National Mental Health
Consumer & Carer Forum

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2 July 2020

The Hon. Alan Robertson SC
Independent Reviewer
NDIS Quality and Safeguards Commission
PO Box 210
Penrith NSW 2750

Email: alan.robertson@ndiscommission.gov.au

Dear Mr Robertson

Re: Independent Review into the death of Ms Ann Marie Smith

Thank you for inviting the National Mental Health Consumer and Carer Forum (NMHCCF) to submit a response into the investigation into the tragic and appalling circumstances of the death of Ms Ann Marie Smith on 6 April 2020. This arises from our Consumer Co-Chair having a position on the NDIS Consultative committee and receiving an invitation to make a submission.

The NMHCCF is a combined national voice for mental health consumers and carers. We listen, learn, influence and advocate in matters of mental health reform.

The NMHCCF was established in 2002 by the Australian Health Ministers' Advisory Council. It is funded through contributions from each state and territory government and the Australian Government Department of Health. It is currently auspiced by Mental Health Australia.

NMHCCF members represent mental health consumers and carers on a large number of national bodies, such as government committees and advisory groups, professional bodies and other consultative forums and events.

Members use their lived experience, understanding of the mental health system and communication skills to advocate and promote the issues and concerns of consumers and carers.

We understand Ms Smith had with Cerebral Palsy. We give our condolences to anyone who knew Ms Smith and have been affected by her tragic death, and the horrific circumstances she allegedly experienced in the last 12 months of her life.

While the NMHCCF does not usually advocate for those with Ms Smith's condition, we, after hearing of this appalling set of circumstances, reflected on the death of a man: Mr David Harris from Sydney; who was found dead after two months of no services in July

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2019. Mr Harris lived with a psychosocial disability, and in both these cases, there are some similarities in the vulnerability of these individuals, and we believe structures and systems failed to ensure their support and care was adequate, safe, and had suitable oversights to protect them.

Psychosocial Disability

The NMHCCF chooses to comment on particular aspects of this investigation which directly relate to protecting those with certain or identified vulnerabilities especially associated with a psychosocial disability that is within the scope of the Terms of Reference for the investigation.

The NMHCCF defines a psychosocial disability as: a term preferred by mental health consumers and carers to describe living with a disability that is associated with a severe mental health condition. As with other disabilities, a psychosocial disability associated with a mental health condition is the result of the complex interactions between limitations in activity (related to impairments associated with usually severe mental health conditions) and the environment in which people live.[1].

The NMHCCF agree with the under s17A of the legislation[2] (The Act) relating to the participation of people with a disability, in particular that people with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives.

Sadly, and has been identified for some participants of the NDIS, they lack the ability, capability or the confidence to actively make decisions and or communicate effectively, despite the intention of the NDIS to ensure people have an active role in their care and decisions. For both Ms Smith and Mr Harris, this appears to have been contributing factors in their deaths.

NDIS Commission

The Terms of Reference for this investigation asks for recommending any changes to the NDIS Commission's processes or systems, or the legal framework governing the NDIS Commission's functions.

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[1] National Mental Health Consumer and Carer Forum (2011) Unravelling Psychosocial Disability, A Position Statement by the National Mental Health Consumer & Carer Forum on Psychosocial Disability Associated with Mental Health Conditions. Canberra ACT

[2] The National Disability Insurance Scheme Act 2013 (NDIS Act) Retrieved from https://www.legislation.gov.au/Details/C2018C00276

In 2017, the NMHCCF made a submission to the Community Legislation Affairs Committee on the National Disability Insurance Scheme Amendment[3]. In this submission we stated:

The introduction of national obligations and standards which will apply to all NDIS providers and workers and the introduction of an NDIS Code of Conduct are important safeguards to participants. Of course, appropriate implementation of these new measures will be critical. We acknowledge the progression of this. We also recognise it is often the implementation which can cause failures and inconsistencies.

We draw attention to the disparity and lack of choice if a participant happens to live in a geographical area with limited or only one service provider, is from a non-English speaking background, or of Aboriginal and/ or Torres Strait Islander descent, who, with a history of intergenerational trauma, has a lack of trust and confidence in institutional bodies such as the NDIA and the Commission. Despite best efforts, the Commission may present an access issue for people.

The Commission is useful to individuals if they are aware of it, and have the ability to contact the Commission. For those with psychosocial disability, this confidence can be limited by their very disability and stigma and discrimination they may have encountered. We also note, for those with a psychosocial disability, having a relationship with someone they can trust is vital to their ability to express their needs, and a mistrust of institutions can be a firmly held opinion.

The NMHCCF has identified some areas we believe will add to the importance of protecting the most vulnerable people in our community who are participants under the NDIS. This submission will address:

- Provider registration and responsibilities
- Worker screening and capability
- Protecting people from harm

Provider Registration and Responsibilities

Current practices are to have two pathways for provider registration; either ‘verification’ or ‘certification’ with the separation being the level of complexity of supports and services being delivered.

