



**Submission to the Joint Standing Committee on the National Disability  
Insurance Scheme**

**Inquiry into Accommodation for People with a Disability and the NDIS**

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## 1. Executive Summary

The Prader-Willi Syndrome Association of Australia (PWSAA) is an Australia wide organisation that is mandated to promote the care, welfare, treatment, interest, education and advancement of persons with Prader-Willi Syndrome.

The PWSAA makes this submission to provide evidence that people with Prader-Willi Syndrome need affordable accommodation, subsidised by the NDIS in combination with the State government that can provide actual land and buildings from public or community housing stock. It points out that people with PWS:

- require a specialist built form of accommodation, and
- depend on the Disability Pension to survive and so must have an affordable accommodation option readily available (eg 'group home').

The PWSAA explains that integrated PWS-specific accommodation and services, delivered in accordance with the international 'Best Practice Guidelines for Standard of Care in PWS (2010)', will provide the kind of support envisaged by the NDIS for vulnerable participants.

The submission lists health and behavioural characteristics of people with PWS, to illustrate their particular accommodation needs, which are complex and challenging.

The PWSAA makes a series of recommendations in relation to affordable accommodation:

- (i) One of the accommodation choices available must be PWS-specific accommodation. The option to choose PWS-specific accommodation must be readily available.
- (ii) PWS-specific accommodation should be small group home style (or equivalent care proximity).
- (iii) The cost of providing PWS-specific land and buildings will be non-standard both in size and construction, requiring a specialist built form. The NDIS needs to reflect this in its benchmark pricing to housing providers so that people with PWS are not disadvantaged.
- (iv) In setting prices, the NDIS must allow for lower occupancy rates in PWS-specific accommodation.
- (v) The PWSAA perceives a risk that housing providers may let building maintenance fall behind schedule. There needs to be a mechanism of standards, monitoring and compliance in place.
- (vi) There needs to be a tenancy contract template available for SDA residents in PWS-specific accommodation.
- (vii) The NDIA needs to make available to community members robust legal 'model contract' templates, to facilitate arrangements where the NDIA and families can contribute to shared equity (or similar) in appropriate accommodation.

The PWSAA welcomes further dialogue with the NDIA to improve understanding and development of appropriate, affordable accommodation for people with PWS.

## 2. Purpose

This submission is a response to the Inquiry into Accommodation for People with a Disability and the NDIS, being held by the Joint Standing Committee on the National Disability Insurance Scheme (NDIS).

### *Need*

The purpose of this submission is to inform the Committee about the specialist accommodation needs of people with Prader-Willi Syndrome (PWS) and make recommendations for accommodation.

The submission provides evidence that subsidised disability accommodation is essential for participants with PWS in the NDIS. It points out that people with PWS:

- cannot hold down open employment,
- cannot sustain full time supported employment,
- depend on the Disability Pension to survive,
- have high support needs that require 24/7 care,
- require a specialist built form, and
- therefore need affordable accommodation, subsidised by the NDIS in combination with the State government that can provide actual land and buildings from public or community housing stock.

### *Best practice*

Another purpose of this submission is to inform the Committee about the internationally recognized management model for people with PWS. A group of multi-disciplinary specialists in the field of PWS collaborated to produce the 'Best Practice Guidelines for Standard of Care in PWS (2010)'.<sup>1</sup> Their efforts were driven by common observations that people with PWS have high and unmet support needs. The patients were not achieving their potential because the complex, pervasive characteristics of their syndrome were poorly understood. The specialists concluded that a holistic and multi-disciplinary approach to the many instances of challenging behaviour and psychosocial impairment is essential. This style of care will minimize the effects of the features of the disability and allow an overall quality of life.

The best practice Guide describes intensive positive behavior support, including structuring the built environment so that food access is effectively managed, tantrums are reduced and danger minimised. **"The preferred form of living arrangement is in a PWS-specific environment.** This allows for consistency in treatment and a sense of fairness to the individual."

