



pwsa

prader-willi syndrome **australia**

Submission to the Joint Standing Committee on the implementation,
performance and governance of the National Disability Insurance
Scheme (NDIS) – Supported Independent Living

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1) Introduction

I represent people who have Prader-Willi Syndrome (PWS), their parents and supporters. People with PWS need significant supports to live an ordinary life. Many live in disability group homes, or will do as they grow older. We welcome the opportunity to contribute to this very important consultation¹, at the invitation of the Joint Standing Committee.

I will provide a general explanation about PWS to improve your understanding, and respond to the specific issues and questions raised in the Paper, from the PWS perspective.

Prader-Willi syndrome (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. Adults with PWS exhibit high anxiety, complex and at times challenging behaviours and cognitive dysfunction throughout their lives. They invariably demonstrate poor judgement and are socially isolated. Whilst they have variable developmental delay, they all have significant cognitive and functional impairments. A defining

'BEST PRACTICE GUIDELINES FOR STANDARD OF CARE IN PWS' have been published, for use internationally. More successful outcomes are achieved when service providers, educators and others adopt the specialist skills and techniques needed to support people with PWS

feature of PWS is compulsive over-eating.

People with PWS typically die young, due to complications associated with obesity. However, when PWS is managed well, quality of life and life expectancy is significantly improved. People with PWS need life-long support specifically designed to improve access to mainstream services and to actively participate in the community.

The rules and regulations around access to, and delivery of Supported Independent Living services, typically within specialist disability accommodation (SDA), need to cater for the significant needs of the PWS cohort.

2) Purpose

The feedback provided in this submission refers to the needs and experiences of people with PWS and their supporters. Its purpose is to provide you with information about how Supported Independent Living (SIL) supports are used by people with PWS, and how to make SIL a better experience for them.

3) Response

The Joint Standing Committee has asked for feedback on a number of different aspects of SIL. The PWSA has responded to each, below.

¹ The Consultation Paper was available from the web page

https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Independentliving, ndis.sen@aph.gov.au

a) *The approval process for access to SIL;*

For people with PWS, SIL is typically needed within the SDA setting.

Participants who were in SDA prior to the transition to the NDIS have had SIL funding added to their plans automatically. But there are concerns about how this occurred. The Participants and their supporters were not involved. So, these people were left with the impression that:

- SIL providers were very inexperienced at doing SIL quotes, putting the PWS Participant at risk of being under-funded
- SIL providers were not given enough time to do SIL quotes
- SIL providers have given quotes based on a formulae for the household, rather than the individuals; That is, if it cost \$500,000 to run the house in the year prior, and there are 5 residents, then the SIL quotes were just equal portions of the total. This is inappropriate for a person with PWS who has a multi-system and multi-stage disability.

The process has resulted in a lack of trust by Participants and their families in the SIL process.

When a person with PWS are not in an SDA, they are typically living in the family home with parents. Funding for adults with PWS has generally been adequate, but inadequate for high school students due to the increasing complexity of their support needs at this life stage.

b) *The vacancy management process, including its management and costs;*

PWSA has limited experience of the vacancy management process at this time. However, it would like the committee to note that it has members whose Participants are in dire need of SDA and SIL. They have been waiting for years whilst family circumstances deteriorate. This is an unacceptable situation for PWSA.

People with PWS almost always live with restrictive practices, in particular food security, which usually includes a locked kitchen. As a result there are fewer group home options available to them. In addition, others do not want to live with people who have PWS, because they too will have to live with the locked kitchen.

In the past, people with PWS have died in the care of service providers due to a poor understanding of their food security and other complex needs.

Recommendations

The right SIL placement is critical, with SIL providers who can deliver the required food security practices, in the least restrictive manner. This typically requires highly skillful staff, in combination with a modified built environment. SIL pricing must encompass those unique requirements and service delivery expertise need.

c) *The funding of SIL*

People with PWS have a complex condition, and require *flexible* SIL services, to live an ordinary life. See Attachment 1 for some Case Studies.

