Rights in Specialist Disability Accommodation Consultation Paper

(under the National Disability Insurance Scheme):

Submission to the Victorian Department of Premier and Cabinet

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1. Introduction

I represent people in Victoria who have Prader-Willi Syndrome (PWS), their parents and supporters. Many people with PWS live in disability group homes, or will do as they grow older. We welcome the opportunity to contribute to this very important consultation[1] at the invitation of Minister Foley.

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 have poor judgement and are socially isolated. Whilst they have variable developmental delay, they all have significant cognitive and functional impairments. A defining feature of PWS is compulsive over-eating.

For Prader-Willi Syndrome, there is an International Standard for the Management of PWS. Over the last two years the Victorian government, through the Department of Health and Human Services has followed a very specific model of support for Victorians with PWS. This Healthy Options Service Model has delivered very successful outcomes.

People with PWS typically die young, due to complications associated with obesity. *However,* when PWS is managed properly, people with the condition can be expected to lead a more ordinary life and live longer. They will need life-long support in purpose built Specialist Disability Accommodation (SDA), designed specifically to accommodate the needs of people with PWS.

The rules and regulations around access to, and support in this specialist accommodation needs to cater for the peculiar needs of the PWS cohort.

2. Purpose

The feedback provided in this submission refers to the needs of NDIS participants who have PWS, that is, with significant cognitive impairments. The feedback is based on what PWS Australia, Victoria Branch, knows about the NDIS at the present time.

PWS is not like other intellectual disabilities[2]. People with PWS must live in a food-secure environment. That means restricting their access to food by locking pantries and kitchens, and applying other restrictive measures. They cannot live without intensive service support to manage food access and the other debilitating aspects of PWS, including challenging behaviors and behaviors of concern. As such, there is an assumption made at this time that people with PWS will have to live in a group situation. They therefore need appropriately designed, robust, mobility friendly accommodation *integrated* with support services.

It is likely that 100% of individuals with PWS will qualify for Supported Independent Living (SIL) services, full time, in their SDA. Most are also likely to need Special Disability Accommodation (SDA) funding.

[1] The Consultation Paper was available from the web page until 23/6/2017: https://engage.vic.gov.au/sda

[2] Evidence about the complexity of PWS is on http://www.pws.org.au/guide-ndia-technical-advisory-team/

3. Outstanding concerns

It is disappointing that the Victorian Government seems to have pre-empted some of the issues in this paper within Offering residency in Specialist Disability Accommodation – Policy and Standards (Victoria) published in May 2017.

http://www.dhs.vic.gov.au/__data/assets/word_doc/0009/986382/Offering-residency-in-Specialist-Disability-Accommodation_20170511.doc

For example "During the screening process, the SIL provider is responsible for representing the preferences and goals of the current residents" (Pg 14). Residents should have some say in who their new house mate is, through their support people if applicable, perhaps through a micro-board model of household functioning. It seems the SIL provider could be in a conflict of interest situation. That is, in their haste to fill a vacancy and maximize income, they may place an unsuitable participant in a new house, and the existing residents have no say.

The release of the Offering Residency Policy and Standards at this particular time, casts doubt on just how much notice the government will take on the feedback contained in *this* paper. However, in the interests of an ordinary life for those with disabilities, the Prader-Willi Syndrome Association of Australia (PWSA) recommends that the above-mentioned Policy and Standards get updated, based on relevant feedback gleaned from this consultation.

It is unclear how resident's contents will be protected by insurance. In this electronic era, and with younger residents moving into SDA, they may well own a mobile phone, computer or flat screen TV. Perhaps there should be a new 'blanket' policy type for SDA contents, at the whole property or SIL provider level, which residents can contribute to.

It is unclear *how* the SDA and SIL providers will work together to optimize stability of tenure for residents. Along with standard mainstream maintenance and inspection activities by the landlord, there needs to be additional communication topics and channels, Eg. see section 11.3.

In terms of smooth operations of the overall tenancy, the NDIS SDA provider or SIL provider, cognitively impaired tenant alliance is an untested model in Australia. As such, there will be unforeseen emerging tenancy related issues that need resolution. In principle, resolution should be attempted at the local level first. Perhaps there should be a mandated annual (at minimum) meeting between the SDA landlord, the SIL, and resident representatives. This would be an opportunity to discuss what's going well and what needs changing. The SIL should be the chairperson (on behalf of its residents), take notes and actions, and circulate to all residents (and their key support). The outcomes should be binding. The NDIA must provide adequate funds for the SIL to undertake this administrative task which will help the tenant retain their accommodation in non-mainstream circumstances.

4. SDA Agreements

4.1. What should new agreements with the SDA provider cover?

SDA Agreements will need to contain broader concepts and more detail than regular agreements that apply between non-disabled citizens and landlords. SDA agreements for those with

intellectual disabilities will need to contain some mainstream and some specialist tenancy clauses. The agreement will need to be written in both full legal terms and in an Easy-read version.

The government must provide a 'model' agreement, for all participants and providers to view. Apart from listing all the categories of information that an Agreement will cover, it must also contain model conditions. (A *very* deficient example of a sample contract[3] is provided to Victorian consumers for Residential Tenancy. It contains only seven 'minimum' terms, whereas a typical Agreement in use in the current rental market contains 45+ common additional terms. A model must be extensive, to help the disabled consumer know what fair, minimum conditions mean).

