

# **Disability Advocacy on the Margins**

## **Feedback on Interim Report**

---

**Participants:** Kerre Willsher, Karyn Lyle, Sam Paior, Pieta Shakes, Amelia Edwards, Jim Gargan, Chris Meaney, Pat Sutton, Sarah Sutton, Zoe Mithen and Leanne Longfellow

**Date of Online Meeting:** Monday 13<sup>th</sup> July, 2020 at 7pm-8pm

This group was formed in response to the recent deaths of disabled people from abuse and neglect, with the aim of raising awareness and seeking solutions to the stigma, inadequate resourcing and barriers to effective supports for those with disability, including psychosocial disability. Each person in the group has connections to people with disability, and most have family members with disability. The name 'Disability Advocacy on the Margins' conveys the idea that many disability services are directed toward the largest group, while those with complex support needs often miss out. However, when supports are carefully crafted for those on the margins, everyone is supported.

Participants were sent the interim report to read. A number of participants provided written feedback prior to the meeting. This was collated and distributed and utilised as an agenda for the discussion. Sam Paior mentioned that most of the following points will be addressed in the final report.

**The report does not mention:**

1. Transition from state to federal funded NDIS
2. Adequacy of funding
3. Access to advocacy

4. Assessment of decision-making
5. Suitability of plan nominee
6. Steps to raise concerns about abuse or neglect
7. Loss of health services or mental health services when people transition to NDIS. This also means a loss of oversight from a health perspective.
8. The transfer of health funding to NDIS (e.g. BiPap, enteral feeds etc, diabetes management) that has been problematic for some people
9. Matching planners with the requisite knowledge to develop a comprehensive plan for a participant
10. Assumptions made about family members being able to provide support.
11. A solid evidence-base for statements
12. Erosion of human capital within the disability space after transfer to federal system
13. How people who do not meet access to the NDIS obtain support for their disability needs
14. Trauma support
15. Behaviour support practitioners-they can play a key role in being another set of eyes. Their role can include an analysis of how the support model and environment impacts the emotional well-being of the person and to make recommendations about how that situation needs to be deconstructed and redesigned in a far more individualised way.
16. Supported decision making- A link was shared to a training module on supported decision-making

<https://www.nds.org.au/events-and-training/nds-training/supported-decision-making-e-learning-module-3039>

## Other concerns

1. While many individuals involved in support provision does increase the opportunity for many 'eyes' to reduce the risk of neglect or abuse, there may also be a reduced responsibility for each of those providers to speak up or act on concerns as they assume others may, furthermore providers may assume that someone else is taking responsibility and therefore they can disengage from service. There needs to be one person responsible and accountable for checking on the person with disability. This could be a case manager. Communication and responsibility are significant issues.
2. While some clinics may be exceptional, the general model of primary care and staffing may limit the potential to ensure the staff feedback to the support coordinators in the event of no contact or refusal from the 'vulnerable' participant. Embedding the coordination of support for health checks should clearly delegate responsibility of the support coordinator to actively follow up with health providers rather than assume they will be contacted if care is not provided or is changed.
3. There must be a continued respect of autonomy of the individual 'vulnerable' participant's wishes. Refusal should trigger assessment and check in by the support coordinator, but not force. There may be a benefit to ensure the limits of this role are documented clearly due to the potential of other health care systems, in particular mental health services, seeing this as an opportunity to discharge participants from services or community treatment orders for those under involuntary care.
4. Lack of teamwork (client, allied health, family, & support workers etc.) under NDIS. While funding is available in early-childhood for multi-disciplinary meetings in capacity building, this does not exist for other groups. The organisation that Pat's son uses manages to organise multi-disciplinary meetings, but it is not standard practice.
5. There was significant discussion regarding training for support workers. There appears to be very different approaches to the employment of support workers. Some families carefully choose their support workers and base their choice on the person who has a positive attitude toward disability. People who

have a positive attitude will learn the tasks they need to do and do not require a Certificate 4. However, another participant described her experience working in group homes where people with disability do not have any choice in who supports them. At times, people working in these roles are doing this as a last resort and have little interest in working with people with disability. It is often hard to obtain staff due to demand related to the NDIS. There is much greater risk in this respect. Sam said ILC grants will provide more training in the future.

6. Lack of opportunities for mentoring, debriefing for support workers
7. Lack of evaluation for support workers, particularly those in group homes who work in isolation. As well, the safety of support workers can be overlooked. There was a case of a support worker who drowned last year.
8. What do support workers do when they witness abuse and it is condoned from leadership? There is no clear pathway for reporting this. The lack of support in this area may explain why a group of whistle-blowers approached Rebekha Sharkie MP about abuse and neglect, as there is no mechanism to address this within the system. This requires immediate attention yet it will take time to bring forward the Adult Safeguarding Unit. Leaders set the culture, but some do not have the skills to establish a positive culture. One participant stated that she has witnessed terrible things in group homes and reported them to her manager, but the response was slow and in some cases non-existent.
9. The role of support coordinators is large and many are not well equipped or funded to take on this role. As well, the role of a Recovery Coach for people with mental illness that began on 1<sup>st</sup> July 2020 is paid less than a support coordinator and is a very large role with enormous responsibility. People with mental illness require well trained staff and many of these have been lost when Partners in Recovery was defunded. People with mental illness require a tandem approach, with Recovery Coaches and Support Coordination (currently it is one or the other). As well, Pat and Leanne have family members who were discharged, or the service has attempted to discharge them from health or mental health services because they are receiving the NDIS. Hospitals are meant to have NDIS liaison staff, but Pat did not meet

one at the Queen Elizabeth Hospital two months ago when they attempted to discharge her son.

10. There is inconsistency within the preparation of plans based upon the LAC's experience, knowledge and understanding and dependent upon participant's ability to advocate for themselves or have support to do so. The 'vulnerable' remain at risk of having inadequate plans to allow for the community access and support that is recommended.
11. Along with the assignment of support coordination, a further safeguarding approach should be considered to limit the potential for inadequate plans.
12. Clarity is required about how a support coordinator is notified about a participant not engaging with a support provider, or when a provider has not attended to a participant (such as sick leave and staff not replaced) or about changes to the care such as in the event of no payment due to issues with plan management.
13. With much responsibility for safe guarding/ check in resting on the support coordinator, for 'vulnerable' participants this role should automatically be designated a 'specialist support coordinator' and there must be checks to ensure that support coordinators are covered during leave and that they are providing an appropriate service.

## **Positives**

1. Case management
2. Coordination of health care (including dental, sexual & mental health)
3. Exploration of the Community Visitor Scheme as an extra set of eyes
4. Adult Safeguarding unit being discussed as a mechanism for reporting abuse and neglect
5. Recommendation for a minimum of 2 support workers for each client
6. Support coordinator being from a separate agency to support workers. Closed systems are much more dangerous.