. All stakeholders chose to be interviewed by Zoom. Each stakeholder was sent the notification of their Zoom appointment and a copy of the Robertson Review.

Each appointment was between 30 and 40 minutes in duration.

At the beginning of the interview, the stimulus questions were asked as a sequential introduction and the consultants then asked the stakeholder to respond with their views. They were also invited to put forward any broader views that might arise from the circumstances of the case.

In some cases, the stakeholder was asked further questions to clarify issues, or to seek responses on areas directly relevant to them.

If stakeholders wished to provide any further material, they were invited to do so by email after the consultation.

D. Themes and views of stakeholders

Direct speech from stakeholders is shown in italics. Points of particular interest within the direct speech are in bold italics.

The observations and recommendations are divided into those directly relevant to the Robertson Review's recommendation 2, and other observations made in the context of this project.

Themes relevant to the Robertson Review recommendations.

1. Stakeholders prefer the language of risk to the concept of vulnerability.

Two long-time disability campaigners and advocates who live with disability and are NDIS participants had this to say about vulnerability:

"The term 'vulnerable' should not be used, but 'at risk' is preferable. For example, at greater or higher risk."

Another experienced advocate added:

"Vulnerable? At risk is preferable terminology".

A person with lived experience of disability said:

"Vulnerable people is a term used in legislation to refer to disabled and elderly people. People who are disabled and not inherently vulnerable."

Another senior advocate said:

"The word vulnerable does have some difficulties as it can fall foul of the international treaty on the rights of people with disabilities.

We need to understand that some participants may need more support than others but that is a question of risk mitigation, not an inherent fault in the person."

An advocate said:

"There is no problem with using the term vulnerable. It is OK to identify a group as vulnerable, but we would not refer to an individual this way."

One stakeholder with extensive experience in advocacy and campaigning as well as living with disability clearly stated:

"At risk does not mean vulnerable."

A specialist advocate said:

"In autism we tend to use the terminology of complex support needs rather than vulnerable or at risk. We don't use and are opposed to high and lower functioning as a terminology."

2. Regulation and reduction of risk by supervision

Stakeholders were overwhelmingly of the view that the circumstances and direction outlined by the Commissioner's condition in response to recommendation 2 of the Robertson Review is appropriate.

Several stakeholders expressed this in different ways:

“Persons living alone should not have a sole support worker and, if so, they should be an overseer who visits regulated checks on participants.”

“No NDIS participant cared in their own home should be cared for by one worker and, if so, a person should be taking responsibility in their plan.”

“A provider has to have some contact with a client other than the direct service provider on a regular basis. Probably at a minimum every three months.”

“Some service providers were irritated by the Commission's response, but I do not think that the response was unreasonable.”

“Having only one person as a carer can have issues of increased risk.”

A representative of a disability sector union said:

“This is a sensible recommendation [a second carer]. The recommendation deals with malice, but it does not deal with the failure of the structure where home care workers are doing the work of disability support workers.”

The CEO of a peak body emphasised that safety is more important than any other factor in the scheme:

“If we take a step back, it is not advisable to ever have one person solely caring for a participant for safety reasons as well as for socialisation in any circumstances. Choice and control should be fettered to preserve the safety of the participant.”

An advocate had the view:

“The natural safeguards in a family is a line of sight between family members and the carers looking after the person with disability. What happens when there is no natural safeguards? Then oversight is critical. A person should be able to choose to have one worker, but then oversight becomes important.”

A CEO of a peak body stated:

“There is an important role to play for regulation as a means of regulating and protecting the participant. We ensure that if there is no family, there is not a person to support decision making and there is no guardianship order, that particular care is taken to check on that client.”

An academic with a focus on disability policy focused on the need for regulation:

“Internationally, self-regulation is shown to be unsatisfactory. You need a system that gives one process of organisational checking, safety, and quality. Does registration of service providers provide a check on quality and the actual outcomes?”

One leader of an advocacy service said:

“The issue is balancing choice and risk.”

A peak body CEO looked forward:

“There is a great interest in the future for large players from overseas coming into the market and the regulatory framework has to be resilient enough to deal with this when it happens.”

Another service provider CEO made it clear that the NDIS Commission's actions had been embraced and extended by their organisation:

“We are a service provider. Where a person is in their own home and does not have more than one carer, supervision is supported. But it is preferable if a person chooses one carer that they are on the register as being at risk.”

We have put in place a procedure, a more senior person, a line manager, who goes and checks on that participant about every month or every quarter. This is then checked by an audit about once a year.

We have been undertaking this supervision since Ann-Marie Smith's passing."

A service provider outlined a particular response to the Ann-Marie Smith case:

"There is a natural safeguard of choice and control. The participant/client has the right not to choose to continue in a higher risk or to continue a relationship that does not work.

After the Ann-Marie Smith incident. We carried out the following actions. We developed a profile of all participants which sets out their needs and we examine them and looked at these factors.

When the Commission imposed conditions, we then continued to extract this information and identify them. We included risk management' feedback at the end of each shift for the client.

As a provider, I would also designate more than one worker. This is good practice in case of illness or holidays. One can balance each other off if there are two carers. There should be a focus on choice and control, but the participant needs to be aware of the risk."

An officer in a service provider with lived experience of disability supported this position:

"A registered provider should ensure the support worker is doing a good job and I support the provider sending out a coordinator to see the service being provided is satisfactory."

An officer in another peak body had a contrary view:

"We are so focused on eliminating risk that we quickly move to regulatory responses without thinking about the consequences."

As did a person with lived experience of disability:

"A strong response is not always so relevant, with such a response sometimes being over response."

Another advocate who lives with disability went further about independent quality checks:

"People with disability must be allowed to take on risk if they want to. It is a balance between that right and keeping people safe. The dignity of risk is important. Not all risk can be managed."