A starting point for the specialist clauses to protect the intellectually disabled will be the (relevant) types of obligations that exist in the Disability Act (2006) and the DHHS Residential Services Practice Manual (RSPM). There *must be transparency about the minimum conditions* in an agreement. This will make it obvious to prospective residents if there are any variations to the particular agreement proposed for them, that differ to a fair model. A public model will reduce the risk of vulnerable residents and their novice nominees being manipulated and disadvantaged by unscrupulous SDA providers, as has occurred for example with owner's corporation contracts, often the standard from the industry association, to the disadvantage of ordinary consumers who know no better.

4.2. Should agreements cover house rules?

No, the house rules should be outside the landlord's agreement, merely cross-referenced. However, there *must* be house rules. The SDA and SIL providers must work together to make the agreement and house rules operate together, with the driving principle being the interests of the residents. The agreement and rules must acknowledge each other and complement each other. For example, the agreement could say that a breach of the agreement must first be considered by any relevant house rules, so that the residents' committee or micro-board can decide collectively whether there are extenuating circumstances for the breach that allow the offender to provide restitution and remain in residence.

The rules should be developed and maintained by the SIL provider. This will allow for:

- Input by residents, and greater likelihood of adherence
- Flexibility based on needs of existing residents as their competence grows
- Adaptability when new residents move in
- Responsiveness if an immediate update to rules is needed (which could be delayed if the landlord needs to be involved)
- Compliance to be monitored by the SIL provider who has responsibility for the rules.

As such, additional NDIA funding *must* be made available to the SIL provider who will be involved with the administrative process around rule development, promulgation, monitoring, recording and enforcement.

4.3. Should residents all have to sign the same agreement?

Yes, all residents in a property should be living under the same conditions/agreement/rules, probably as co-tenants. This seems fairest. This will reduce the risk of misunderstandings and arguments. Rules can then be supplied in alternative formats (eg Compic posters). It would be

[3] An inadequate example of a model contract https://www.consumer.vic.gov.au/housing-and-accommodation/renting/types-of-rental-agreements/lease-agreements-or-contracts

difficult and confusing if there were numerous agreement rules pinned up around the house applying to different individuals. In houses where people with PWS live, restrictive practices will be in place. New residents may be impacted by those practices and would either need to abide by those practices and rules, or choose a different SDA residence.

4.4. What happens if a resident cannot sign an agreement?

If a potential resident cannot sign, their Nominee/Guardian/main supporter should be empowered to sign on their behalf. The Nominee/Guardian would need to play a role in encouraging the resident to abide by the agreement (and rules), and be prepared for the resident to move if the agreement/rules were broken.

4.5. Should landlords be allowed to make different agreements for residents in the same property? When could this be required?

Generally, no. A principle of fairness should prevail. The agreement should be the same. *However*, there are some circumstances where a variation would be applicable:

a) Probation - An *optional* clause should be available for the agreement: The clause would provide for a 'probationary period' of tenancy. The clause could be invoked in the instance of a potential resident having been asked to move out of a previous accommodation due to violence, assault, aggression or other unacceptable behaviour. They would effectively be 'on trial' in the new SDA, and moved out immediately by the landlord if probationary conditions were broken. Monitoring and reporting during probation would need to be done by the SIL provider. NDIS funding for the new resident would have to cover that additional administration.

   To ensure stability for the majority of residents, it is important that *the perpetrator move out*, not the victim(s). To ensure the safety of complying residents, there needs to be an 'SDA provider of last resort', adequately funded by the NDIA. Such a service should be available for purchase *from the State government*, to avoid the risk that there was nowhere for the perpetrator to be moved to. The purpose is to provide SDA to those participants who do not pass the probationary period and whose challenging behaviours are too disruptive for other SDAs available at the time. Given that the SDA, is effectively the family home of the residents, victims must never again be put in a situation where the perpetrator gets to stay on, just because there is no alternative accommodation. There must always be an alternative, and it must be government run so the SDA provider cannot resist taking in the difficult and expensive participant. There has to be an SDA provider that cannot say no. Every disabled person moving out of SDA has to have another appropriate home, no matter how bad their challenging behaviour.

b) If a resident is on some sort of Order (eg a Treatment Order), or has other specific restrictions that protect the other residents, compliance may need to be written into the agreement. The resident must abide by that Order because otherwise the other residents may be adversely impacted. If a resident does not participate with the Order, it could be treated as a breach of the agreement and they have to move out.

c) Another circumstance is where the 'fabric' or configuration of the accommodation offered to a new resident differs to the general situation in the rest of the property. For example a resident may have a courtyard or a car parking spot associated with their residence that others don't have. So additional clauses about that may be relevant in the

agreement for a specific resident, for example to cover maintenance of the special circumstances, or rental amount that differs from other residents.

