

Gaps in oversight and safeguarding for people living with disability in South Australia



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Introduction

The untimely death of Anne-Marie Smith has highlighted the extreme vulnerability of people living with disabilities. In response to this, there is an acute awareness that the gaps in safeguarding must be identified so that measures can be taken to redress these.

Following discussion with the Family Advisory Committee (a committee of the Board of Lighthouse Disability) a series of 'Challenging Situations' have been identified which highlight gaps in relation to the safety of clients, in the context of Supported Independent Living (SIL) services.

Issues:

1. Challenging Situation

One person who is sharing group accommodation is behaving in a way that poses a serious threat to the safety of staff and/or other participants.

- Service providers have no decision making authority with regard to participants, other than to remove the service provided as specified in the Service Agreement, which usually requires a notice period, and in any event, such action would leave an already vulnerable person in a more precarious situation.
- Service providers cannot insist on a person leaving his/her accommodation because s/he has a lease with the housing provider.
- There is no guarantee the nominees will assist in these situations as they have no alternatives either, and in most instances it is not an option for the participant to return home. (Most people move to group home accommodation because it is not possible for them to remain with family).
- It is usually very difficult to find alternative suitable accommodation at all, much less in an emergency situation.
- If a different staff configuration would make a difference to the capacity of the service provider to keep all people safe, that would probably require a review re 'change of circumstance', and these processes take months.
- At some point, there is likely to be a suggestion that a Behaviour Support Plan be created and implemented. This takes time and in the meantime the safety of many people maybe compromised.
- The nominee of another person living in the group home may not have the capacity or opportunity to advocate on behalf of the person for whom s/he is responsible. In any event, even if they could advocate, to whom would such advocacy be directed? Who is the umpire here?
- An order might be sought through the SA Government Office of Public Advocate or South Australian Civil and Administrative Tribunal (SACAT). However, assessment/eligibility processes are required – these take time and in the meantime, the issues concerning safety continue to exist. There is a further question of the resource capacity of such government departments to provide the needed services.



- There appears to be an assumption that serious issues will not arise. When they do, there is no oversight process in the disability system. This results in a serious gap regarding the safety of all participants and staff.

2. Challenging Situation

As people who have complex disabilities age, almost invariably their vulnerability increases and often quickly. For example, someone with dysphagia has now deteriorated such that medical advice has been provided that she is at high risk of choking overnight and therefore needs an 'active night'.

The NDIA system does not have the capacity to review/assess such needs quickly, and most service providers' experience of seeking a 'change of circumstance' is that it takes months.

This leaves the service provider in a very high risk situation of not providing the required 'active night', or providing the service with no funds. Either situation is untenable.

There is a serious gap in the NDIA system which does not accommodate urgent and changing circumstances. There are many ways in which this could be addressed – and one such is for the NDIA to negotiate with a service provider that the service will be funded from the date that it is provided with the proviso/requirement that there is medical advice/assessment that the service is required as per funding criteria. If the NDIA is not able to process applications for additional funding quickly, this arrangement would enable service providers to meet participant needs and manage risk quickly.

Failure by the service provider to demonstrate such evidence could/should result in a refusal by NDIA to make any payment, which should act as a deterrent for service providers to fund staff who are not required.

3. Challenging Situation

Another of the assumptions made by the NDIS legislation is that all families/nominees have the interests of their family members 'front and centre' when making decisions. While this may be true in the majority of situations, it is not true for some. Arguably, people living with disability are already vulnerable, and when their 'choice and control' is not respected by those deemed responsible for honouring this, their vulnerability increases significantly.

There is a serious gap in the NDIA system where there is no one designated the right or responsibility to protect the interests of the person living with disability with regard to decisions being made by the nominee. This is a Human Rights issue and must be addressed. Where there is a concern that the nominee is acting contrary to the interests of the participant, there needs to be an independent arbiter to whom such concerns can be addressed and access to such a service needs to be immediate.

4. Challenging Situation

There are some people living with complex disabilities who have no one able or willing to take on the responsibilities implied with being a nominee. This leaves this cohort of participants in a very precarious situation with no one providing oversight regarding the management of their situation. Nor is there any opportunity to identify those clients who are particularly vulnerable. Under these circumstances, people can disappear from view, with sometimes disastrous consequences.



