



26 July 2020

Joint Standing Committee on the National Disability Insurance Scheme
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Parliament House
Canberra ACT 2600
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Dear Committee Members,

Re: Inquiry into the operation of the NDIS Quality and Safeguards Commission

I represent people across Australia who have Prader-Willi Syndrome (PWS), their parents and supporters.

PWS is a rare, life-threatening condition. It is a complex, multistage genetic disorder affecting multiple systems in the body. It significantly impacts on behavior, learning, mental and physical health. As such people living with PWS have a great need for NDIS support from a wide variety of service provider types. Participants with PWS do not have the cognitive ability to recognise when they have been cheated, or the executive brain functions of planning and organizing capability to follow through complaints about poor quality or unsafe services.

I am writing at this time to let you know about the members' expectations of the Quality and Safeguards Commission (Q&SC), in relation to supports for people living with PWS. In particular, Prader-Willi Syndrome Australia (PWSA) notes that the Commission has dual responsibilities. The Q&SC has to both safeguard Participants, keeping them safe from unsuitable providers, **and** ensure the quality of services that providers are delivering.

The PWSA makes the following observations and recommendations about the problems encountered so far by members, and what the Q&SC should be doing about it.

Over-servicing and under-servicing by providers must be stopped

Underservicing

The PWSA is deeply troubled by the death of Anne-Marie Smith in SA, who was so disabled she needed 24/7 care, but did not get it. It seems Ms Smith died because of a lack of independent oversight, and under-servicing. (It is appreciated that there is an investigation underway into the circumstances). A man died in another State after his NDIS Plan ran out and no-one cared enough to ensure he had ongoing support. There are clearly many gaps and failings in the NDIS that allowed these deaths to happen.

Families of people with PWS are very concerned about the potential for a similar pattern of neglect, fraud and abuse to be inflicted on their loved ones. This is more likely to happen when there are commercial supports in place, and no-one independently responsible for monitoring welfare and quality of care. (That is not a Support Coordinator's role. They are little more than a service broker).



When there is a lack of independent care vulnerable Participants with cognitive impairments are at significant risk. Where a person no longer has any informal support(s) to help hold providers accountable, then the Q&SC should appoint a case worker to oversee the Participant's holistic welfare. The case-worker's role must also include holding providers accountable for the quality and safety of services. The SIL staff need to play a role in monitoring third party providers who support their residents to access the community. Otherwise, who will? Only the Supported Independent Living (SIL) staff have visibility of the service quality, time management, note taking, and adherence to hand-over protocols.

This under-servicing risk would be readily identifiable from the data held by the NDIS. The Q&SC could locate people in the system with 24/7 supports needs and compare their status with the amount of budget in their NDIS Plan. A minimum budget amount (Reference Package) should be assumed to apply. And if it is not in place an independent welfare check should be physically conducted. A phone call will not suffice. If there are deficits in the Participant's supports, a Q&SC-appointed case worker should be activated. This could be out-sourced to a proven, trusted independent body like the Public Advocate's Office in each State and Territory.

Over-servicing

An over-servicing risk would be readily identifiable from the data held by the NDIS. Individual Participants can't know about unusual patterns of servicing by a provider, and so can't report it. Only 'big data' analysis will reveal that. Over-servicing data should serve as an alarm to the Q&SC. If the alarm points to misconduct, then the level of integrity of such a provider means they are unfit to be supplying services to vulnerable citizens, who are unlikely to be able to avoid being impacted by unscrupulous practices. The Q&SC must take the lead on identifying and removing unscrupulous and fraudulent providers from the disability sector. The Q&SC should publish examples of inappropriate practices that have been reported, so that the public can be more aware and alert.

Proactive monitoring and investigation of Supported Independent Living (SIL) services in Specialist Disability Accommodation (SDA) is needed

People with PWS have an eating disorder. They will die young unless their access to food is carefully supported. They have died before, in disability care, from obesity related complications, allowed to arise by the care provider.