4.6. Under what circumstances should a resident be asked to sign a new agreement?

Typically, a new agreement should be available for signing at the end of the term of a previous agreement at the request of either party, however, holding-over could also be a viable option. In addition, if a resident breaches an agreement, they should sign a new agreement with new clauses that address the problem, and provide clarity for them as well as the compliant residents. If an existing tenant moves from one part of the property to another, and the new room has materially different conditions to where they were before (eg an ensuite) a new agreement, or new clause in an existing agreement could be applicable.

4.7. How long should the agreement be in place for?

There must be a level of certainty for intellectually disabled tenants. It is extremely unsettling for them to be forced to move from their home and community ties. They also experience difficulties re-establishing connections elsewhere, and have much less choice of alternative accommodation than mainstream renters. PWS is a lifelong disability. People with PWS need intensive support throughout their lives. The SDA agreement should be for five years at minimum. An agreement that's too short may prove destabilizing and stressful for residents.

Given the complexity in accommodation choices for the intellectually disabled, many families have proposed that there should be a 'tenancy-for-life' concept for residents in a property, if they so choose. A longer agreement gives the resident more choice and control over their housing arrangements, helps with NDIS Plan reviews and is more economically sustainable. A longer agreement provides some certainty for all concerned, and allows for a more ordinary life for the participant. The introduction of a 'right-of-first-refusal' may go some way toward addressing a tenancy-for-life option, ie. If the tenancy is being re-leased then the sitting tenant has the first right to take up the tenancy.

The agreement must contain clauses that enable residents to move out within the period of the agreement, without undue disadvantage. This might become necessary if family supporters were situated elsewhere, or a vacancy unexpectedly became available in more suitable accommodation, as forecast by the participant's Plan.

If there is unresolvable conflict between residents, the instigator/perpetrator may be obliged to leave, before the expiration of the agreement.

5. Housemates

5.1. What role should residents have in choosing the new housemate?

Residents must have the opportunity to influence the selection of a proposed housemate, based on known grounds. Prospective housemates should provide a reference or profile to demonstrate their likely compatibility. The NDIS will need to fund the SIL for this administrative process for both the incoming participant, and the selection process in the SDA. The situation must not occur again, where unsuitable housemates are housed with residents without any kind of input from the existing residents (and their key supporter, where applicable). For example, with PWS, there is a specialist

management framework, that includes ongoing restrictive practices (eg food access). Existing residents would want confidence that their health and well being would not be jeopardized by alternative food access arrangements for a new resident.

5.2. What would that role look like and what are the different interests that should be considered?

The existing resident or their nominee/advocates would need to support the existing residents through the selection process. Ideally each SDA would have a micro-board or residents' committee that could perform the selection function in consultation with the SIL provider. The SIL provider could 'short-list' applicants. In relation to compatibility, the interests that should be considered are:

- Ability of new resident to comply with agreements and house rules
- Acceptance of restrictive practices already in place in the property
- Compatible ages
- Similar values and therefore behavioural expectations
- Gender (if a preference)
- Whether they already know each other and like or dislike each other
- Willingness to use the same SIL provider for 'daily life at home' support in the property, to minimize the intrusion of many different provider companies coming and going
- Have a similar level of tolerance to the amount of activity in the household. For example, some people may find noise, music or involuntary vocalisations by others disturbing, which increases stress and disrupts their own behaviour. Some people may be upset by others roaming the house at night.

5.3. Who should oversee disputes about this process?

Residents' views should be given priority. A group of representative stakeholders may attend a mediation meeting as a preliminary step, which could be chaired by the SIL provider. Alternatively, it could be chaired by an independent advocacy organisation or the Consumer Affairs Victoria's free conciliation service. The dispute may be resolved there. Stakeholders who are in a conflict of interest situation (such as the SDA or SIL provider who may desire to 'fill a gap' for financial reasons alone, or the state government seeking to transition its former clients in a hasty manner) should not be the ones to settle the dispute. The NDIS must fund appropriate supports for the resident who initiates the dispute resolution process. Standard rules should apply to such NDIS mediation sessions, so that the disabled and their supporters know what to expect.

5.4. Who makes the final decision?

An independent body should settle the dispute, if not resolved through earlier mediation – preferably the independent statutory complaints body (eg NDIS complaints Commissioner), because they will have the best experience of the issues with this cohort. Alternatively, Consumer Affairs Victoria's free conciliation service could open a specialist unit for NDIS matters, or, since it's a federal program, which should be delivering nationally consistent decisions, the AAT.

6. Accessing the house and room

6.1. When should a service provider or landlord be able to access the house?

The landlord should not be able to access the house any more often, or for reasons different to those that exist for mainstream tenancy arrangements under the Residential Tenancies Act. At times, the SIL provider may also be the SDA provider. If so, a 'Chinese wall' should exist, so that the SIL provider contacts a 'landlord' representative for any matters related to the tenancy agreement.

There are broadly two SIL service types: supports for 'daily life at home' and the supports for everything else, out of the home, for example to access the community. In principle, there must be absolute clarity and transparency for the residents, and their nominees, about who will be in their home, and when. Therefore, a fortnightly roster should be in a prominent place at all times, that illustrates when this service provider can have its 'daily life' staff in the house. This way, residents can be confident and comfortable with a predictable arrangement.