One stakeholder thought the requirements should be clarified:

"The prohibition on one worker needs to be defined. Does it mean one person at the same time or does it mean at different times."

Some stakeholders commented on some practical barriers:

"It may not be possible to have more than one worker when they only have a carer for a few hours a week."

There was a general view that participants with only one worker was not common. As one person with lived experience of disability said:

"Having a single support worker seems to be very rare."

This view was shared by a service provider:

“We had potentially 500 people in the group of concern, but by examination we have determined that at this point only a small percentage of our clients (are in this group).”

One stakeholder thought the response should be more nuanced:

“The registration requirement put in place in response to the Ann-Marie Smith case is naive as it does not take into account different levels of participants and also does not take into account people who are self-managed and don't have a provider.”

The CEO of provider argued strongly for choice and control (as opposed to regulation) – in particular, emphasising that people with disability are not inherently vulnerable:

“We have some clients who only have one worker when we received a letter from the Commission about the requirement to have a supervisor. But this is no longer the case as we have no clients with one worker as circumstances had changed.

We nonetheless wanted to deal with this issue. What safeguards should be put in place? We do ring up once a month and visit once every three months, all our clients, but particularly those who live in their own home.”

A stakeholder advocate pointed to the relationship between the nature of risk and risk mitigation:

“The use of contract carers is an issue. Maybe there should be a requirement for a registration certificate or blue card for support workers. Possibly workers providing personal care there should have a minimum requirement of a certificate 3.

The key to a good quality organisation is that they adjust when there is a small problem.”

Another said:

“This incident reflects a failure in the NDIS ecology and the handover from the state to the federal NDIS. Originally the NDIS was meant to be 3 tiers. If the original architecture of the scheme were in place the risk of an Ann-Marie Smith incident would be theoretical zero.”

One stakeholder suggested another method of monitoring risk:

“Engagement is more important than registration. There should be a red flag if the invoices are identical week after week, month after month.”

3. There should be separate overview of at-risk participants, preferably not by the service provider employing the frontline Disability Support Worker.

This is a view expressed by one stakeholder:

“It is essential to have a second person to do a secondary check.”

But not who that second person doing the overview should be:

“Not only people designated vulnerable, but all NDIS participants living alone should have a person designated to ensure that they are OK. The person who is designated should not be a support coordinator”.

Service providers were divided on the issue as to whether the person taking responsibility for the at-risk participant's safety should be an employee of the same service provider or from an independent body:

“A registered provider should ensure the support worker is doing a good job and I support the provider sending out a coordinator to see the service being provided is satisfactory.”

“A provider must have some contact with a client other than the direct service provider on a regular basis. Probably at a minimum every three months.”

A CEO of a service provider living with disability said:

“I think it would be overkill to have someone external to the organisation overseeing the direct service provider worker.”

A service provider suggested:

“We think the rule should not be so prescriptive, but we should be directed to deal with risk and then advise the Commission how it is being managed.”

Other stakeholders thought supervision should not be done by the same service provider.

An advocate suggested:

“But who should be doing this oversight? I don't think it's sufficient that providers should provide oversight for themselves. This is tantamount to self-regulation. An independent check is probably better than someone who is part of the same service provider.”

A senior policy contributor said:

“I do not think it is good enough to just have a check internally from someone in the same service provider.”

“The persons appointed to take responsibility for the safety and quality of support to a participant should not be the primary service provider as there is a conflict of interest.”

Many service providers have already put in place supervision of clients prior to the introduction of a compulsory supervision.

A not for profit provider said:

“We have put in place a procedure, a more senior person, a line manager, who goes and checks on that participant about every month or every quarter depending on the level of risk. This is then checked by an audit about once a year.”

Should the person doing the overview be private or external?

Supervision of the support worker should not be done by the local area coordinator. I prefer community visitors, which exists in Victoria.

A service provider CEO said:

“The independent person should not be from the NDIA but can be organisations such as those who do case management or independents.”

The general view was that there was presently no immediate practical alternative to the supervisory role being carried out by a person from the service provider.

Most stakeholders thought that it was more practical and workable to have a line manager overseeing the quality of care with possible auditing by the NDIS Commission or the National Disability Insurance Agency (NDIA or ‘agency’).

One well-respected stakeholder who lives with disability thought information was necessary to manage the issue:

“Data is required on (participants) who is living in their home and the different types of disability. This should be collected by the agency.”

4. The overview of participant’s welfare should be done in person not by telephone or email.

Most stakeholders thought the overview should be in person and at the participant's home:

An advocate said:

“You also can't really get their circumstances unless you have an in-person on-site meeting. Even Zoom is not sufficient. It is much better in person. You have to be there to see how they interact with the worker. Even how the door is opened is informative. The oversight has to be proactive, not based on complaints.”

In dealing with the issue of where the supervisory visit should take place an advocate was firmly of the view:

“A person should be visited in their own home.

The person checking should see the participant in their home and the carer should not be there.

The planning or safety assessment must be in person and in the person’s own home to review a plan. There are several risk factors that need to be considered, including living alone, the degree of cognitive impairment, the age of the person and the lack of informal supports.”

One person that lives with disability recalled the role of the community nurse as a model for the current situation and emphasised personal contact:

“Previously a community nurse was responsible for coordinating services. I am very supportive of a person being designated to take responsibility for the person being OK and it should be a physical visit.

It is important that there are visits in a person's own home at least quarterly preferably by the regulator or a representative of the regulatory body.

Provider management should be done by officers in each state. Quality checks need to be done by visits on site and questioning the worker.”

5. Isolation and lack of independence increases risk for most participants. Personal contact with the community is the best guarantee that a participant will be safe.

The reasons for the participant’s risk were discussed by participants.

