

HAVE YOUR SAY – NDIS REVIEW

Experience and suggestions of a Registered NDIS Provider relating to participants under legal guardianship – ‘GIVE THEM A VOICE’

INTRODUCTION (Background)

Good Family Care is a small organisation, a Registered NDIS Provider, founded by Elisabeth Good to support her former foster children (now adults on the NDIS). We currently provide a Supported Independent Living arrangement to our 2 ‘participants’ who have high and complex needs and who have been living in a shared house in New Norfolk, Tasmania, for the past 4 years. As a Registered NDIS Provider, we are a local business, employing 10 people (many local) to form a care team. Our 2 young men have profound disability – ‘O’ (age 23) has Down Syndrome, moderate intellectual disability and a significant trauma background and ‘T’ (age 22) has severe Autism, intellectual disability and is non-verbal. Being from a background of trauma and neglect, both young men have multiple challenging behaviours that require intense and constant positive behaviour support. We are fortunate to have a dedicated support team, who the participants have built a happy and trusting relationship with (8 direct care workers), who work with them round the clock. Our participants require 1:1 staff ratio in the SIL, meaning that 2 workers will work together while on duty to support the participants and each other in delivering the necessary care.

In our last official NDIS Audit, our staff were praised for their ‘passion and commitment’. We passed all Practice Standards with no ‘non-conformities’ and are truly doing our best to provide a happy home.

Both our participants are deemed to have ‘lack of decision-making capacity’ and are represented by the Office of the Public Guardian (OPG) Tasmania, who is the Nominee for their NDIS plans. However, for the past 2 years, for unknown reasons, the current OPG delegate has displayed a certain degree of suspicion round our Provider status, where we live, who our staff are etc., without affording opportunity to discuss matters that need clarifying or discuss rosters etc. In 2021, the OPG decided to bring another provider into the participants’ shared home to run a ‘day program’, stating ‘diversity and transparency’, as it is the OPG’s right to have ‘Choice and Control’ round support providers (our participants cannot attend day centres or undertake employment). This program would be for 5 days a week, in the home. We raised concerns (with the OPG and the 2 plan support coordinators) that this would be ‘too much’ and why not try a day or so to see how it works for the participants. With a sense of urgency, the OPG proceeded to engage a provider for the full 5 days, regardless.

We raised the issue that this could create a big ‘turnover’ of staff and unsettle the participants who have gradually built-up relationships with a local care team (8 staff) and are doing well, considering their many challenging behaviours. Big changes and unpredictability can soon de-stabilise such participants, resulting in escalations in behaviours of concern. (*Please refer to the NDIS Commission Own Motion Inquiry into Aspects of Supported Accommodation, Jan 2023 – page 30 – which I have quoted on the following page.) We also pointed out the need for other provider staff to do meaningful activities, which keep the participants happy and engaged (as they were enjoying a variety of special activities provided by us, i.e., tricycling, trips out etc.). We were told by a support coordinator that the other provider can ‘do what they want with them’.

As part of our Provider Obligations and duty of care, it was necessary to raise the above issues, as risk and behaviour management are obligations of all NDIS providers. The happiness and wellbeing of our participants, is our main priority, given our long historical connection to them (15 years). It was our opinion that bringing in another provider for a ‘day program’, with no specific focus (or activities), other than to take over hours from an existing team of workers, would be very difficult for the smooth-running of

the house, the effects on participant behaviour and the constant need for the SIL provider to re-roster staff, when other provider staff don't attend.

For the last 1½ years, since the introduction of another provider into the house, there have been at least 8 staff from that provider, some only coming a few times, others for longer. A big escalation in participant behaviours followed, with an increase in physical assaults on staff, theirs as well as ours (knock-on effect). Some staff from both providers, decided not to work with 'T' or 'O' anymore. We lost 2 of our own staff in one week, due to an assault, which is very detrimental to a small support team who need to deliver 24/7 care. The day program provider decided to withdraw services from both participants due to 'increase in challenging behaviours'. Our autistic participant has also developed more OCD-type behaviours than ever before, needing more care and attention from our team.

Despite our concerns, and the experience of this past 1½ years, the current OPG delegate is now going to send 2 more other providers into the house - 2 separate 'day program providers' - one for each participant. We have been warned not to 'interfere' by past delegates sent by the guardian, to ensure that they can enable this 'transition'. (We have previously been accused of 'interference' and blamed for our participants' behaviours when incidents occurred; something our team finds extremely distressing, given the fact that we are not present during another provider's service delivery hours.)