In relation to other supports, a different service provider may attend the home to support a specific resident. At minimum, the attendance times must be documented in each resident's file. That way, a reconciliation can be done with planned services, services actually delivered and services charged. This record will inform the staff providing 'daily life at home' support of the times when other providers should or should not be entering the house. The 'daily life' staff in the house are the only ones who can verify that another service provider met their service level agreement, so those SIL staff must have adequate NDIS funds to undertake this administrative monitoring on behalf of the participant.

At times, a particular resident may invite a service provider into the house outside documented plan hours. This would be on a 'guest' basis.

At times the provider of in-home supports may also provide some other supports.

6.2. When should a service provider or landlord be able to access the room?

The landlord (SDA provider) and SIL providers are different. The landlord should not be able to access the property any more often, or for reasons different to those that exist for mainstream tenancy agreements.

At times, a particular resident may invite the SDA service provider into their room. This would be on an ad hoc, verbal consent basis, perhaps to assess an immediate maintenance issue.

The SIL staff providing 'daily life at home' support have an obligation to ensure the property and its residents live a safe and ordinary life. The SIL provider should enter the room to support the participant, on request or as indicated by the resident's NDIS Plan. In addition, the SIL provider should enter the room in an emergency, and to provide health support.

The SIL provider must ensure there are no OH&S issues in the property, including in individual rooms. It means entering a room where a resident is hoarding to an extent beyond the ordinary, where an unclean room either smells bad, becomes un-cleanable or otherwise impacts adversely on other residents. So, whilst entry to a room or ensuite should in principle be by invitation of the resident only, if the resident has demonstrated that they are not able to keep their room(s) in an ordinary condition, then the SIL provider must enter the room, preferably on a scheduled weekly basis agreed with the resident, to support the resident to tidy and clean the room and its contents (to an ordinary standard). People with PWS typically lack adequate executive brain function and then cannot, without support, adequately plan, organize and do the series of steps needed for finishing housework.

6.3. How much notice should a service provider or landlord give the resident?

The landlord should give the same amount of notice, as in mainstream tenancy agreements. A service provider, who is not part of the regular, tasks of daily life care team should give at least 24 hours notice.

7. Paying rent and money management

7.1. Should SDA residents have to pay a bond?

No. SDA residents are typically low income. However, when a resident moves out, if the room is not clean (which a Nominee/key supporter may choose to assist with), then a charge to the former resident for packing and cleaning should be allowed. This expense should be included in a participant's tenancy obligations funding, when they are moving out. (Also, see 9.1 about damage).

7.2. Who should manage disputes about rent?

The independent statutory complaints body (eg NDIS complaints Commissioner) should have an SDA 'branch'. They would have the most experience with this cohort and the unusual circumstances of group home arrangements. However, Consumer Affairs Victoria has a free conciliation service that may assist if they were trained in the group home model and SDA obligations, then VCAT or the AAT should decide rent disputes. However, there should be a step beforehand, to attempt a mediated resolution. A body like the Dispute Settlement Centre of Victoria could assist. There must be clarity about who can support the resident lodging the dispute, for example a 'support for tenancy obligations' person, who will build a body of knowledge about how the SDA rent program works, and can identify any unfair or unreasonable practices if they are attempted by a landlord, and costing the NDIA money.

7.3. What could be done to prevent financial exploitation by service providers?

SDA users must have access to credible, neutral market comparison information. Information asymmetry must not be allowed to occur. Strong regulatory mechanisms must be in place to protect participants, particularly those vulnerable through cognitive impairment. There must be transparency about all charges in SDA, at the per room level. That is, participants should be able to see the board and lodging charges in a property at any time – before moving in and while residing at the residence. There must be clarity about baseline charges for generic daily life tasks ('housework') services and how a service provider proposes to apportion such shared services across residents. Each incumbent resident (and their nominee) must be able to look into the NDIS portal to see their charges *itemized* on their invoices.

NDIS participants must be able to learn the rental price of a room in any SDA vacancy in Victoria, so that they can make a choice about whether to apply, should a room become vacant (similar to the process that enable people to see the amount for ordinary rental vacancies advertised on real estate websites). Also, at any point in time all residents in a particular property should be able to see the charge for every other room/unit in their property, not just when a vacancy arises. That time would be too late to take action on any inconsistency.

In terms of SIL providers, there is an expectation that the staff in the SDA will monitor any third-party service providers on behalf of their participants. So, for example, if a third-party provider is running late without an excuse, or doing it often, or taking out more than one participant when they are funded for a one-to-one service, then it must be reported to the disabled person's independent support coordinator, Nominee or other responsible person, such as the Administrator. Action can then be taken to either confirm expectations and have those met, or change provider.

A centralized body, preferably the independent statutory complaints body (eg NDIS complaints Commissioner) must participate in managing the risks of exploitation, in case providers delivering SIL and SDA supports are not totally honest. A central authority can manage risk by using 'big data' to analyse trends and identify potential risks. The central body should be collecting data from across Australia to give insights that will allow prevention of problems before they happen. Centralised 'big data' will also allow the independent statutory complaints body (eg. NDIA Q&SF Registrar / complaints Commissioner) to identify emerging issues and opportunities and make recommendations about improved NDIS operations.