“We should focus on the environment, which causes that risk.”

“There are several factors that put a person at risk or at a higher level of risk and these include if the participant has no family engagement, no alternate decision makers, and higher medical needs.”

“Factors of vulnerability include communication differences, no family members, or close contacts and only one caregiver. This is not an exclusive list. There may be several other factors that may cause vulnerability.”

“Lack of community connection is an extremely high-risk factor.”

An advocate stated:

“There are integrated elements that work together to safeguard which are both formal and informal. Where there is a complete failure of natural safeguards then more formal safeguards will need to be put in place.”

A stakeholder representing the views of many contributors stated:

“It is important to be in the community and develop connections as this has a protective impact. Developing ties is important and not being segregated from the community. For a person with limited informal supports, then formal supports to build informal supports should be included in their NDIS plan.”

This was a theme from several stakeholders.

One academic emphasised the evidence of social engagement as risk factor.

When do you have time for risk assessment? This is a real risk, not a Unicorn. A red flag is living alone at home, no connection with an LAC, no connection with family or friends and one single support worker.

You may be unsafe in your home when none of these risk mitigations are present.”

A service provider and person with lived experience of disability says:

“Intellectual, cognitive impairment and psychosocial issues often make people more at risk than a person who is physically disabled.

Lack of social interaction and connection seems to put you at risk.”

Another stakeholder living with disability emphasised the importance of a framework aimed at building capacity rather than protection:

“National safeguards are the best and building people's capacity to make decisions and building relationships with the community.

Factors that indicate vulnerability include social isolation or lack of connections to a wider social life.”

The views of a stakeholder expressed typical views summarised below:

*“Risk arises from a range of factors in addition to living alone at home and having a sole carer. **Not every participant in their own home with a sole carer is vulnerable.***

A participant may be at high-risk if they have underlying conditions and only one support worker. The person taking responsibility for quality should meet the participant and the worker in person and preferably in the participant's own home. See them in their environment. There should be a family member or other support present if possible.

Often, community engagement is only brought into the commercial sector by payment, such as going to a cafe. You are essentially paying for experience, such as going to the movies. Often this is not development of real community connection, such as friends.

Isolation is a risk. A participant's plan should aim to deal with this risk.

The NDIS is very professionalised. There is a role for service organisations like clubs, churches and community groups, not just paid workers.”

One service provider thought there was a role for primary health carers in the safety of participants:

“What happens when there is no family? The role of a GP should be to check on the overall health and welfare of client, at least once a year.”

Advocates with a focus on children and young people in the scheme were concerned to have the NDIS Commission focus on their unique risk factors:

“There is a unique risk for young people and children with disability.”

“There is a high level of guardianship orders, but this is not particularly well understood.”

6. Social isolation of clients could be prevented by incorporating socialisation objectives and capacity building in participant's plans.

Many stakeholders emphasised the need for capacity building as part of individual plans:

"Participants be given training in how to properly direct their carers and to advocate for themselves."

"Building capacity in the participant and in the worker is an important issue."

"This should be a focus on building capacity for providers to manage risk rather than narrow prescription."

The CEO of a peak body had the view that:

"This NDIS is about supporting people to achieve social and economic outcomes. Therefore, it should include a plan to enhance their socialisation. I think it is reasonable and necessary to fund the enhancement of the participant's socialisation."

An advocate said:

"Capacity building is important for building natural safeguards, but just sessions aren't enough. There has to be agency to create something happening. Building social capital is often difficult for people with disability that do not have connexions through school or work circles."

An officer of a service provider with lived experience of disability said:

"The developmental safeguards should be in place to ensure that persons with disability know when there is a problem and know what to do about the problem if it does exist. The more people the person has around them, the safer that they are. How to build more of these friends and connections to community is a difficult issue and resolving this would solve half the problem. The problem is greater than the NDIS it is about how society reacts to difference. I don't know how to solve that problem."

An officer of an advocacy organisation emphasised the importance of building the social capacity of participants was the best way to reduce risk:

"There should be more funding in support to build the capacity to make more connections in the community."

A disability advocate said:

"For a person with limited informal supports, then formal supports to build informal supports should be included in their (NDIS) plan. The problem of abuse and neglect is real but an unusual situation rather than a normal part of the scheme. It is still important, though, to develop safeguards. It's important that we can't always control the physical environment, but we should ensure that there is support."

The strong view of one advocate was that:

"People with an intellectual disability should be provided with training for them to advocate on their own behalf. There should be formal training for participants in a group setting. Supported decision making must be done by a person or body who is independent from the service provider. There should be skill improvement training for participants. To up their skills and capability, including how to advocate for themselves."

Another stakeholder living with disability particularly concerned with psycho-social disability emphasised the importance of a framework aimed at building capacity rather than protection:

“There is a real gap in capacity building and developing supported decision making.”

An academic said:

“It is very important that there is contact with lots of people to bring in the sunshine. That means that any person who only has a few or only one person their life is at risk. Risk is directly correlated with how many people are in your life.

It is in no one's interest to only have one support worker in your life.

“There is important role for participants in being educated, the Advisory Committee of the NDIS had a subcommittee on safeguards which talked about personalised safeguards.

- *Developmental safeguards*
- *Protective safeguards*
- *Corrective safeguards.*

Building circles of support is important, which is both protective as well as cost controlling.”

A service provider specialising in providing support for people living with intellectual disability said:

“People with an intellectual disability are not really have capacity building developed. The NDIA is setting up a framework for supported decision making but at this stage there is little provided for in plans.”

Some stakeholders thought the community and neighbours should be engaged with people with disability more:

“What is the role of neighbours and the community and how can work be done to enhance engagement with the community?”

“Where is the spirit of caring for one another while not impinging on people's privacy? Consider the re-introduction of neighbourhood centres. Let us break down fear in the community.”