Some SIL service providers are reluctant to provide the robust level of support required for food access management. The PWSA has published a Position Paper¹ on significant individual supportive needs for food security in PWS. But due to their impairments, the person with PWS cannot effectively hold the SIL provider accountable for the service quality, or enable a change in provider. It is entirely unclear within the NDIS service system who will hold the provider accountable for delivering a quality and secure food service.

¹ Significant Individual Support Needs – Supportive Practices and Modified Environments for people living with Prader-Willi Syndrome <http://www.pws.org.au/wp-content/uploads/2020/07/Choice-and-Control-Supportive-Practices-in-PWS-July-2020.pdf>



In the absence of an independent case worker, it is up to the Q&SC to monitor the performance of the SIL provider in relation to the obesity-related health status of the Participant with PWS. It will be easy for the Q&SC to proactively identify Participants with a PWS diagnosis, and whether they have diet management as part of their NDIS Plan. The Commission can then monitor any SIL provider involved, to ensure they are delivering a quality service in relation to this life threatening aspect of the PWS disability. And if not, take action to improve the quality of the service.

SIL quotes are still hidden from Participants and their supporters, but must be transparent

Participants and their families have not been allowed to contribute to SIL quotes. Nor are they shown the SIL quote, or Roster of Care, after they have been implemented. When the NDIA reviews a SIL quote and amends it, the Participant is not given the rationale. At the same time, a Participant with a Behaviour Support Plan in place needs a higher level of skill in their staff, who should get paid more. But the skill level applied for in the SIL quote is also hidden. Therefore, the Participant has no opportunity to determine whether the hours and quality of staff being paid for by their own NDIS budget are in fact being delivered.

It is up to the Q&SC to start investigating this issue. The Commission can proactively obtain SIL quotes for PWS Participants who have BSPs, then obtain the data about actual roster hours recorded and the money paid in wages. This type of quality assurance activity can easily commence on the basis of data analysis, before site visits. The Q&SC then needs to take action on any shortfall in service delivery.

Related to the Roster is the presence of the SIL House Supervisor. The Service Agreement says there is a full time House Supervisor. The Supervisor's full time physical presence is required on the premises because a) the Participants have paid for this service, b) a Behaviour Support Plan (BSP) will be in place to meet the food support requirements which need expert oversight, and c) the causal staff need close supervision, coaching and mentoring to deliver the BSP. Some providers have been splitting the Supervisor over two premises in what looks like an unscrupulous practice. The Q&SC can analyse roster and wage patterns to pick up inconsistencies, seek input from the provider and ensure this quality component of the Service Agreement is met.

Service provision should commence with a fairly balanced the Service Agreement

A fair Service Agreement is the foundation of a quality service. Members of the PWSA are generally novices with the NDIS. They have little understanding about what a fair Service Agreement looks like. They rarely have the skills to get into contract negotiations with Service Providers and do not have spare time in which to challenge Agreements where the Provider has used a professional to design the agreement. An example of an unbalanced Agreement regularly experienced by members is that the Provider states a session cancellation notice period for the Participant, but does not commit to a session cancellation notice period themselves. Whilst there is some information on the NDIS website², it is not enough to protect cognitively impaired, time poor, uneducated, or English-as-a-second-language Participants.

² 'Things to think about when making a service agreement' <https://www.ndis.gov.au/media/2429/download>



Therefore, the Q&SC should take a role in helping Participants and their families to learn what a fair Agreement contains. Examples should be given that illustrate the *detailed description* of services, as this is where Participants are often caught out, eg how transport applies. Also, the Q&SC needs to expose examples of unfair clauses that have been used by providers in the past.

Adequate resources must be available for the Q&SC to scrutinize providers and inflict timely penalties

The NDIS is a new scheme. Dubious businesses exist in the marketplace and will be eager to personally profit by finding and exploiting weaknesses in the Scheme's monitoring and oversight. It should not be up to Participants to firstly be the victim, and then the only line of active defense against cheating providers. This would result in an added administrative burden of collecting evidence and lodging a complaint.