7.4. How much notice should landlords give of a rent increase?

For people on a Commonwealth Disability Pension, it should be written into their tenancy agreement that there shall be no rent increases if the tenant has not had an income increase. Then it should be stated that *if* a resident has a pension and/or a Commonwealth Rent Assistance and/or an SDA funding increase, then the landlord can time an *optional* rent increase to coincide with the resident's income increase.

7.5. How often should landlords be allowed to increase the rent?

Rent rises must not be allowed at all if Commonwealth income (eg Centrelink pension, Commonwealth Rent Assistance, and the NDIA SDA payment) have not *a* been increased. A landlord cannot seek disproportionate rent increase (eg from all sources of the resident's income) if not all sources have been increased. In other words, if a participant's income has not gone up, then neither should the major outgoing, accommodation, go up. Even if regular rental returns in the same geographic area have gone up, disabled people must not be put at risk of being priced out of their own home.

Prices charged for all rooms in a property should be reviewed at the same time, not more than twice per year as occurs with ongoing mainstream rental agreements, subject to residents' income from the Commonwealth, as mentioned above. Any rent increase should be synchronized amongst residents. This helps the resident with their budgeting and provides transparency for options in the property itself. It also helps the SIL provider who may be impacted in some way, for example fielding questions and administering paperwork.

8. Modifying the house

8.1. What are the key issues when considering obligations to make modifications?

- Modifications must meet Australian Standards
- Modifications must be made in a timely manner (ie process of getting quotes and commencing work to start immediately when the need is confirmed)
- Where will the resident(s) live whilst modifications are made? (See 10.2)

- Modifications should not adversely impact on other residents' amenity (for example the size of, shape of, or light and ventilation into other residents' rooms)
- Modifications should not detract significantly from the overall aesthetics of the property, inside or out (for example tiles or paint colours should conform to existing, etc)

8.2. Who should oversee the landlord's responsibility to make modifications?

The NDIA independent statutory complaints body (eg NDIA Q&SF Registrar / complaints Commissioner) must oversee, monitor and enforce Landlord's responsibilities. This is because it will (a) make it easy to report transgressions or tardiness to the NDIA, (b) the NDIA will be able to take appropriate action through its SDA arrangements, and (c) holding *centralized* data will allow for proper analysis and detection of outliers and repeat offenders, thereby enabling proactive action to be taken.

8.3. What should happen if part of the property cannot be used while modifications are made?

Perhaps there should be a discount in rent for existing residents who are inconvenienced during a modification process (eg one bathroom unavailable). The SIL provider will need to advocate for fairness for residents who will not know how to negotiate, or when. The NDIA will have to allow NDIS funds for this type of tenants' rights support, which may apply equally to all residents, or just individuals. A landlord should not be deterred from making modifications however, so if a vacancy cannot be filled until after the modification, the SDA fund should make up the rental difference, not the residents who are adversely impacted.

8.4. How will this intersect with the role of the NDIA Registrar under the Quality and Safeguarding Framework (Q&SF)? (please see section 2.4 of Consultation Paper)

Ultimately the Q&SF Registrar / Complaints Commissioner must take on any SDA problems not being properly dealt with by the States. The NDIS is new, and the gaps in the system are yet to emerge and need action. Where gaps are identified, the NDIA must step to protect the individuals and modify the Q&SF scope, where required. Also, to protect the disabled, the Q&SF Registrar must hold the providers to account if providers find loop-holes in State based rules and regulations,.

9. Repairing damage

9.1. When should SDA residents have personal liability for property damage, if ever?

The house will be attracting funding for a particular NDIA design category, applicable to those residents. This means for 'robust' designs, the landlord is already being paid an offset amount of SDA funding. If deliberate damage is done, then the resident should pay for that on an ad hoc basis, subject to hardship considerations and the cognitive understanding of the individual, and after the SDA funding and insurance have been factored in.

9.2. Who should oversee disputes about repair and maintenance of SDA?

An independent statutory complaints body, or VCAT should decide rent disputes. (with the AAT or NDIA Q&SF Registrar / complaints Commissioner stepping in if it's found that there are circumstances that don't allow State bodies to intervene, or State body decisions would result in inconsistency nationally). However, there should be a step beforehand, to attempt a mediated resolution. A body like the Consumer Affairs Victoria's free conciliation service or Dispute Settlement Centre of Victoria could assist.

9.3. How will this intersect with the role of the NDIA Registrar under the Quality and Safeguarding Framework? (please see section 2.4)

Ultimately the Q&SF Registrar / Complaints Commissioner must take on any SDA problems not being properly dealt with by the States. The NDIS is new, and the gaps in the system are yet to emerge and need action. Where gaps are identified, the NDIA must step in to protect the individuals and modify the Q&SF scope, if needed. It must also hold the providers to account if they find loop-holes in State based rules and regulations, to protect the disabled. The Q&SF Registrar / Complaints Commissioner will build up the best knowledge and expertise about the more contentious aspects of the NDIS and so should always be ready to participate in untangling disputes where this has not been achieved in a more local jurisdiction.

10. Notice to vacate and relocation

10.1. How should landlords consult with residents about temporary relocation?

Consultation must be with the resident, their Nominee or Guardian and the SIL provider simultaneously. The mechanism must include both a written proposal, and after the consultation a written conclusion detailing what was finally agreed (Refer to 10.2).