“The paid workers should have some role in developing connections with the community and the more extended family.”

An academic looked longer term:

“Long-term preventative action is to build social networks around those participants that have no one.

It is important to empower women with disability so that they understand their choices and healthy relationships. This is early and not after parents are close to passing away.”

An advocate suggested a greater role for advocates:

“An option could be to have visits by advocates to each participant, but this would require more investment in advocates. We need to build capacity in participants to know how to access support and advocacy.”

7. An assessment of risk should be made when individual plan is developed and at each review.

One leader of an advocacy service said:

“The risk factors should be considered as part of the plan, e.g. lack of connection to community is a risk.”

Most stakeholders were of the view that the risk of the participant should be considered and provided for as part of the planning process.

“Now there is no evaluation of the risk that participants are subject to.”

“I am supportive of a pre-assessment of or triage of risk prior to plans and proactive action in these circumstances”.

“I support a supervisor overseeing the care of the participant and this should be designated in their plan.”

“We think it should be mandatory that a person checks and audits to see if a participant is OK even when some clients don't want an additional person in their home. The initial step at the planning stage, looking at risk could be the agency or someone other than the service provider.”

A service provider said:

“I completely agree that is not just about regulation, is about building a plan that provides the necessary supports that keep participants safe.”

One advocate with lived experience said:

“There should be a mechanism equipping people (i.e. participants and the people who support them) to identify their vulnerability. Participants should be triaged to assess their vulnerability. This should be identified at the planning or preferably pre-planning stage.

Community engagement seems not to have taken to account in plans. This is not just a quality-of-life issue. It is also a safety issue.

An assessment of risk should be made when or before an individual plan is developed and approved.”

Another advocate said:

“People who have both a single carer or many, may be at risk. They are only as safe as the quality of that care. Abuse still happens when there are many carers, even in group homes. The service provider should get regular feedback from the participant to see if they are being properly cared for. There should be someone who regularly checks on someone in their home and this checking should be part of the plan.”

A service provider said:

“The person put in the plan is fine to oversee safety, but it should be organically linked to the risk assessment.”

Another experienced advocate continued the theme of participant capacity and carer skill:

“Participants should be triaged to assess their vulnerability. This should be identified at the planning or preferably pre planning stage.”

One policy researcher said:

“There is no assessment of risk during the planning stage. There should be an assessment of risk during the planning process. There can be triggers, particularly for disabilities such as autism. The plans should deal with these types of risk.

This should be a team approach around creating a programme that deals with the risk.

The programme should deal with the issue of what the participant does if something has gone wrong."

There was a strong emphasis amongst stakeholders on dealing with the issue of risk as part of the planning process, and ensuring these issues are identified in the plan. They felt that there should be a dialogue with the participant on the risks involved and how much they are prepared to accept when making their choices:

"It is appropriate in funding plans to consider a person's risk. This should be done as early as possible in the planning process."

"Sometimes risk must be considered and managed even if the person/participant does not consent. This scheme is open to a range of risks, and it is important we badge these risks and deal with them."

"There was meant to be capacity building with peer support or advocacy for participants to help with developing their plan."

A stakeholder who is a parent of a young person living with disability engaged in NDIS policy advocacy and disability campaigning said:

"There is a real gap in capacity building and developing supported decision making in the NDIS. Advocate services are stretched to the limit. There is a serious gap in support coordination. The at-risk assessment should be a matrix and it is not just high support needs. If a person is at high risk, you could have a more experienced planner dealing with the planning and reviews."

One peak body CEO said:

"The difficulty is that the NDS often does not see participants during the planning stage and on revision of plans, particularly those with very high needs. It is important that at the planning stage there are eyes on the participant. Either meet them if they are unable to stay for the whole planning session or in some very limited circumstances, the person preparing the plan should at least view the participant."

An advocate said:

"A plan review should include consultation with the participant. And even if it's not possible for the participant to be present for the entire review, they should least meet and have their views sought."

All NDIS planner should have training to recognise family violence, including control. The narrow focus on service provides providers, ignore the possible abuse from other people."

An advocate for children with disability said:

"We should focus on the environment, which causes that risk."

Two stakeholders took an alternative view stating:

"I am not in favour of pre-assessment of risk."

"Having a risk assessment done could be seen as an imposition. I only had a 15-minute phone interview with the person from the NDIA. They did not really consider my view or my life. The statement that that you can review your plan at any time looks good, but it is very difficult to achieve this."

A service provider set out the factors of risk:

"There are a number of risk factors that need to be taken into account, including:

- *living alone*
- *the degree of cognitive impairment*
- *the age of the person*
- *lack of informal supports.”*

There was some concern by an advocate about risk assessment:

“We must make sure risk assessment is not used to prevent people doing what they want.”

Others thought risk should be reduced by the participation of LACs.

“What is happening with the support coordinators? Their role is confused.”

Representatives of larger service providers expressed concerns that support coordinators were not fulfilling their role, adding to the inadequate assessment of risk:

“The Commission or the NDIA must review the role and purpose of support coordinators as it does not seem to be clear what function they perform. Support coordinators seem to be almost unregulated.”

This was a particular concern for young people:

“There should be separate overview of at-risk participants looking at the intersection of various risk factors including those unique to children and young people.”

An advocate thought the risk should be assessed when a client transferred from the state system to the NDIS:

“The interaction between the NDIA and the state system of care is an issue. This seems to be a missed opportunity to assess the risk of participants when they join the NDIS. What is the responsibility of the state to identify persons at risk?”

8. The proper implementation of choice and control is the best assurance of the safety and quality of care in the scheme.