The Act currently requires only those providers who are working in areas and with people at ‘high risk’ to require certification, and it is the responsibility of those providers to ensure their workers receive the mandatory and extra training and certification required by the

[3] https://nmhccf.org.au/sites/default/files/docs/nmhccf_-_submission_-_ndis_amendment_quality_and_safeguards_commission_and_other_measures_bill_2017_0.pdf

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Commission to work in those roles. Clarity is required on the determination of what is considered to be 'complex' or 'high risk' as it currently appears this is reliant on the complexity of the conditions someone is living with, rather than taking into account their vulnerability and ability to communicate and have independent supports and safeguards in place.

The employer is also responsible for assessing whether or not a worker requires an acceptable check. As was highlighted in the case of Ms Smith, the worker did not apply for registration until after the death of Ms Smith, and, despite concerns regarding theft from another person, the worker achieved registration on April 24. This calls to question the legitimacy and process for registration of workers. There is too much reliance on the registered body to make a decision on ensuring workers are registered, receive training, and when they can commence practice.

Under the Act, it appears this is the sole responsibility of the provider to make those determinations. The Act is also unclear whether or not individual workers are required to be registered with the Commission, or only their employer, as the "Registered Provider" requires registration. The requirements are also 'overly confident' the employer will make a decision if a worker can provide a service in a risk-assessed situation prior to their commencement of practice. We also recognise the ongoing challenges of the emerging workforce and the demand and availability of that workforce, and the challenges faced by organisations needing to 'onboard' quickly the necessary staff to work with participants.

The NMHCCF understands these tensions, and would advocate that only workers who have undergone the necessary training, registration and appropriate checks are permitted to work with those individuals placed in an 'at risk' category. Please see our section on protecting people from harm for further exploration of this matter.

The NMHCCF respects the Commission is required to provide accreditation to providers, and believe the process of accreditation may identify areas of practice and policies which do not align with the NDIS Provider Registration and Practice Standards Rule (2018). The NMHCCF also commends the Commission on its Code of Conduct, although sadly in the case of Ms Smith, and based upon public reporting of her death, it would appear there was a breach of this.

The NMHCCF believes greater oversight is required for workers engaged and providing support individually and sometimes remotely of their governing body. Despite the reliance on organisations to make arrangements for staff supervision, registration and monitoring, the vulnerable in our community are often only served by one worker, and there is a lack of an alternative and for independent scrutiny over the practices of that worker.

This, in practice, may be a requirement of the registered provider to ensure two workers/ alternative workers are appointed when working with someone identified as 'at risk' and

vulnerable. This must be a mandated part of a person's NDIS plan if they have been identified as at high risk or vulnerable, We understand there is a tension with this and the current funding structure set by the NDIA, where a person's plan may not provide allocation for a second support worker. This anomaly would need to be addressed in the context of ensuring safeguarding is in place at an organisational level.

Sadly, for many participants, the contact with the registered provider organisation responsible for employing their workers has a transactional type relationship with the participant. This was highlighted in Ms Smith's situation when the only contact was made as her funding package was due to be renewed. The Act appears silent on the requirement of the registered provider to have regular monitoring of their workers performance and the participants safety.

Recommendations

- A minimum of two workers are engaged to work with people identified as vulnerable and at risk
- Worker registration is required prior to commencing working with individuals identified as vulnerable and at risk.
- Attention is paid to the integrity of registration processes
- Registered provider organisations are required to provide greater oversight of the quality of their staff and the participant experience.

Employee worker screening and capability

The NMHCCF is encouraged by the development and implementation of the Worker Capability Framework currently being developed by Bendelta Pty Ltd on behalf of the NDIS Commission, and to be included in the National Disability Insurance Scheme Quality and Safeguarding Framework. The new national registration screening for workers is welcomed, as it will provide linkages and identification of workers who have previously been found negligent or are unable to be registered to deliver supports to participants. We believe this will begin to address the matter such as that of the carer of Ms Smith who had previously been found negligent.

The Capability Framework contains different levels of capabilities required by different workers, and this will be dependent upon the needs of the participant. While all workers will be required to receive training in core capabilities, the complimentary and technical capabilities are aimed at specialist areas. It is unclear how it is determined who is required to undertake which level of training, and if the registered body is the one who decides what the worker requires.

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The NMHCCF believes the engagement of workers for these individuals identified as vulnerable and at risk must be selected from those able to achieve certification for providing complex or high risk supports and services.

Under the current Act, it appears only the registered provider is required to be listed on the Commission's database, rather than the individual workers. This raises concerns about the transparency for participants to explore the validity of a worker's registration. The NMHCCF advocates for the requirement of an accessible database of all registered workers- similar to that used by the Australian Health Practitioners Registration Agency (AHPRA).