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<sup>1</sup> International Prader-Willi Syndrome Organisation, <http://www.ipwso.org/#!/best-practice-guidelines-for-pws-care/c1jg>

### 3. About the Prader-Willi Syndrome Association of Australia

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*Our Vision: That society recognise, as individuals, all people with Prader-Willi Syndrome and acknowledges and supports their right to participate in all facets of community life.*

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The national Prader-Willi Syndrome Association of Australia (PWSAA) was set up in 2000. It comprises representatives from those States in Australia where there is an affiliated Prader Willi Syndrome (PWS) group. If a State or Territory does not have its own Association, individuals have become members of the Association in their nearest State.

The State Associations provide support and services for members in their local area. The national Association is involved in issues that are relevant Australia wide. These include such things as the development and dissemination of educational material about the condition, liaison with Government on funding for pharmaceutical treatments and the promotion of ethical research into management of the condition. PWSAA promotes the interests of people with PWS where this is more valuable than the State Associations progressing alone.

#### *Mission*

The PWSAA is committed to enabling people with Prader-Willi Syndrome to live their lives to the full through:

- promoting the care, welfare, treatment, interest, education and advancement of persons with Prader-Willi Syndrome by any appropriate means
- acting as a unified group federally and internationally to seek funding on behalf of State/Territory affiliated Prader-Willi Syndrome Associations and the Association
- informing health professionals, families and the public in general about the disorder by any appropriate means.
- raising funds and to invite and receive contributions by way of subscriptions, donations and otherwise.
- requesting research funding on causes and prevention of Prader-Willi Syndrome, knowledge of the condition and other associated conditions and promoting existing Australian research and encouraging further new research in Australia into the Syndrome
- acting as a national central Association for the collection and dissemination of internal and international developments and information of interest to all affiliated Prader-Willi Syndrome State /Territory Associations.

## 4. Overview of Prader-Willi Syndrome

Prader-Willi Syndrome is a rare and complex disability. It is a multi-system disorder which includes intellectual disability and results in both health issues *and* challenging behaviours. It has a genetic cause, and is life-long. People with PWS cannot live independently.

### Health

The international PWS organisation highlights the typical health issues<sup>2</sup> for a person with PWS. :

*“Life [is] dominated by a voracious appetite and drive for food. This striving for food combined with a lower than normal calorie requirement and, frequently decreased activity related to the hypotonia, will result in rapid weight gain if not controlled externally, leading to obesity and eventually the consequences of obesity: respiratory difficulties, heart disease, diabetes, and other problems.”*

In addition, IPWSO reports other common issues including back and joint problems, oedema (fluid retention), dry skin (picking, sensitive), osteoporosis, stomach and bowel problems, sleep problems, unexpected reactions to some medications, temperature instability and sensitivity, increased risk of psychiatric behaviours, hormone deficiency and dental problems.

If food access is left unmanaged, people with PWS die younger, and have a higher mortality rate than other (matched) intellectually disabled people, due to obesity factors.<sup>3</sup>

### Challenging behaviour

People with PWS have chronic behaviour disturbance and can be argumentative, aggressive and destructive. They tell many lies. Due to cognitive impairment, they are impulsive and have poor executive functions, leading to very poor decision making. When they get into an anxiety state, they present a risk to themselves and others around them. The variety of challenging behaviours means they cannot earn an income sufficient to pay for accommodation on the open market. Evidence shows that:

- There is “a typical neurobehavioral profile that includes altered intellectual functioning and centrally driven maladaptive behaviors” and a “commonality of hoarding; cognitive rigidity along with the need for sameness, temper outbursts and emotional lability, repetitive and perseverative behaviors”. Also found was “cognitive dysfunction, social and emotional immaturity” along with “manipulative and sometimes illegal behaviors designed to acquire food” and “increasing oppositional tendencies”<sup>4</sup>

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<sup>2</sup> Description of PWS clinical features <http://www.ipwso.org/#!/what-is-prader-willi-syndrome/clxd>

<sup>3</sup> Einfeld, S.L. and Kavanagh, S.J., Mortality in Prader-Willi Syndrome, Am J Ment Retard. 2006 May; 111(3): 193–198. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2422866/>