Another service provider CEO took a particular perspective on the issue of sole carers:

“The issue is balancing choice and risk. There are sometimes advantages in only having one sole carer. One of the important issues is the isolation of the person who is receiving the NDIS services.

It is a problem that the provider may want to keep clients to retain their income.”

Another stakeholder who lives with disability and is an NDIS participant and an advocate and consultant in the disability sector affirmed the importance of choice and individual rights and the possibility that blanket rules could limit the options of participants:

“Participants should be able to control who comes into their home and sometimes particularly, in rural areas, there may only be one support worker.

I am against blanket rules that take away control. Once we are making these types of rules then it takes away control.

I would like to maximise support for the participant’s own decisions and lifestyle choice.

There is a dignity of risk. How do you allow people to determine what they want to accept and how to mediate this risk?

We must make sure risk assessment is not used to prevent people doing what they want.

Over protection of people can put them at risk in the future.”

9. The dignity of risk/informed choice can be achieved by mandating at-risk clients to have training in personal safety at the planning stage of their entry to the scheme.

One advocate who lives with disability and whose care is predominantly provided by their intimate partner affirmed the dignity of risk:

“Choice and control. I live in my home and my partner is my carer.

Ann-Marie [Smith] was not encouraged to develop independence and apparently was not prepared to care for herself after the death of her parents. Women with disability tend to be assumed to be incompetent.

The intrusion of the state is not wanted by many people with disability. There is dignity in risk.

Flexibility in funding is part of the solution.”

10. Workforce training in skills and ethics is an investment in safety as well as quality of the scheme.

A CEO of a peak body emphasised the impact on workers of the supervision requirements:

“We're looking at workforce spans of control. How many people are supervised by each supervisor? Much of our workforce works on the road and they aren't in the office to be dealt with by supervisors directly. These changes (supervision of single workers) have put a lot of pressure on the frontline managers.”

A union representative covering disability workers said:

“We have observed the hollowing out of opportunities for supervision. Not just being given instructions but having the opportunity to reflect and look at the quality of care that you are providing and possible improvements.

One researcher emphasised the importance of training in both skills and ethics in the disability sector:

There should also be support for support workers. They need to have training and indications of what they should report.

Training should be made mandatory.”

A union representative covering workers in the disability sector said:

“In practice, we have a disability support worker being replaced by Home Care worker. The level of worker is determined by the capability framework”.

One service provider peak CEO looked to a future where the care industry workforce had single regulation and certification:

“The National Workforce Strategy refers to the caring workforce and this includes Ageing disability and Veterans Affairs. This means that. Regulation may mirror each other eventually, including such requirements as workers having a certificate 3 as a minimum standard.”

An academic in the disability sector said:

“On the job supervision is the most important thing. It embeds responsibility for frontline workers. Regulation of service provider should be more than once off thing. It should be ongoing and provide for self-assessment and reporting. Oversight should then include random checks.”

A policy and advocacy specialist was concerned about the connection between worker skills and ethics and outcomes of the scheme:

"I think that all workers both registered and unregistered providers should have their workers checked for skills as well as integrity."

An academic with expertise in disability policy said:

"Research shows that quality care requires frontline workers to be supervised by a practice leader. Registration should say that every support worker should be supervised by a practice leader with learning in disability practice and this should include in situ observation of the worker with the participant. The Robertson Review at page 42 refers to service supervision."

An NDIS participant who lives with disability made the following observations:

"They need to work on the workforce. It is rare to find good carers so that you tend to stick with them. With new carers you must train them and that can be exhausting and frustrating. Make it (the job) is more attractive. Provide a greater range of work and career paths so that they can be retained. There should be a requirement of a certificate four or at least a higher rate of pay."

A researcher in the disability field made the following observations about training and quality of care:

Workers are critical to building long-term preventative action that is to build social networks around those participants that have no one.

Frontline workers should be trained in active support, at a minimum."

A union representative specified.

"In relation to training, we believe that all workers must have:

- a. Induction level training on the code of conduct*
- b. They should have at least a cert three training and*
- c. They should have ongoing training while a worker is employed.*

This would allow their skills to stay up to date and they could specialise in particular areas. There is a big gap in specialist areas such as women with disability caring for their children and women suffering domestic violence.

Finally, we believe that the training should be a portable model so that disability workers moving from employer to employer can take their qualifications with them."

Another activist, advocate in the disability sector offered the view that better quality and safety and choice and control can work in tandem:

"Training for support persons is poor and they know nothing about the person they are supporting. Generally, the background of the participants is not passed on to the carers and this needs to be. The caring must be a team effort which includes frontline workers and a hands-on supervisor/team leader. The carer must have time to carry out the task in a quality manner. The participant needs to know how to raise issues."

*One of the areas that has not been dealt with well is peer-to-peer workforce participation. The mental health quality and safety guide and the National Mental Health Commission **raises the issue of lack of peer support or engagement.***

Make sure that the NDIA is established as this affects the liability of the taxpayer as it covers compensable injuries that cause a disability.

Safeguards should be included in the training of workers. Participants should be included in the discussion of what safeguarding plans are in place and what level of risk they want and are prepared to accept.

It is very important to have this face-to-face contact."

Another service provider who is also a parent of an NDIS participant was passionate about the promotion of compulsory community engagement:

There should be a positive duty of care in the disability sector.

The NDIS is very professionalised. There is a role for service organisations like clubs, churches and community groups, not just paid workers.

A buddy in the community could be linked to the participants to develop relationships. To assess issues and to give them some context."

11. Platform providers: Is the NDIS Code of Conduct enough to regulate them?

A person with disability who self manages thought the requirement should be extended:

"Self-managed people can use people who are not registered. If not registered, then someone else must oversee the person alone in their home. This could either be the support coordinator, the agency or community visitor."

A union's view was:

"We are of the view that the Commission should be able to regulate platform providers."

