Report to the Safeguarding Task Force

Date: 11 September 2020

Purpose of Paper

This paper is a response to the Safeguarding Task Force Terms of Reference which has been established to *'… consider gaps in safeguarding arrangements for people with disabilities in South Australia arising from the policies and practices of:*

- *the National Disability Insurance Agency*
- *the NDIS Quality and Safeguards Commission*
- *State Government Instrumentalities'*

Nature of disability and vulnerability

In a paper titled 'The Disability and Wellbeing Monitoring Framework: data, data gaps and policy implications'[1] it is noted that people with disability are not a homogeneous group and disparate factors include the type and severity of impairment, life-course stage, age at onset of disability, socio-economic status and whether people live in urban, rural or remote areas (p.231). In addition, the nature of family and community support are relevant factors.

Given that there is a very broad scope concerning the experience of disability, it is logical to expect that there will need to be a similarly broad range of options based on a range of different assumptions to address different needs and experiences.

The authors of 'Explaining Low Subjective Well-Being of persons with Disabilities in Europe: The Impact of Disability, Personal Resources, Participation and Socio Economic Status[2] found that Subjective Wellbeing (SWB) is '… explained substantially more by a model including personal resources than by models including the level of disability, socio-economic status or degree of participation in work. ..'. The largest positive impact on diminishing the gaps in most countries was attributed to '… personal resources, vitality and social supportiveness' (p. 850).

People with complex disabilities and who do not have a nominee (or have a nominee who is not able to contribute to 'social supportiveness') are very vulnerable in the NDIA system. There is no process to identify people who are particularly vulnerable or take account of the different factors which contribute to such vulnerability – or conversely, assess the significance of personal resources and social supportiveness.

It is the experience of service providers that some participants have nominees who really struggle with the responsibilities expected of them for a range of reasons.

Support Coordination

Support coordination is a service that works well for many people who live with disability, and it is clearly intended that the number of support coordination hours will diminish as participants are assisted to build their capacity (this in itself reflects an assumption about the capacity of all people with disability to build enough capacity to manage without assistance). Further, support coordinators are not funded to provide advocacy services, and nor are they funded to provide case management.

Case Management Approach

While everyone has the right to support to develop their capacity, it is considered that a different approach is needed for some people living with complex disability. For example, people with an intellectual disability and/or inability to communicate verbally are likely to need considerable assistance to navigate the system. They may also need advocacy because of an inability to present information required to establish eligibility

[1] Fortune N, Badland H, Clifton S, Emerson E, Rachele J, Stancliffe RJ, Zhou Q, Llewellyn G. The Disability and Wellbeing Monitoring Framework: data, data gaps, and policy implications. *Australian and New Zealand Journal of Public Health 2020* Vol.44 No.3: 227-232.

[2] van Campen C, van Santvoort M. Explaining Low Subjective Well-Being of persons with Disabilities in Europe: The Impact of Disability, Personal Resources, Participation and Socio Economic Status. *Springer Science+Business Media B.V. April 2012:* 839-854

for some services. Further, their capacity to ensure that services are delivered as required may be limited. In the absence of follow up when services are not delivered as required, gaps in service delivery are almost inevitable because there is no one with overall responsibility to provide an overview or take action.

The key aspects of case management that differ from support coordination are that;

- It is a comprehensive program (not a series of unrelated activities) which is coordinated and links different aspects of service delivery
- It includes advocacy
- It implies that the case manager has a responsibility to ensure that plan is implemented (in the context of an ongoing relationship) as compared with a very limited number of funded hours).

Eligibility for case management

There needs to be a mechanism for identifying who needs a case management approach, instead of support coordination given the inherent limitations noted above in the current construct of the support coordination role. At present there is none as there is no formal recognition of the importance of identifying client vulnerability. From the perspective of ensuring participant safety, this is considered essential.

In another submission to the Safeguarding Task Force, Richard Bruggemann and Marj Ellis recommend that there be an assessment of participant vulnerability. Assuming that this recommendation is adopted, there will be information about who should be considered for a case management approach.

It is further suggested that the allocation of funds for a case management approach be reviewed periodically because it is possible that the environment of the person living with complex disability may change – e.g. a family member is willing to, and capable of, taking on the responsibilities of nominee which means that a case management approach is no longer needed. Conversely, someone who was adequately supported may no longer be. This means that there needs to be a mechanism to both assess vulnerability in the first instance, and in the second review vulnerability if/as circumstances change. This begs the question of who could alert 'the system' to a need for such a review.

Concerns about the risk of a paternalistic approach to case management

As with any social support or intervention, practitioners bring a variety of values which impinge on how a service is provided. It should be noted that this is not an issue about case management as a valid form of service delivery. It is a reflection of how it is practised. As with other aspects of NDIA service provision, expectations about how case management is practised should be made explicit and reviewed in relation to compliance with expectations.

Case Studies

A number of case studies are provided below to illustrate the vulnerability of various participants in the NDIA system.

The following case studies (of two external and one internal participant) illustrate in some detail the role taken by the support coordinator, which are consistent with case management (and therefore are not funded).

There are clearly ethical issues at play here which will not be addressed in this paper in any detail. Suffice to say that had the support coordinator stayed true to the role, it is likely that none of these very vulnerable participants would have had their needs adequately addressed. It is considered that being aware of such vulnerability, it would have been unethical to overlook this, and in the context of the NDIA system there were no other options that could be pursued.

It is also pertinent to note that these situations are indicative of unrecognised participant needs which are unfunded. Many service providers, in the absence of the acknowledgement of the NDIA about the vulnerability of participants, address these needs. It also highlights that service providers frequently plug the gaps and thereby mask the inadequacies of the system.