<sup>4</sup> Cataletto, M., Angulo, M., Hertz, G., and Whitman, B., Prader-Willi syndrome: A primer for clinicians, Int J Pediatr Endocrinol. 2011; 2011(1): 12, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3217845/>

- “Many individuals also have specific emotional and learning disabilities which can impact on behaviour... evident even where the person is functioning at a relatively high intellectual level”<sup>5</sup>
- “Individuals with PWS typically have intellectual disabilities (borderline to mild/moderate mental retardation) and exhibit a higher overall behavior disturbance compared to individuals with similar intellectual disability.”<sup>6</sup>
- “People with PWS are more prone to temper outbursts than people without PWS at similar levels of development”<sup>7</sup>. This can result in property damage. Reinforced construction is necessary.
- There is “...a striking autistic-like behavioral phenotype in the majority of the PWS individuals, particularly deficits in the quality of language and communication and of imagination and interests.”<sup>8</sup>
- “...the most common error is to underestimate the complexity of the disorder”<sup>9</sup>
- “...competitive employment is rare...”<sup>10</sup>

In relation to the impact of specialised accommodation for people with PWS, research has found a significant and beneficial impact on resident health, with a reduction in weight and diabetes medication.<sup>11 12</sup>

“For adults with PWS, one successful living situation for behavior and weight management is a group home specially designated for individuals with PWS. Affected individuals generally require a sheltered employment environment.”<sup>13</sup>

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<sup>5</sup> PWSA UK, Behaviour Management in Prader-Willi Syndrome, 2002, [www.pws.asn.au/Behaviour%20Management.pdf](http://www.pws.asn.au/Behaviour%20Management.pdf)

<sup>6</sup> Ho, A. Y. and Dimitropoulos, A., Clinical management of behavioral characteristics of Prader-Willi syndrome, *Neuropsychiatr Dis Treat.* 2010; 6: 107–118o <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2874334/>

<sup>7</sup> PWSA, UK, Behaviour management in PWS, 2014, [www.pwsa.co.uk/assets/files/behaviour\\_management.pdf](http://www.pwsa.co.uk/assets/files/behaviour_management.pdf)

<sup>8</sup> Descheemaeker, MJ, Pervasive developmental disorders in Prader-Willi syndrome, *Am J Med Genet A.* 2006, Jun 1;140(11):1136-42, <http://www.ncbi.nlm.nih.gov/pubmed/16646032>

<sup>9</sup> Gourash, L.M., MD and Forster, J.L., MD, Pittsburgh Partnership, 2009, [www.pittsburghpartnership.com/handouts/The%20Behavioral%20Challenge%20for%20Professionals.pdf](http://www.pittsburghpartnership.com/handouts/The%20Behavioral%20Challenge%20for%20Professionals.pdf)

<sup>10</sup> Reynolds, C.R and Fletcher-Janzen, E., Prader-Willi Syndrome, *Encyclopedia of Special Education (3rd Ed.)*, Vol 3, 2007,

[http://50.30.47.15/Ebook/bangla/Special\\_Education/Encyclopedia\\_of\\_Special\\_Education\\_\(3rd\\_edition\\_2007\).pdf](http://50.30.47.15/Ebook/bangla/Special_Education/Encyclopedia_of_Special_Education_(3rd_edition_2007).pdf)

<sup>11</sup> Kaufman H, Overton G, Leggott J, Clericuzio C., Prader-Willi syndrome: effect of group home placement on obese patients with diabetes. *South Med J.* 1995 Feb;88(2):182-4 <http://www.ncbi.nlm.nih.gov/pubmed/7839160>

<sup>12</sup> Stevenson, D.A., MD, Heinemann, J., MWS, Angulo, M., MD, Butler, M.G., MD, PhD, Loker, J., MD, Rupe, N., BS, Kendell, P., BS, Cassidy, S.B., MD, and Scheimann, A., MD, Gastric Rupture and Necrosis in Prader-Willi Syndrome *J Pediatr Gastroenterol Nutr.* 2007 Aug; 45(2): 272–274. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3241991/>