An advocate noted:

"It is possible to purchase NDIS services through Gumtree. They are advertised. That does not auger well for quality".

A service provider suggested that that people using unregistered providers were in a particular category:

"Many of the participants are self-managed or are managed by their own parents."

Another service provider said:

"Self-managed people can use people who aren't registered. If not registered, then someone else has to oversee the person alone in their home. This could either be;

- *the support coordinator or*
- *the agency or*
- *community visitor"*

An academic discussed the relevance to non-registered providers:

"What about self-managed services, using contract and unregistered support workers? This is a very small group. Usually, parents and family are managing for the profoundly disabled. Should people be checked to see if they are ok?"

Referring to unregistered providers, one stakeholder said:

"The first principle is that I think there is a real case for deeming all subcontract workers as employees."

A service provider said:

"How do you build in supports in an unregistered provider? These providers should also be regulated to be a level playing field."

One advocate considered children particularly:

“Every provider in the early childhood services should be registered in our view.”

Other comments on the scheme not concerned with the Robertson Review’s recommendations.

1. There should be a regime of mandatory reporting for GPs, dentists, Meals on Wheels counsellors, etc.

“We should consider mandatory reporting in much the same way as child abuse has mandatory reporting or a concern that might be occurring. Should there be a regular 6-monthly health checks for disabled participant in the NDIS?”

“Mandatory reporting should be put in a place. Like child protection, people such as doctors, teachers, Meals on Wheels, and counsellors should be required to report suspected abuse of people with disability in the same way as they presently after children. We should mobilise the community. And then they can be put them [people who are at risk] on a watch list.”

One alternative suggestion looked to aged care for a possible technology-based solution:

“Maybe consideration can be given to vital calls where a participant who needs urgent assistance can push a button like what operates in aged care, though this could be a problem when the participant has severe cognitive deficit or psycho-social issues.”

2. The NDIS Commission’s role and complaints

There was generally a high level of satisfaction with the performance of the NDIS Commission and its personnel. However, a number of stakeholders expressed a variety of reservations which they put down to the NDIS Commission being under-resourced and the Commissioner having too many limitations on the statutory and regulatory powers. Frustration was also expressed at the lack of information sharing between critical bodies, including the NDIA and children’s services.

A service provider spokesperson said:

“The Commission should have powers of entry balanced against a participant right to privacy.

The Commission should give example scenarios and provide reflection on common situations and how they will be approached by the Commission as both a guide and an educative assistance to providers. This would be much in the same way as the Taxation Department issues tax rulings.

There are systemic issues in the interface between the NDIS and children services and other safeguarding mechanisms. The NDIS should make a disabled child safer. There needs to be more sharing of information to protect children between the NDIS, the Commission and Child protection.”

Some stakeholders commented on the role of the NDIS Commission:

“There is a concern that regulations are often delivered in a bureaucratic manner without sufficient regard to individual difference.”

Some argued that there is no clarity on what the remit of the NDIS Commission is regarding complaints:

“There are many participants who do not know they can complain without losing their services. When discussing issues, participants, families, and service providers should be in the same room.”

“The Commission’s model is a complaints model and that is often inaccessible for participants with an intellectual disability. This means the role of advocates is important to speak up for them. Often family and friends cannot report and deal with complaints due to privacy reasons.”

One service provider said:

“There is little contact between the Commission and the participants, except if there is a complaint. The participant with the most complex needs are the ones that often complain the least.”

An advocate said:

“Presently the Commission can't access information with the agency, and this must change. Information must be up to date and in real time.”

A disability advocate and other stakeholders thought there should be a greater role for the NDIS Commission.

“How are offline online complaints dealt with? Any complaints should trigger a visit.”

The Commission should have information on all medications that participants are taking even if they are for treatment reasons not just restricting practises. Preferably technical expertise should record the doses of drugs, particularly psychotropic drugs.

Service providers should be required to provide information on how to access the Commission. More people should be aware that the complaint mechanism exists and how to access it.

I believe that the NDIA or the Commission should have powers to go into people's homes.”

An advocate with lived experience of disability said:

“There should be a high-risk category and they should be put on a visitors list from the agency or the Commission.”

Provider alerts should have more information, more empathy, less stick, and more carrot. Language should be more empathetic. I refer to language used to deal with the age care as a reference.”

A leader of a peak body said:

“I have been saying since the Commission was formed that is not sufficiently resourced. I think that the Commission is at risk of going in the same direction as ComCare being unable to effectively regulate the sector.”

3. National Visitor Scheme

A service provider CEO was adamant:

“I am supportive of community visitors to participants.”

The leader of an advocacy peak said:

“We think the Community visitors’ scheme should apply to all NDIS participants. We understand that the Commission has the capacity to make unannounced visits, but generally they don't.”

Another service provider had a proviso:

“A community visitor programme is a good concept, but it has to be well run and consistent, with good quality visitors.”

One advocate observed:

“Community visitors are OK, but can they go into private homes if the participant does not want a visit? A person who is appointed to oversee participants and ensure they are looked after they should be independent.”

A service provider said:

“I have considered community visitors. In NSW there are visitors to residential services. Maybe this should be extended to people in their own home. These visitors should have no connection with the paid carers. The visitor should be more of an advocacy role and should check with the participant to check they are happy with the service.

The NSW service is not perfect as they are not expected to engage with the residents. The person who checks on the resident should be different from the provider. It is good to include it in the plan. The support coordinator appointed for that participant should particularly deal with their isolation and community connection.

I support a community visitor scheme to check on participants.

If a national visitor scheme happens then it should be consistent in all states should be paid and linked to advocacy.”

The CEO of a peak body said:

“At the planning stages if the participant is going to use one worker it may be worthwhile to ask if they would like a community visitor coming to see them in their home.”