Recommendations:

- The NDIS Commission is responsible for determining the level of training for workers
- Only workers who have attained certification to work with complex needs or in high risk supports can be assigned to individuals identified as vulnerable.
- Workers are not permitted to support a person until they are registered
- A revision of the worker registration process is undertaken
- An accessible database of all registered workers- similar to that used by the Australian Health Practitioners Registration Agency (AHPRA) is established

Protecting people from harm

Under the Terms of Reference, the investigation is to explore the points, if any, at which concerns about Ms Smith's safety could or should have been identified and responded to by service providers, government agencies or regulators. The Act, Objective (ga) is to "protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the National Disability Insurance Scheme". From our perspective, this was a failure in the life, and death, of Ms Smith.

For those individuals living independently and in isolation, often NDIS service providers and workers are their only interaction with others as a result of their conditions. Some people do have other services, such as was the case with Mr Harris, however the withdrawing of funding to mental health and other community support services to fund the NDIS, has seen a gradual decline in services available, or alternatively services a person is referred to by their Local Area Coordinator (LAC) or the Support Coordinator (SC) do not exist.

When services are forced to close, or do not exist, the person is left solely reliant on people who are paid to support them. Some people gave up long ago on asking for what they needed, or are not able to be assertive if they received poor service - sometimes after the experience of making a complaint and having their care impacted. These people may not

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have a phone or internet access, may experience cognitive issues as a result of their illness, or medication or a combination of both, and have lost all other 'natural' supports. There is no one to talk to, no one to simply 'drop in' for a chat, no one who even knows if they are struggling, unwell, or dead. These are the people we believe are most likely to be the ones who are exploited and treated poorly - our most vulnerable.

During the process of writing NDIS plans, and in accordance with the Act, the LAC or the SC is required to identify other supports within the environmental and personal context of the participant's living arrangements. Currently, there appears to be no requirement to undertake any further action or response to people who meet some criteria such as living alone; are isolated (geographically or emotionally) from personal and alternative supports/ carers/ family independent of service provider organisations; have cognitive or communication difficulties; or who may be particularly vulnerable to abuse, exploitation and neglect. A measure of 'vulnerability' needs to be included in the assessment and plans of individuals triggered by the identification of the person's ability to communicate, or their level of isolation. For both Mr Harris and Ms Smith, the withdrawal socially from other supports and their inability to self-advocate, left them isolated, extra-vulnerable, and unprotected leading to their tragic deaths.

Despite all intentions of the NDIS to fund participants to achieve a high quality of life, unfortunately some people (and particularly for those with a psychosocial disability) may and do experience a decline in their abilities and/ or their natural support base. All reviews of plans for participants need to include changes in circumstances which would trigger an extra layer of protection and safeguards built into their plan.

The gradual decrease of funding inclusion for participants for Support Coordination over time is of concern to the NMHCCF, particularly for the vulnerable in our community. We believe there is a need for greater involvement and oversight by Support Coordinators and Local Area Coordinators in monitoring the quality and safety of care and support. The roles of the LAC's and SC's needs to extend beyond linking a person with an agency, to include the ability and capacity to oversee and evaluate the effectiveness and suitability of a registered provider and worker, with the needs of the person. This requires guaranteed funding allocation for SC's to continue over the lifetime of a participant's involvement with the NDIS.

We recognise, after complete rollout of the NDIS scheme, extra safeguarding processes will be put into place using mechanisms such as advocates, guardians and nominees. As we identified in our submission to the original Bill, *we recognise it is often the implementation which can cause failures and inconsistencies*. Attention to providing consistency, quality and assurance will be required.

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An added protection for vulnerable individuals would be, if identified as vulnerable, the participant would be registered with the NDIS Commission, and there is a requirement for the workers supporting that person to be linked to that registration to ensure vulnerable individuals are being supported by workers who are registered and have undergone the necessary screening and training. Through the use of technology, the ability to link data and mechanisms of protection could be entrenched to ensure no participant is placed in a position of being cared for or supported by a worker or provider where there may be concerns regarding suitability and safety.

The concept of a Community/ Official Visitors Scheme is not new, and has, in the past, not been accepted as viable. The two deaths we have spoken to in this submission suggest there is a requirement to provide an extra level of protection for these people in the form of external and independent direct oversight of people's experiences and care, which is regular, mandatory and reportable to the Commission. The NMHCCF strongly recommends the establishment of a Community/ Official Visitors Scheme.

Recommendations:

- Guaranteed funding allocation for Support Coordinators to continue over the lifetime of a participant's involvement with the NDIS.
- LAC's and SC's are responsible for ensuring identification of vulnerable individuals during the drafting of a support plan by using a measure of 'vulnerability'.
- All reviews of plans for participants need to include changes in circumstances of vulnerability, which would trigger extra protection and safeguards built into their plan.
- Vulnerable individuals and the people who work with them, are registered with the NDIS Commission.
- An independent "Community/ Official Visitor" scheme is established

Yours sincerely

Keir Saltmarsh	Hayley Solich
Consumer Co-Chair	Carer Co-Chair