The nature of the situations below highlight the complexities involved, the high levels of vulnerability for each person, and the absence of nominees and/or their limited capacity to address the issues. In the first case study, it appears that there was no one able or willing to assist the participant.

Case Study 1 : (External Participant)
Male: Age 35 years. Undiagnosed ID – Unresolved Childhood trauma. Poor impulse control, substance misuse. Forensic history (physical aggression).
OPA and Public Trustee (P/T) Orders current.

- Referred for support coordination (SC). NDIS Plan with limited support coordination hours.

Initial meetings only permitted by participant at MacDonald's or the Lighthouse Office. Extremely poor personal hygiene noted. PBSTS referral live – two meetings occurred at Lighthouse. All following appointments were refused.

- Accommodation (previous history of homelessness) Short term Lease only.

Refusal to allow entry into home. SC built rapport by visiting and parking in street. Non-judgemental rapport. Hoarding evident in home and in garden. Participant displayed OCD behaviours in relation to cigarette butts and electrical items (collected from street placed for Council pick up). Agreed to weekly meeting in the car.

- Participant arrived at Lighthouse Disability in crisis.

Participant had physically threatened support workers and they had been withdrawn due to Work Health and Safety issues. Participant had also threatened Security Guards at shopping centres when he was directed to cease refuse collection/removal. Banned from local shopping centres due to behaviours of concern. Multiple SAPOL visits to home due to confrontation with neighbours (as reported by partner).
No food in home.
No medication.
No money
SC made appointment made with GP and transported participant to ensure attendance.
SC transported Participant to chemist, food shopping and funded same. Arranged food parcels with local support services to cover basic needs until P/T could arrange alterative shopping plan.
SC arranged Squalor Clean to ensure accommodation met basic standards prior to Housing Inspection.

The limited SC hrs expired and NDIS advised SC is "Not a Case Manager". As NDIS had declined funding SC Lighthouse Disability supported ongoing engagement.

Current:
Participant well settled with new support team that have been very gradually introduced to participant.
Regular, supported, attendance at Medical Centre. Physical wellbeing improving with positive Diabetic Management.
Accommodation secure.
Decreased reports of confrontation with neighbours with subsequent reduction of SAPOL visits.
Substance mis-use reduced
Participant being supported to manage hoarding e.g. when shopping trolleys reached 10 in number negotiated to reduce to five and assisted to move to street for pick-up.
Ongoing cigarette butt fixation requires support staff to distract/redirect when in the community.
Personal hygiene improving

Support staff engaging participant in garden maintenance which is enjoyed. Possible future employment in garden employment planned (P/T supported purchase of lawn mower but regrettably sold by participant for scrap).

N/B:

- Mental Health Service declined to engage as participant has a "NDIS Plan".
- OPA kept informed on the issues as they presented but advised that they are 'Not Service Providers'.
- P/T supportive and have provided shopping options.

Case Study 2: (Internal Participant)
Female: Aged 47
Autism, spastic quadriplegia, inflammatory polyarthritis, epilepsy, ID, dysphagia, autoimmune haemolytic anaemia. Significant behaviours due to physical, emotional and cognitive issues.

Parent – Mr. & Mrs XXXX Appointed Guardians.
Guardianship document states: "Making decisions about in-home and/or other services to be provided to XXXXX including under NDIS Plan.

Support Coordinator – on reviewing NDIS Portal – noted plan for XXX unable to be opened when all consents had been sent. Contacted NDIS to be advised that participant has 'no Nominee'. All forms signed by parents null and void. Mother has completed nominee forms but not processed as NDIS waiting for 100 points of ID not confirmed. *No one was advised of this nor addressed at the NDIS Planning Review.*

SC requested how to address and advised "Participant is to phone the NDIS". Advised participant is unable to phone due to significant disabilities.
Advised that parents are to visit the NDIS with 100 points of ID. Parent is frail, aged and is currently are managing a serious and life-threatening medical issue.
Neither parent drives.
Advised that parents are to upload on to the NDIS Portal their 100 points of ID. Parents do not have a computer.
Locating 100 points of ID may also be an issue as no Drivers Licences are held nor Proof of Age Cards.

Participant requires service agreement to be re- signed by??? Urgent assessments needed due to dysphagia – urgent assessment needed for AT (sling) for her health and safety.

Is SC to support parents to obtain 100 points of ID then to transport to local NDIS Office? If so – this is a case management role.
If not the Support Coordinator – then who?

Case Study 3 (External Participant)
Male 47.
I.D. (moderate). Mental Health presentation - Anxiety and Depression.

Parent – elderly frail female. Stated to support coordinator that she is the nominee – incorrect.
Participant has no nominee listed with the NDIS.
Brother manages participant's finances. Brother often overseas and participant has no way to access own funds. Tenuous relationship with brother.
Support Staff have reported great difficulty in accessing funds for basic needs. Community engagements have had to be restricted as no funds available.
No Guardianship nor Administration Orders held.

Application to SACAT is not a recognised responsibility for Support Coordinators.
If not the Support Coordinator – then who?

Summary
The draft Safeguarding Task Force – Final Report July 2020 notes that;

'In a nutshell, the DNIS is an insurance based arrangement whereby the NDIS is responsible for funding and broad system parameters but does not take responsibility when things go wrong for the individual'.

For many participants who do not have a nominee at all, or a capable nominee who is focussed on participant needs, there are no adequate safeguarding provisions.

The above examples are indicative of the gaps in safeguarding arrangements for some people with complex disabilities.

The information provided also indicates that there are some conceptual gaps in understanding the needs of, and how to most effectively respond to this cohort people.

Unless the system is changed, serious gaps in safeguarding will continue.

Marj Ellis
Chief Executive Officer
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