Therefore, the Q&SC has to be ready to 'go early and go hard' in terms of holding providers accountable. The PWSA expects its members to be protected from unscrupulous providers through the Q&SC finding them and removing them early. It is essential to take a thorough and firm approach early in the Scheme to send a signal to the unethical providers that there is proactive monitoring in place. It will demonstrate that there are consequences for low quality and unsafe performance. A 'hard and early' approach should remove the inappropriate providers from the sector and deter others from poor performance.

Excessive casualization of the workforce in SIL SDA settings needs to be rectified

Quality service within the SDA home can rarely be optimized by casual SIL staff. They come on shift not knowing the Participants well enough, and with little commitment to house culture and the holistic welfare of the residents. Casualisation adds to the risk of adverse events for people with PWS because casuals do not consistently deliver the Behaviour Support Plan. Research has shown that for people with cognitive impairments, such as PWS, the assignment of a Key Worker³ within the group home is part of a quality service and leads to better outcomes. But assignment of Key Workers is only effective if there are permanent staff to take on those tasks.

Participants are not forewarned when they are considering a SIL provider about the excessive use of casual staff – Participants are often unskilled in choosing their SDA or SIL providers anyway. This 'capture' of customers is a severe disincentive to SIL providers to deliver a quality service and live up to their Service Agreement. External scrutiny has become necessary.

Therefore, the Q&SC must become involved in examining why there is an over-representation of casual workers at some SIL providers and put a stop to it. It would be easy for the providers to employ permanent staff, and supply Key Workers as agreed. PWSA does

³ Bigby, C. and Clement, T: Making life good in the community. Implementing a keyworking system in a group home for people with intellectual disabilities. <https://www.semanticscholar.org/paper/Making-life-good-in-the-community.-Implementing-a-a-Clement-Bigby/bdc03d5cfa88e3569eab102d302a376487c6d73>



not want to see disability group homes become like the aged care sector where profit drives service levels rather than adequate support for residents. The Q&SC will need to specify a ratio of permanent staff so that cognitively impaired Participants get a better quality SIL service in their SDA. The Q&SC will need to regularly audit SIL providers about assigned Key Workers so that the records of who is performing the role and their reports can be assessed to determine if the Participant was getting a quality and safe service.

Training and skill level of community access support workers needs to be transparent

Some people with PWS have Behaviour Support Plans. They have funding in their NDIS Plan budget to engage more highly trained and skillful support workers. Due to cognitive impairments, the Participant will not be employing anyone directly. Their Support Workers are most likely to be through a Support Coordinator or provider organisation. But the provider who sends the worker does not demonstrate the credentials of the worker.

The Q&SC needs to implement a requirement or mechanism that makes it easy for the Participant to learn about the background and credentials of any support worker who is under consideration for engagement.

In summary:

- The Q&SC needs to be proactive in ensuring quality services; The Commission must not depend on reporting by Participants or the public to monitor, identify and reprimand recalcitrant providers.
- The Q&SC must be adequately resourced to take a proactive role in identifying and addressing quality and safety issues, because the fragmentation of the disability service system has left the cognitively impaired even more vulnerable than they have been in the past
- The Q&SC must facilitate the provision of better services in the sector. Better services means that service gaps are filled, poor quality services are nudged to improve, and roles such as case-workers be introduced into the NDIS to provide a holistic, independent welfare oversight for certain vulnerable Participants.
- The Commission must reach wide and deep to identify and remove unsafe, low quality providers from the Scheme. This will build trust for Participants and make the industry more professional, thereby attracting a better caliber of and dedicated workforce.

The PWSA believes that such interventions by the Q&SC will lead to better quality and safer services. Thank you for the opportunity to contribute to this important Inquiry.

Yours sincerely,

James O'Brien
Chair