Members of PWSA have been disappointed with the providers' approach to SIL (within SDA) so far. The problems that have been encountered include:

- No transparency in the quoting process

- No involvement of the Participant, or their Nominee / supporter in the quoting process
- No clarity about whether the budget amount in the Plan matches the quote
- Refusal by providers to supply a copy of the quote, even after the Plan has been approved
- No clarity about how many hours are in the quote for:
 - the critical services of a Key Worker, and their extra training
 - 'back of house' administration, away from the Participant (of which there is plenty for PWS Participants)
 - Specialist training hours to upskill staff for the unusual support requirements of this group of Participants (they are known internationally to have expensive support requirements, due to the complexity of their disability and related behaviours)
- No transparency in how the budget/ funding will be spent. That is, the Participant and their Nominee should be able to see the roster hours. They should know which hours are the 1:1 support worker hours, and the ratio of staff on duty at other times of the day and night. Otherwise, how will the Participant be able to monitor whether the service has been delivered in accordance with the Agreement?

The lack of inclusion and transparency means that the Participant, Nominee and supporters have no opportunity to build their understanding and capability around SIL budgets. This seems to be against the principles of the NDIS. Not knowing the structure and amount in a quote means that the Participant has no opportunity to compare service offerings, to make a choice of the one that best suits their needs.

Recommendations

SIL service providers should:

- Include the Participant and Nominee/supporter in the development of the SIL quote, if the Participant chooses
- Share the draft quote with the Participant, in full detail
- Be prepared to explain how they arrived at that quote
- After the Plan is approved, explain to the Participant how the services will be delivered, based on the actual budget
- Inform the Participant (and Nominee) each time there is a change to the SIL service in comparison with the quote and Agreement, and any savings that result
- Show, on the quote, the specific times the Participant's SIL Key Worker will be available
- Ensure the quote allows for flexibility, to meet unexpected needs

d) *Any related issues.*

People with PWS strive to live ordinary lives, and like to do lots of things in the community. They are often out seven days per week. Indeed, it is important to behaviour support plans that Participants with PWS have a full schedule, as this reduces the food seeking and other counter-productive behaviours, plus helps with their fitness goals. Being able to leave the house with a SIL worker on the spur of the moment, can often diffuse a situation where challenging behaviour was commencing.

As a result, to ensure a seamless, and anxiety free day, the SIL provider needs to do 'back of house' trouble-shooting when the day's routine does not go to plan. For example, this might mean buses have replaced trains, which the Participant can't negotiate, and so needs sudden alternative transport arrangements for a day or two.

Another example is when the Participant needs an unexpected medical appointment; The SIL worker must organize the appointment, transport and attendance. If the doctor is running late, the person with PWS could easily become more anxious, needing a skilled staff member, not a casual who is unfamiliar with the individual's complex support needs, to manage the behaviours whilst still achieving attendance. The SIL provider then has to follow-up, perhaps visit the pharmacy and cancel the day program (or other community access service). The SIL provider must then do the administration to reconcile the invoice from the community access provider, as the SIL workers are the only ones who can match records of sick days with the invoice.

The SIL house staff ensure holistic service delivery at the granular, hour by hour level. That service is outside the realms of the Support Coordinator role; It is completely impracticable.

Recommendations

The PWSA recommends that SIL quotes, and NDIS Plans include funding to:

- address the non-face to face services needed by those with PWS
- include funding for unexpected services, to be delivered flexibly
- be prepared to support the Participant, and go with them out of the house, on the spur of the moment
- recognise that it is better for some 'just in case' funds to be in the Plan from the start to meet the predictable complications, rather than having to activate and urgent review part way through a Plan

4) Conclusion

The PWSA is very committed to enabling the best possible supports for people with PWS to become more independent and live an ordinary life in the least restrictive environment. Appropriate reasonable and necessary SIL funding is an excellent way to help achieve this. But the right support is highly dependent on thoroughly identifying SIL needs during the quoting process. PWSA urges you to recognise the complexities of this multisystem, multistage syndrome and require more transparency in the SIL process to safeguard best practice support delivery.