<sup>13</sup> Driscoll, D.J., MD, PhD, FACMG, FAAP, Miller, J.L., MD, MS, FAAP, Schwartz, S., PhD, FACMG, and Cassidy, S.B., MD, FACMG, FAAP, Prader-Willi Syndrome, *GeneReviews*, Initial Posting: October 6, 1998; Last Revision: January 23, 2014, <http://www.ncbi.nlm.nih.gov/books/NBK1330/>

## 5. Recommendations

Adults with Prader-Willi Syndrome have a low income and complex needs which require integrated housing and service support. For people with PWS to receive the supports that meet the purpose of the NDIS<sup>14</sup> and to have a quality life, the PWSAA makes the following recommendations about accommodation:

- (i) *One of the accommodation choices available must be PWS-specific accommodation. The option to choose PWS-specific accommodation must be readily available.*

The integration of the built environment and services needed to support those with PWS is best met with purpose built (or retro-fitted) accommodation. The 'Best Practice Standard of Care in PWS' management model can be readily implemented in the appropriate physical environment.

- (ii) *PWS-specific accommodation should be small group home style (or equivalent care proximity).*

A household is in itself a little community, within tiers of community. There is an opportunity for feelings of connectedness, and to build social skills. A safe and predictable home environment with 2 or 3 housemates and skilled staff reduces anxiety and challenging behaviour. PWSAA supports endeavours by individuals to find single person accommodation, however, given that people with PWS have high, 24/7 support needs, group accommodation may be more sustainable than 24/7 care in single-person accommodation. There are health and safety benefits of a group home (or collection of 'bungalows' or 'apartments' with main residence having 24/7 disability support), which provides social interaction.

- (iii) *The cost of providing PWS-specific land and buildings will be non-standard both in size and construction, requiring a specialist built form. The NDIS needs to reflect this in its benchmark pricing to housing providers so that people with PWS are not disadvantaged.*

An example of a purpose built shared supported accommodation home for people with PWS by Interaction Disability Services Ltd for planned construction in Sydney is at Attachment 1. Also, the state of Florida in the USA recently built a PWS specific home. The specs could be made available to the NDIA. It includes features like a locked kitchen and reinforced construction to withstand excessive weights or damage caused by violent outbursts of residents and sufficient breakout areas to provide chill-out opportunities.

- (iv) *In setting prices, the NDIS should allow for lower occupancy rates in PWS-specific accommodation.*

If there is a vacancy, it is likely to take longer than usual to fill. This is because people *without* PWS are unlikely to want to reside in accommodation that has a practice restriction on food access, even though this measure is vital for maintaining good health and reducing the risk of early death. Also, due to social deficits and high anxiety in PWS, the introduction of a new housemate must be done with caution to avoid escalating undesirable behaviours. A PWS-specific group home will ideally have 4 or less residents (based on recent experience in Australia).

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<sup>14</sup> What are reasonable and necessary supports: <http://www.ndis.gov.au/participants/reasonable-and-necessary-supports>

- (v) *The PWSAA perceives a risk that housing providers may let building maintenance fall behind schedule. There needs to be a mechanism of standards, monitoring and compliance in place.*

It is expected that an independent supplier be involved in monitoring and reporting.

- (vi) *There needs to be a tenancy contract template available for SDA residents in PWS-specific accommodation.*

In particular, to ensure PWS care standards continue to be met, there needs to be clauses about the process for selecting new tenants, facilitating choice around exiting the facility for tenants and removing unsuitable tenants. A clause needs to inform tenants about food restrictions that apply. There needs to be clarity about how service providers will be selected and given access to the premises, because food restrictions apply to care staff as well.

- (vii) *The NDIA needs to make available to community members robust legal 'model contract' templates, to facilitate arrangements where the NDIA and families can contribute to shared equity (or similar) in appropriate accommodation.*

At present community members and housing providers have no clarity about, or confidence in the arrangements for secure joint funding models.

It is not practical or cost effective for legal contracts to be obtained by families of housing providers on an individual basis.

Contracts under these new conditions where there are at least three parties to the contract (provider, disabled person/their rep and the NDIA) are untested. The NDIA should work with stakeholders to develop model contracts, or facilitate an advocacy group such as the Prader-Willi Syndrome Association to work with a legal provider to develop draft for consideration across Australia.