It has been made very clear that Support Coordinators are not advocates, and nor are they case managers. In addition, they generally have less than the equivalent of one full time week of hours/year to provide services to the participant – and given that the NDIS is based on an insurance system, there are many predictions that the hours allocated for Support Coordination will decrease with time. There is a clearly stated expectation that participant capacity will have developed and therefore the need for a Support Coordinator will diminish. For people who have complex disabilities and no nominee (or a nominee who is not capable of providing the oversight that is needed) this constitutes a significant gap regarding their safety.

It is argued that for some participants, there is a need for a case management approach funded by the NDIA where a case manager will work with the participant (and/or nominee) to ‘join the dots’ and ensure that service providers are accountable for the provision of funded services. It is proposed that the case manager would also be an advocate for the participant.

It is pertinent to draw attention to the fact that neither SACAT nor OPA offer case management for people who have orders with those organisations. There is clear evidence of gaps in these systems for vulnerable participants, for example, orders have been revoked because papers have been sent to people who can’t read or respond – which have left them even more vulnerable. It has fallen to the service provider to negotiate the reinstatement of these orders. Again, this is something which is not the responsibility of the provider and therefore there is no funding for same. As such, this is also another example of service providers ‘plugging’ gaps in the system and masking significant systemic issues.

5. Challenging Situation: Transport

The lack of funding for transport continues to be an issue. The assumption that all participants can use public transport is flawed. In these instances, it is considered that the NDIA should make provision for adequate funding to enable people with complex disabilities to participate in activities outside of their home. One of the qualities that promotes participant safety is visibility. Lack of funding for transport will result in many participants being confined to their home with the strong possibility that there is little participant interaction with others except paid carers.

It is also noted that the OPA will not manage participant transport funds (even though other financial matters are managed because participants are deemed unable to do this). This leaves vulnerable people in a situation where they can easily access their transport funds and spend them with the result that they have little or no funds left for transport.

Recommendations:

- 1.** That there be an acknowledgement that there are underlying assumptions that shape the operation of NDIS and NDIA which are extremely problematic – that is;
 - The system needs to acknowledge that disability comes in many different forms which require different responses tailored to address particular needs: one size does not fit all. Intractable problems do arise and when they do, there needs to be an effective process for addressing them.
 - The system is inflexible and cannot deliver timely responses. This is an issue in crisis situations and in other situations, the inflexibility in fact creates crisis situations.
 - The assumptions that all nominees can and will act in the interests of the participant are flawed and there needs to be a process whereby those concerned about vulnerable participants can seek assistance from an independent arbiter.



- There is no problem solving process in place where there is conflict within a group home that a service provider has the authority to address. All participants can become very vulnerable under these circumstances – and again, there needs to be an agreed process to assist providers and nominees to protect the interests of all.
 - It is accepted that there is a huge variation in the capacity of people living with disability to manage their circumstances and this includes at one end of the spectrum those who are very capable, and at the other, those who are not. There needs to be a process whereby people who are very vulnerable are identified and who are allocated a case manager, as needed to pre-empt them falling through the cracks of the system.
2. In order to address the above circumstances, there is a possibility that parallel systems will be introduced instead of addressing the assumptions that are identified as problematic. This is not considered a useful approach.

However, it is acknowledged that changing systems will take time, and that the immediacy of the issues outlined above means that an interim system should be introduced as soon as possible to address the gaps to protect participant safety.

Therefore, it is suggested that an interim system be developed and implemented on the understanding that efforts will be directed to amending the underpinning assumptions of the NDIS (that one size does not fit all) so that the gaps are addressed pending a longer term systemic response.

Summary:

It is widely acknowledged that the philosophy of the NDIS is important and that many participants are very happy with the funding provided to access services that are deemed reasonable and necessary.

The case is made that there are a series of assumptions that underpin the administration of the NDIA and while these are appropriate for some participants, they certainly are not for a sizable group of others. It is this group for who there are considerable safeguarding concerns.

We look forward to the opportunity to speak to these in the interests of collaborating to find some workable solutions to these concerning matters.

Signed by members of the Family Advisory Committee:

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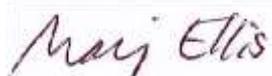
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