10.2. Should temporary relocation continue to be regulated? How?

Yes, it must continue to be regulated to ensure minimum disruption to residents and removal of any risk of the relocation being unfair, unpredictable and unmanaged. Disabled people must not be left uncertain or homeless.
The current provisions in the *Disability Act, 2006 (as amended*) and the DHHS Residential Services Practice Manual 3rd Edition are adequate protection.

10.3. How much notice should a landlord give a resident to vacate?

As in the current Disability Act or longer if no alternative accommodation is found and secured.

10.4. Should a landlord require a reason to notify a resident to vacate?

Yes, all relevant parties must know the reasons, to ensure there is no exploitation or unethical practices by landlords. Reasons given by landlords must be retained and reported to the Q&SF Registrar / Complaints Commissioner so that they can build up a pattern to identify if any SDA providers are performing below expectations (ie to protect residents with cognitive impairments).

10.5. What kind of reasons are acceptable?

As per the current Disability Act, 2006 (as amended) and the DHHS Residential Services Practice Manual 3rd Edition.

10.6. How should residents notify the landlord that they are initiating a change of accommodation?

Residents should notify their landlord and service provider of their intention to leave in writing. The resident's Nominee or other supporter may assist with this notice. However, residents with PWS can be ill prepared for a move; they do not have the cognitive ability to foresee the consequences or do the planning needed to ensure a suitable alternative SDA placement. A vulnerable person could be lured to a new SDA with inducements (eg a free computer) but actually be worse off. So, a notice to vacate cannot and must not be accepted by the current property landlord or SIL provider unless it (a) has been endorsed by the participant's own NDIA SDA Tenancy Planner/ Coordinator, and (b) they have received written proof that the moving resident has guaranteed sustainable accommodation / SDA placement somewhere else (otherwise the resident could become homeless).

10.7. Should there be a minimum notice period?

Yes there should be a minimum notice period, based on the current Disability Act and RSPM.

10.8. What should happen if a resident vacates without any notice?

If the departure was voluntary, the resident would forfeit their rent for the number of days that fall short of the agreed notice period.

10.9. Who is responsible for sourcing alternative SDA after a notice to vacate?

For people with PWS, sourcing alternative SDA must occur before a notice to vacate. Otherwise the resident may have no home to go to. The NDIS must urgently supply funding for an NDIA SDA Tenancy Planner/ Support Coordinator (if not already in the Plan). The state government must retain ultimate responsibility for the safety and housing of its most vulnerable citizens. The state government must ensure there is a provider of last resort who cannot refuse to take on an NDIS participant if they are forced to vacate their SDA.

10.10. Who is responsible for sourcing alternative SDA during a temporary relocation?

If a participant has breached the rules and has been asked to move by a provider, the NDIS must urgently supply funding for an NDIA SDA Tenancy Planner/ Support Coordinator (if not already in the Plan).
If a provider (SDA or SIL) is causing the temporary relocation for reasons other than unsuitability of the resident, they must be proactive in sourcing alternative accommodation.

10.11. How should residents be supported to complain or request review?

For those with intellectual disabilities and/or cognitive impairments, there should be provisions in place that mirror those under the current Disability Act, 2006 (as amended) and the DHHS Residential Services Practice Manual 3rd Edition. Independent advocates are crucial.

11. House management

11.1. Who makes decisions about how the house operates?

There could be some generic, 'model' house rules supplied by the 'Daily life' service provider, that they have proven as a good model. The rules could cover some of the operations. Other matters that require more flexibility such as meal times, shower rosters, housework rosters, TV usage, noise levels, etc must be decided by the residents firstly, where they are capable.

The residents and their supporters can assess those model rules and operational suggestions from the service provider, and amend, for local, agreed preferences.

In terms of 'how' a change to model rules could occur, each property should have a 'micro-board'. The board would enable local discussion of house rules and all sorts of house operations matters, including performance of the service provider.

The micro-board should consist of representative residents, their supporters and the service provider. The NDIA must make funds available for the service provider to administer the micro-board, arrange meetings, takes notes, share outcomes, etc.

11.2. Should decisions require agreement between housemates?

In principle, there should be a drive to reach agreement between housemates (or their supporters). If agreement cannot be reached, then the model rule, for that topic should prevail.

11.3. Does the landlord have a role in managing the house?

No. In the mainstream rental market, the landlord has no say in what goes on in the house after the contract with the tenant is signed. At times, the landlord and the SIL provider may be one in the same organisation. As such, there should be a 'Chinese wall' between the SDA operations and the SIL operations.

In the mainstream rental market, a landlord usually has a role in choosing a tenant. However, in SDA, it is preferable that the landlord *not* be involved in tenant selection. This is because the landlord cannot be assumed to understand intellectual disability, nor to prioritise supporting the disabled over making the biggest possible investment return. If necessary, it should be optional for the landlord to participate in tenant selection. And if the landlord does participate, this needs to be moderated, to ensure the privacy of prospective tenants is not breached. (For example, in mainstream rentals the landlord has no access to a prospective tenant's health, disability or police-record status.) The SIL provider, in their role to pre-screen applicants could act as the landlord's delegate in the choice. Alternatively, the SIL provider could give a short list to the land lord with a recommendation. NDIS tenancy support funding should cover this.