The introduction of another provider for participant 'O' started gradually in November 2022. On 30th Dec, a serious (Reportable) incident occurred, with this other provider, where the participant was left 'for over an hour' outside in a small clam/shell pool to have 'an outdoor bath'. He sustained severe sunburn to his entire back and ended up in the Hobart Hospital for New Year's night, after receiving treatment to scrape of blisters under NOS gas. He was extremely distressed. This is a participant with a significant trauma background, who suffered former hurt and abuse, and who has a huge need to feel 'safe and secure' in his home. Despite the advice of a clinical psychologist, that this will add to his trauma experience, the OPG has decided to send this worker back (along with 3 more from that same provider), in due course, to continue delivering supports to him. Participant 'O' is distressed and clearly articulating to his SIL team "I don't want him; he will burn me!" and "I'm leaving, off to the airport". It is distressing for him, but for us also, as his dedicated team, to have to experience this distress. We have asked the plan coordinator to consider 'O's reactions and the things he is saying – of his own accord (and not by influence of his care team, as some may want to suggest).

It seems clear that when it comes to OPG determinations round participant supports that neither 'O', 'T' or their SIL team have any say, or any voice at all in the matter. We are 'bracing' ourselves for what 2023 will bring...

*Please see below extract from

RECENT NDIS COMMISSION INQUIRY INTO SUPPORTED ACCOMMODATION:

In relation to the situation occurring in the participants' shared home, I would like to draw your attention to an extract from a recent publication by the NDIS Quality and Safeguards Commission - '**Own Motion Inquiry into Aspects of Supported Accommodation**' (January 2023, p.30 - quote):

“A number of factors might point towards the importance of considering the preferences and needs of NDIS participants who live together in a group or shared living arrangement collectively, as well as individually – which is a different concept than would be the case for most other NDIS supports and services. For example:

Support workers: Some participants and their families or supporters may have concerns if another resident in the group home chooses a different SIL provider who brings in **support workers with whom they do not feel comfortable or safe.**

Predictability in who is coming and going from the house: Predictability can be particularly important for some participants to be and feel safe. **If there are multiple providers involved in support within one group home this can mean many different rosters operating concurrently, or regularly adjusting. For some people changes to their environment or routines could lead to behaviours that may involve risk of harm to themselves or others. Changes driven by the choices of a person’s co-residents may make them individually, and the residents of the group home collectively, less safe if the changes are not carefully coordinated and managed.**

Awareness of the needs and preferences of all residents: In some group homes, a number of residents may have behaviours of concern that involve **risk of harm to themselves, other residents and/or support workers.** In these circumstances, it may be particularly **important for all of the support workers supporting any of the residents to understand and be trained in the behaviours and other specific support needs of all of the residents, not just the resident they mainly support.”**

OUR SUGGESTIONS FOR THE NDIS QUALITY AND SAFEGUARDS COMMISSION

- ❖ The NDIS Quality and Safeguards Commission could **strengthen the ‘voice’ of participants who are deemed to lack ‘decision-making capacity’ and who are under the Office of the Public Guardian.** Such participants also cannot access any other form of independent advocacy, as advocacy organisations only represent disabled persons who can speak up for themselves. Once a participant is assigned to an OPG delegate, the decision-making stops there. It can be an ‘intimidating’ process for those involved in their care, who try to ‘speak up’ to raise concerns or point out issues that could affect the participant.
- ❖ Perhaps the Commission could have a panel/team of disability experts who can review contentious decisions made by OPG delegates and see if the decision really brings benefit to the participant concerned – **a Review Panel (consisting of disability experts).** The ‘many voices’ of direct care team workers (SIL providers), Allied Health professionals, or relevant others involved in the participant’s **direct care**, could be listened to, as they can collectively offer their views on how a certain decision could impact that participant. In hearing the various parties, who are **involved in the direct care** of that participant, a more balanced outcome could be achieved (OPG decision could be changed or modified so as to deliver a better result for the participant and thus protect their basic human rights). This would provide an avenue for others to ‘speak up’ if concerned about supports that a participant is receiving and the effects of those supports on that participant.
- ❖ **The Nominee Rules** in the NDIS Act (2013) could be strengthened/expanded to include a ‘review mechanism for contentious guardian decisions’, thus further protecting the human rights of the most vulnerable group of persons with a disability in the NDIS Scheme. There are many factors that play a role in the full-time care of a vulnerable person and when decisions affect their daily care, those involved in that care, should be heard.
- ❖ The Commission could truly **exercise its function of ‘Quality and Safeguarding’ this group of participants, and give them a bigger ‘voice’, with collective representation** from various parties, rather than leaving it all in the hands of one OPG delegate who may or may not get it right (even though it may be ‘well-intended’). From a human rights perspective, this would be seen as a positive effort by the Commission, giving the most vulnerable people in the NDIS Scheme a stronger

voice and broader representation. This would provide a form of 'checks and balances' for participants who cannot exercise their own 'choice and control' independently and would give true meaning to the term 'supported decision-making'. It would be a means of applying 'best practice' to proposed decisions by a guardian round disability supports, considering all factors and possible outcomes for the participant.