Another stakeholder believes visitors are not the answer.

“The visitor’s system is really a 19th century concept that does not really work as well as tier two of the NDIS.

They should be a high-risk category of participants and they should be put on a visitors list from the agency or the Commission.”

Another person with lived experience of disability said:

“Community visitors have been integral to safeguards in [state]. The [state] model has been useful, but it doesn’t prevent everything. The visits are very few and often they only talk to the facility manager and possibly not the participants”.

4. Pricing for safe and quality care

The CEO of a peak service provider body said:

“With choice control, people are consumers and making their own choices. The Commission has been heavy handed because this issue has been politicised. The leanness of the private pricing environment is an issue.”

The CEO also added:

“For people with a high physical need there it is worthwhile expanding independence. With high needs participants it is important that the participants have access to services that are properly priced to ensure the quality of care and the safety of the workers.”

An advocate emphasised:

“If a person is identified as vulnerable, then the funding for the services must recognise that as the cost of providing the services is higher to deal with when it includes that risk. If this isn't done, then it will not be viable to provide services to this particular group of participants.”

Referring to the supervisory requirements, a service provider said:

“They should not only be a regulatory response as the pricing model does not provide sufficient pricing to do this all.”

A union representing the disability support workers said:

“This is a common issue that both providers and clients have said to us that there is not enough time for breaks, let alone supervision with the pricing structure as it is now applied.”

And later added:

“The NDIS gives a package for work done for by a disability support worker as determined by the pricing at that level, but then the platform provider sends out a home care worker rather than a disability support worker. Home Care workers do not have the skills, including the knowledge of the participant's rights and the capacity to uphold them. This means that quality of care the participant is receiving is not what was funded in the package provided by the NDIS.”

E. Commentary on NDIS Commission survey

The survey was conducted by Factivity in conjunction with Discourse Consulting.

General

During May, NDIS participants and advocates were given the opportunity to respond to a survey which examined in detail the NDIS Commission's response to the Robertson Review. A link to the survey was included in a special edition of the NDIS Commission's *SAFEGuard* newsletter for people with disability. It was also emailed to disability advocates, and included in the NDIA's Participant First Engagement Initiative newsletter.

At the survey's designated cut-off time, 142 complete responses had been received. This commentary provides a summary of key insights from the survey results.

There is remarkable consistency and overwhelming (93%) support across all demographics, domestic circumstance, and form of NDIS participation, for the suggestion that NDIS participants are at higher risk if they live alone.

There was a similar endorsement (78%) across all demographics of the proposition that it is safest to have more than one support or care worker if the participant lives alone. The only significant demographic outlier from this proposition was in the 45–54-year-olds – 89% of whom thought it safest to have more than one carer. This is a generally larger percentage than other age groups.

Argument testing

The argument that there should be “special” rules for those participants who live by themselves was agreed to by 81% of respondents, while 70% agreed that participants living alone should be supported by more than one worker. Overall, 63% agreed that there should be an additional specific person from their service provider checking the safety and quality of their care. Although this score

was lower than some of the other arguments, in the context of this type of survey this was a very robust score.

The one argument that indicates a need for the NDIS Commission to exercise caution is the effect of any perceived change on the participant's apparent capacity to exercise choice and control. A high level of opposition was apparent to specific rules if they impact on a participant's choice and control.

Strategy

The apparent anomaly around specific rules and choice and control is best understood as a form of cognitive dissonance. Stakeholders want participants to be safe and strongly endorse the measures the NDIS Commission has taken, but remain concerned that any change may limit choice and control. This is an ideological and policy touchstone for the scheme.

Instituting specific safeguarding regulations around single worker support while living alone is overwhelmingly supported. Clarifying the impact of specific rules while preserving choice and control is a communication challenge for the NDIS Commission, rather than a substantive policy challenge.

The project needs to be underpinned by a communications strategy which ensures that safeguarding is not seen to – and does not substantially – interfere with or counteract the choice and control of participants. For example, this result confirms the stakeholder consultation which favoured the view that the second person from the service provider taking responsibility should be seen to be – and in fact actually be – supervising the worker, rather than impinging on the choices or privacy of the participant.

When the full statements are reviewed, the same trend is evident. There is overwhelming support for the NDIS Commission's initiatives in relation to participants living alone who are supported by a sole worker. There remains a strong qualification that participants do not want any specific rules to interfere with choice and control.

Respondent contrasts

The statement in favour of special rules does throw a few interesting relational points. The lowest level of support for the NDIS Commission's initiative is among those who manage their own plan and those in the youngest age bracket. These groups, however, still show strong levels of support for the NDIS Commission's decision. The strongest support for this initiative was in the 35-44 age bracket. While those not living alone supported the initiative most strongly, those that live alone also overwhelmingly supported the NDIS Commission's actions.

On the issue of making an additional person within the service provider responsible for quality and safeguarding, respondents that manage their own plan exhibited a lower level of support. Interestingly however, an overall majority of all respondents supported the NDIS Commission's approach.

In response to the statement that "special rules should be made for participants who are at risk", support was overwhelming. Overall, there was strong support for the NDIS Commission's approach to the Robertson Review outcomes.

Conclusion

This survey of stakeholders strongly supports the NDIS Commission's response to Recommendation 2 of the Robertson report, and underlines that there is a high level of confidence in those actions. The one point of caution is to ensure there is adequate communication about the choice and control

that participants can exercise over their lives more generally and their NDIS support packages in particular.

F. Recommendations and observations

Several recommendations and observations are set out below.