11.4. How should issues with or disagreements about house management be resolved?

A house micro-board should be established and be in place at all times. This should be the first avenue to address house management issues. The micro-board should consist of representative residents, their key supporter and the service provider. The NDIA must make funds available for the service provider to administer the micro-board, arrange meetings, takes notes, share outcomes, etc.

If the matter can't be resolved, and/or the service provider is in a conflict of interest situation, then the issue should be escalated to an independent body for mediation, such as the Victorian Neighbourhood Dispute Centre (which must develop specialist expertise in in SDA/SIL obligations and the risk for intellectually disabled residents). The next escalation point would be the NDIS Q&SF

Registrar / Commissioner, who is well equipped to deal with the types of issues confronting the cognitively impaired in the NDIS.

12. Legislation

12.1. What types of oversight functions are needed to protect tenancy rights?

Within the NDIS, there are broadly two tiers of needs: (a) the physical and sensory, with no cognitive impairment, who can potentially self-manage, plus understand mainstream tenancy arrangements and (b) the more vulnerable, those with cognitive/intellectual disabilities who do not have the capability to understand and manage a tenancy by themselves. The Victorian Government had already recognized the vulnerability of the intellectually disabled through the Disability Act (2006). Therefore, people with cognitive and intellectual disabilities need more protections than the mainstream Tenancy rights of ordinary Victorians. Protections need to be regulated, not only dependent on the availability of an NDIA tenancy coordinator.

The types of oversight functions for those with PWS, therefore need to be very protective and robust. Oversight must be driven by proven instruments being legislation, the current Disability Act, 2006 (as amended), and policy and practices being the' Disability Act 2006 Policy and Information Manual, December 2012' and the DHHS Residential Services Practice Manual 3rd Edition. Properly resourced, through NDIS funding, these instruments can bring to life their intent and live up to appropriate quality.

Safeguarding entities need to be acting on behalf of this cohort, to do what they cannot. That is, the landlords need to be monitored, questioned if engaging in outlier practices, held accountable, and be subjected to penalties if they fail to deliver fairness and equity to intellectually disabled tenants. The mainstream tenancy rights regulatory mechanisms, as they stand, will be inadequate to protect this cohort. See Table 1 for an example of operational oversight priorities.

Table 1: A summary of types of day to day oversight functions needed to protect intellectually disabled / cognitively impaired tenants

Rental process overview	**Tenancy Agreement proposed by landlord**	**Value and fairness reviewed and assessed, and negotiations done by:** **(NB could be new or ongoing tenancy)**	**Tenancy Agreement changes (eg rent increase)**	**Value and fairness reviewed and assessed by:**	**Tenancy Agreement breached (eg maintenance not carried out as required)**	**Who notices?**	**Escalates to landlord, and all options above, as required to resolve**	**Systemic protections**
Who notices and actions in mainstream?	A model Agreement is available from CAV. (One Agreement per property leaves no room for confusion)	Prospective tenant	Tenant	Tenant	-	Tenant	Tenant	N/A
Who has to pay attention and/or take action on behalf of the intellectually disabled?	In order of priority, with participant's best interests uppermost: 1. SIL provider – should know the conditions of the other tenants and ensures compatibility with the SIL Agreement 2. Family member/ Nominee/Guardian 3. Advocate from organisation	In order of priority, with participant's best interests uppermost: 1. Family member/ Nominee/Guardian, in consultation with 2. Tenancy Support Coordinator from NDIA 3. Advocate from organisation 4. SIL provider	Tenant's main support and/or whoever signed the agreement on tenant's behalf (eg Financial Administrator). They alert the NDIA Tenancy Support Coordinator.	In order of priority, with participant's best interests uppermost: 1. Tenancy Support Coordinator from NDIA 2. Family member/ Nominee/Guardian 3. Advocate from organisation 4. SIL provider	-	1. SIL provider – should observe problem first hand and report to landlord and 2 below. 2. Tenancy Support Coordinator from NDIA 3. Family member/ Nominee/Guardian 4. Advocate from organisation	1. SIL provider – should know the process and engage 2. Tenancy Support Coordinator from NDIA 3. Family member/ Nominee/Guardian 4. Advocate from organisation	NDIA Safeguarding Registrar receives a pattern of complaints from participants about a landlord. Registrar alerts all Tenancy Support Coordinators who are dealing with that landlord, to exercise extra vigilance in ensuring landlord meets obligations.

12.2. In what legislation should SDA tenancy rights be regulated?

There should be amendments to the current Victorian Disability Act, 2006, as amended (not the Residential Tenancies Act or new legislation). The DHHS Residential Services Practice Manual 3rd Edition should be retained and updated too.

12.3. Should VCAT continue to hear and arbitrate disagreements?

An independent body that has specialist NDIS understanding and experience is essential. That is, the body *must* have a specialist understanding of the interplay between an intellectually disabled tenant (who must not become homeless), a SIL provider's rights, obligations and potential conflicts of interest and SDA landlord's obligations as they differ from mainstream.