Reasons why we think it is necessary for the QS Commission to give a 'broader voice', a collective representation for this group of participants:

- Participants, who are deemed not to have decision-making capacity are often the most vulnerable of all NDIS participants as they do not have, and cannot exercise, their own 'Choice and Control' – a fundamental principle of the NDIS. Nor do they have any other form of 'independent' advocacy available to them, once they are assigned to the Public Guardian.
- Life-changing decisions which impact the daily lives of such participants are made by OPG delegates, who often have no expertise in the area of complex disability-related support needs and who do not know the participant well, as they may only meet them briefly.
- OPG delegates rely heavily on plan support coordinators, who also seldom see the participants (maybe only 'in passing'). Many plan support coordinators have a very limited knowledge of the complex issues relating to the support needs of participants with very high and complex needs. They also have little time to engage with the direct care team of workers to find out about the participant's wishes and preferences (those on the 'front-line' of caring – the support workers – are best placed to describe what works well for a participant and what doesn't).
- 'Duty to consult', as stated in both the Guardianship Act and the NDIS Act, is often not a consultation with 'those who know the participant well', with a view to 'ascertain what would be the wishes and the preferences of the participant', but rather an implementing of what the OPG delegate thinks should happen, without giving weight to the issues or concerns raised by those directly involved in the daily care of the participant (such as a Supported Independent Living care team).
- It is easy for such a guardian to immediately dismiss the views or concerns of those who know the participant well, while implying that they have 'influence' over the participant and are resisting impending changes due to protect their own (provider) interests. Caregivers or providers should be able to genuinely 'speak up' for a participant and give their opinion as to why proposed changes could have an adverse effect on that participant.
- When the views or concerns of those providing direct care are not heard, certain changes in the participant's existing supports can lead to a diminishing of preferred activities and an increase of participant anxiety with possible escalations in behaviours as a consequence.
- At the end of the day, if a guardian makes a decision which causes upset to a participant on a daily basis, it is the participant who has to 'live with it', not the guardian or support coordinators. The daily care team of that participant may also suffer the 'knock-on' effects of increased challenging behaviours, if the participant is in an agitated state.
- Outcomes and decisions made by OPG delegates, should not 'depend on which delegate has been appointed' (where one might be empathetic and understanding and another really doesn't want to know....). To put the control of a substantial NDIS plan with SIL supports and other daily supports in the hands of one person, is limiting possible outcomes for that participant.
- There is an imbalance, creating 'Power and Control', not 'Choice and Control', when direct carers are silenced, and those who make the decisions can press ahead regardless of concerns raised. It is

very concerning that total control over someone's NDIS plan is put in the hands of bureaucrats who don't know the participant well and who have to decide on major supports such as daily care provision. Why is it acceptable to give OPG delegates and support coordinators full control, while those, on the frontline of care, who raise concerns are silenced? This means the participant has no 'voice' at all in the matter, nor those who are tasked with their daily supports and care.

- The Commission could strengthen its role in ensuring such participants are 'safeguarded' and receiving the right 'quality' supports they deserve. A greater effort should be made by the Commission to protect the rights of such persons, and make the NDIS Act (Nominee Rules) work in the way that it was intended to. The Commission is in the best position to deliver 'disability-focussed' mediation for contentious decisions, where experts with disability knowledge can assess the 'real-time' impacts on a particular participant of a decision relating to their daily care.
- Specifically, decisions by an OPG delegate which impact the functioning of a group home or SIL shared living arrangement, should be reviewable by an independent body (not related to the Office of the Public Guardian), when the SIL provider raises concerns about such impacts on the stability of the home and the effects on participant behaviour.
- Participants without their own voice can easily become 'commercial products' under the NDIS Scheme and easily handed over to providers chosen by support coordinators, whether these are the 'right fit' for that participant or not. There is a danger, where large funding packages are involved, that such participants become more vulnerable to such 'trading' and making of 'deals' which are arguably not in their best interests at all.

Thank you for your consideration of our experience and suggestions. Please feel free to contact us to discuss any aspects of the above further,

Regards,

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Good Family Care

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