Recommendations

1. The NDIS Commission should continue with the current condition on service provider's licences.

There was no consensus among stakeholders that the literal interpretation of the Robertson Review's recommendation 2 was either practical, desirable, or necessary. There was, however, general support among the stakeholders for the NDIS Commission's initial response to the Robertson recommendation, being the additional condition attached to service providers' registration. None of the stakeholders interviewed expressed any concern that the NDIS Commission's response was other than appropriate given its statutory and regulatory obligations.

2. The NDIS Commission continuously reviews the operation and application of the condition to ensure that the intention of the regulation remains effective and is being applied consistently within and between service providers and participants.

There was stakeholder support consistent with the NDIS Commission's response to the report. In particular there was widespread support among stakeholders for the practice of a second person taking responsibility for the quality of support and the safety of NDIS participants. There were, however, three qualifications for this view.

- a. Stakeholders were almost unanimous that the role of the second person should be supervisory over the worker, not intrusive on the participant's right to privacy.
- b. There was near unanimous support for the view that the additional supervision of quality should be conducted "in person" and "eyes-on" and not via phone or Zoom, etc.
- c. Several stakeholders were concerned that the regulation was being inconsistently applied by some service providers.

Some stakeholders took the contrary view that the second person should not be an employee of the same service provider that employs the disability support worker.

Observations

Stakeholders were near unanimous in their dissatisfaction with the use of the descriptor "vulnerable" for participants. The preferred terminology is "at risk". Several stakeholders indicated that the framework of risk allowed for relative evaluation and sectorising the various factors that create risk. *A more analytical and descriptive language of risk.*

Most stakeholders advocated that an assessment of risk should involve assessment of several risk factors, rather than just the risk of the sole carer living in their own home. Many stakeholders thought that the NDIS Commission should keep under active review possible mitigating and intersecting risk factors, especially the risk of social or familial isolation.

Most stakeholders explicitly mentioned the importance of maintaining maximum choice and control for participants. A considerable number of stakeholders used the framework "the dignity

of risk” to emphasise that participants should be able to make their own choices in the context of a transparent description of risk in their plans and plan reviews. Many stakeholders stated that the supervision of workers and building the socialisation capacity of participants were the two most tractable ways to reduce risk for the participant.

Most stakeholders, including service providers submitted that the conditioning of service providers should be directed at the supervision of workers for safety and quality by the responsible person rather than a focus on the vulnerability of participants because of the privacy risk and the risk to individual dignity.

Many stakeholders argued that risk to participants would be reduced if plans included capacity building for the participant in:

- a. assisted decision making
- b. social and community participation
- c. identifying risks and how to make complaints or advocate effectively on their behalf.

Many stakeholders argued the critical importance to the mitigation of risk of understanding the demographic and disability characteristics of the participants potentially at risk. It was strongly argued by a number of experienced stakeholders that *Data should be collected about participants living alone and their disability type so as to allow an evidence base to inform risk minimisation strategies in the future.* This is consistent with Mr Robertson’s recommendation that the Commission and the NDIA develop a shared view of risk and improved data sharing arrangements.

Annexure A: Stakeholder list

Name	Stakeholder organisation	Role
Dr. Leanne Beagley	Mental Health Australia	CEO
Professor Christine Bigby	La Trobe University	Director, Living with Disability Research Centre
Mr Alan Blackwood	Young People in Nursing Homes National Alliance	Director, Policy
Professor Bruce Bonyhady	Disability Institute	Director Melbourne Disability Institute
Ms Janene Cootes	Intellectual Disability Rights Service Inc.	Executive Officer
Ms Liz Cohen	CARA	CEO
Ms Samantha Connor	People With a Disability Australia	President
Ms Lisa Cox	Media Diversity Australia	Writer
Ms Kirsten Deane	The University of Melbourne	General Manager, Melbourne Disability Institute
Emeritus Professor Leanne Dowse	UNSW	Professor and Chair in Intellectual Disability and Behaviour Support
Ms Liz Forsyth	Northcott	CEO
Ms Lyn Franco	Australian Community Industry Alliance	Former CEO
Ms Carolyn Frohmader	Women with Disabilities Australia	Executive Director
Mr Frank Hall-Bentick AM	Australian Disability and Indigenous People's Education Fund	Chairperson
Mr Dougie Herd	Community Connections	Executive Director
Ms Yvonne Keane AM	Relmagine (formerly Early Childhood Intervention Australia)	CEO
Ms Tricia Malowney OAM	NDIS Independent Advisory Council	Member
Ms Catherine McAlpine	Inclusion Australia	CEO
Mr Kyle Miers	Deaf Australia	Former CEO
Mr David Moody	National Disability Services	Former CEO
Ms Bronwyn Morkham	Young People in Nursing Homes National Alliance	National Director
Ms Jess Timmins Ms Hayley Curran	Hireup	Senior Director of Service Head of Complex Support
Ms Caterina Ponzio	First Peoples Disability Network	Advocate
Ms Liz Reid	Australian Federation of Disability Organisations	President
Ms Clare Robbs	Life Without Barriers	CEO
Andrew Rowley	Ability First Australia	CEO
Ms Mary Sayers	Children and Young People with Disability Australia	CEO
Mr Keir Saltmarsh	National Mental Health Consumer and Carer Forum	Consumer Co-Chair
Mr Jim Simpson	NSW Council for Intellectual Disability	Senior Advocate
Ms Melanie Southwell	SDA Alliance	CEO

Name	Stakeholder organisation	Role
Mr George Taleporos		Advocate
Ms Carmel Tebbutt	Mental Health Coordinating Council	CEO
Mr Mark Tonga	NDIS Independent Advisory Council	Member
Mr Rob White	Alliance 20 and Cerebral Palsy	CEO
Mr Giancarlo De Vera	People with Disability Australia	Senior Manager Policy
Mr Jess Harper	Disability Intermediaries Australia	CEO

NOTE: There were other stakeholders consulted who have requested to remain anonymous.