To learn more about the complexities of PWS, visit our website, in particular the Residential Guide <http://www.pws.org.au/residential-guide/>. I would be happy to meet with you, if you require further information.

Case study 1

Scenario

- A number of disabled people live in a group home; Specialist Disability Accommodation (SDA) with full time Supported Independent Living (SIL) service
- They have been a household for a number of years, and know each other well
- Each Participant attends a day program, with no SIL staff in the house during those times
- A member of their household dies suddenly
- The housemates want to attend the funeral, as ordinary people would

Issue

- The daily support arrangements have to change suddenly for the remaining housemates, to enable them to attend the funeral
- There is an expectation that SIL staff will take them, in the house vehicle
- The SIL provider demonstrates some administrative barriers to the housemates being able to exercise their choice to attend the funeral:
 - There are no SIL staff 'rostered on' in the time period in which transport to, and attendance at the funeral would be required
 - There was no SIL funding in the quotes for unexpected events
 - The residents needed support from familiar staff for a traumatic event, not casuals
 - Administration was needed to rearrange the normal day time activities
 - Extra time was needed from SIL staff by residents to try to process the sad and frightening event, compared with a regular week

SIL provider requirements

The SIL provider must factor flexibility into its quotes; unexpected events occur in ordinary lives, and the disabled must be supported to participate at short notice.

Case study 2

Scenario

- Young adult Participant lives in group home (SDA and SIL) with a number of others
- She had been acting in an unusual manner in the last few days, and caused some minor property damage
- No Guardianship Order in place
- House is not locked
- She normally comes home from daytime activity on public transport, and stays in for the rest of the night
- One 'sleep over' support worker staff is on duty
- The Participant leaves the house, after dark, without informing staff member

Issue

- The staff member cannot leave the house due to other residents being indoors
- There is concern for the state of mind of the Participant who has gone missing
- Staff member has to seek assistance and so cannot sleep; Shift fee will be higher

- The overnight emergency support manager (manages several SDA's) also becomes involved, trying to locate missing Participant
- It is not appropriate to call the police because there is no Order in place; it would be misuse of police resources; it would frighten the Participant
- The SIL staff are best placed to resolve the unexpected emergency. This is because they are able to act quickly, are well known to the Participant, and will be able to deliver the best outcome for the Participant. (In these circumstances, no third party provider or a Support Coordinator could deliver the right service, at the right time)
- The Participant eventually answers their mobile phone to the known caller, the emergency support manager, and is located many kilometers away. The emergency support manager travels to pick up the Participant, and they safely return home
- As a result, when the Participant is at their program the next day, a number of administrative actions must be taken, back at the SDA, by the SIL staff. The house supervisor:
 - ensures an Incident Report has been completed
 - liaises with the Participant's specialists
 - draws up a new behaviour support plan
 - briefs all staff on how to put that plan into action
 - an even more senior manager at the SIL service provider is briefed

SIL provider requirements

- The SIL provider needs to be ready to service the extra, unexpected needs of complex Participants, at times within less than an hour. This will ensure the Participant's welfare, well-being and ability to continue an ordinary life
- There are many additional costs in the scenario above, spent on planning and administration (ie more than just the Participant face-to-face hours)
- The NDIA must allow SIL service provider quotes to encompass scenarios like the above, for PWS Participants
- SIL provider needs to have adequate staff on duty, to step in when there is an urgent support demand out of hours
- A number of 'layers' of support workers in the hierarchy need to know the Participant well enough so that an appropriate response can be mounted, and the Participant has trust in their supports; This means the provider has to make 'get to know you, just in case' opportunities available, between the Participant and the emergency manager