Since the NDIS is national, it would seem more appropriate for the Administrative Appeals Tribunal Australia (AAT) to develop specialist NDIA expertise within a new Branch, to address participant tenancy issues. This would support consistent decision making.

12.4. What other options should Government consider?

Tenancy in SDA is not the same as mainstream tenancy. People with intellectual disabilities and cognitive impairments need extra protections. The State Government should:

- Become an 'SDA-SIL *integrated*' service provider under the NDIS, not able to refuse or eject a participant, for the most needy participants, and
- Set up an independent decision making body with exclusive expertise in NDIS dispute resolution.
- Participate proactively in 'weeding out' unsuitable providers (and individuals) before they become a major problem, by harnessing the power of 'big data'. That is, State Government has 'instruments' that regulate service providers. These instruments must compel providers to report on minor incidents (not just major) to DHHS (or a disputes body. The data must be captured and analysed centrally. This body (or DHHS) must then act on any patterns of concern, to hold providers and individuals accountable, report them to the NDIA Q&SF Registrar/Commissioner and/or bar them from NDIS participation.

13. Other matters

13.1. Is there anything we have missed?

Victorians with intellectual disabilities and cognitive impairments must be protected by the Victorian Government, when the NDIS vision falls short in support. The State Government will need to continue with the Disability Act, Policy and Manuals to provide options to Victorians who are cut out of support in SDA, even when the participant is NDIS funded, for example, complex participants with challenging behaviours.

The landlord must be compelled to work with the SIL provider and vice-versa. The landlord (or his agent) must have a service level agreement for communications from the SIL. These might be maintenance requests or modification requests or anything. OH&S risk are greater for people with PWS who have reduced mobility and ability to cope with change. Restrictive practices may include modifications to the physical environment that other NDIS participants don't need. However, for PWS residents the modifications *must* be done.

It is *not* appropriate to move violent participants from one house to another, like occurs in the current system. There must be an improved process. There should be a process for potential resident reference check, that existing residents can access when a participant applies for SDA. It should not be up to the SIL provider alone, who might be in a conflict of interest situation.

13.2. Is there anyone missing who should be covered by this new framework?

The roles of the Public Advocate and Community Visitors in supporting those with intellectual disability must be included explicitly in the amended Disability legislation, regulations and rules about SDA and the SIL in SDA. People with intellectual disabilities are at great risk of being under serviced, whether deliberately or not. Such participants need a variety of safety mechanisms available to them because they will have varying levels of capability as individuals and within their own support networks.

14. Conclusion

Adults with Prader-Willi syndrome (PWS) exhibit high anxiety, complex and at times challenging behaviours and cognitive dysfunction throughout their lives. They also typically have an intellectual disability.

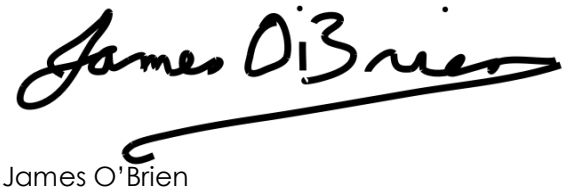
The members of the PWS Association are very concerned that the tenancy rights of people with PWS are protected by a series of strong and inter-connected legal mechanisms for this very vulnerable cohort.

The recommendations of the PWS Association members are broadly that:

- tenancy agreements should aim to be the same, except for room differences; they should be available to all residents to reduce unscrupulous practices, and maximize choice; SDA rent offerings and charges should be visible to the public, across Victoria
- protections must be in law: the current Victorian Disability Act, 2006, as amended (not the Residential Tenancies Act or new legislation) should contain the SDA tenancy laws. The DHHS Residential Services Practice Manual 3rd Edition should be retained and updated too.
- tenants should be empowered to have the maximum possible input (in line with their capability) into the operations of their home, and who lives there. This input could be supported through the introduction of local house rules and a micro-board for each house, to act as a local governing committee
- residents/tenants have the right to have a Nominee/key supporter help them in all their tenancy matters if they choose
- various roles within the tenancy 'ecosystem' must cooperate and coordinate in protecting the rights of the PWS resident (where a person without an intellectual disability could perform most of those roles alone)
- temporary and permanent relocation must be carefully and tightly managed to avoid uncertainty and homelessness
- the landlord should have a minimal role in the operations of the house after the tenancy agreement has been entered into, and perform in accordance with the contract (as in mainstream arrangements)
- the landlord must not jeopardise a resident's tenancy (for example by adding unsustainable costs when the resident has not had the same relative increase in income), or by manipulating rents within one property where conditions are identical

- the State Government should become a service provider under the NDIS, offering an *integrated* SDA-SIL service package, to ensure that people with PWS will always have at least one option for these types of supports, with low risk and low administrative overheads
- an independent dispute resolution body(s) must exist that has NDIS expertise, particularly in relation to the intellectually disabled, and the assurance that they must not become homeless.

Current SRS accommodation as regulated by DHHS is, in most instances, not suitable for people with PWS. Experience has shown the level of support is wholly inadequate. People with PWS must have access to PWS-appropriate SDA (and SIL) and MUST NOT be allowed to become homeless or under-serviced.



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