## 6. Conclusion

Prader-Willi Syndrome is a complex condition. People frequently display challenging behaviours that present serious risks to themselves and others. They are not able to survive without affordable and appropriate specialist disability accommodation and intense support. This helps to minimize the adverse impacts of their disability.

The right provision of affordable, integrated housing and support services through the NDIS will enable people with PWS to:

- pursue their goals, objectives and aspirations
- increase their independence
- increase social and economic participation, and
- develop their capacity to actively take part in the community.

When all is going well for people with PWS, they enjoy a good quality of life and make much lower demands (and cost impact) on other service systems such as health and justice.

Therefore, the NDIA needs to acknowledge that a diagnosis of Prader-Willi Syndrome means that affordable, specialized accommodation will be “the norm” to allow these people to have a life envisaged by the NDIA. .

The PWSAA looks forward to continuing to work with the NDIA to get affordable and appropriate accommodation in place for this very misunderstood and vulnerable group of participants.

*Mr James O'Brien*

President

Prader-Willi Syndrome Association of Australia

## Attachment 1 – Interaction Disability Services PWS Home

### PWS House Specifications - Interaction Disability Services Ltd

Interaction Disability Services (Interaction) established Australia’s first accommodation model specifically for three adults with Prader-Willi Syndrome (PWS) in 1992. In 1993, this residential model was internationally recognised by the International Prader-Willi Syndrome Organisation as best practice for individuals with PWS. This model continues to receive quality accommodation support from Interaction and recurrent funding from NSW Ageing, Disability and Home Care (ADHC).

Innovative design features include:

- Single storey house to address poor muscle tone, poor gait and high incidence of obesity;
- Identically sized bedroom with relaxation area and ensuite, this is to address the innate need for fairness and equality of resources;
- Access to each bedroom door will be spaced apart to ensure the safety of individuals in periods of behaviours of concern;
- Recessed bathroom fittings, to meet safety requirements in relation to seizure activity;
- Calming, relaxation area and sensory garden, to reduce behaviours of concern and anxiety levels;
- Centralised secure kitchen, to reduce food related anxiety and food seeking behaviours;
- Designated exercise area, to reduce weight gain, increase muscle tone and metabolic rates;
- Additional individual storage, to reduce anxiety related to hoarding and to increase personal sense of privacy and security;
- Glazing on kitchen walls, to assist with supervision around meal times and exercise;
- Under floor heating and insulation, to assist with body temperature regulation and decrease behaviours of concern;
- Interactive activity and routine board, to assist with forward planning, communication and program stability;
- Ceiling sprinkler system, to assist in the case of a fire.

- Function-specific environment

<i>Design feature</i>	<i>Evidence</i>
A single storey house	Due to poor muscle tone, poor gait and the high incidence of obesity, a single storey house is the safest option to minimise trips and falls for individuals with PWS.
Five large bedrooms with built-in wardrobe, small relaxation area and ensuite	Individuals with PWS have an innate need for fairness and equitability of resources amongst their peer group. Individuals with PWS, due to their need for a rigid and consistent routine and environment can extend this possessiveness to their physical environment. Therefore, the model is based upon the provision of identically sized bedrooms with each individual decorating and furnishing their own room to meet their personal preferences. Furthermore, the size of bedrooms will provide adequate space for up to a queen size bed, small television and sitting area, display and storage of personal items and clothing. The ensuite will have a toilet, shower with hand shower fitting, tap ware and vanity. All ensuite fittings will be recessed into the wall where possible. The provision of an ensuite also assists with health monitoring. Individuals with PWS commonly skin-pick and spot-pick their limbs, face, nails and in some cases their rectum and

	<p>genitalia as a form of endorphin stimulation. Coupled with their high pain threshold, this activity needs to be regularly monitored by staff to ensure the wound does not lead to serious infection.</p>
Secure kitchen with adequate bench space and storage	<p>Individuals with PWS experience feelings of hunger, even after a meal, and thus are driven to eat and seek out food. This can result in individuals with PWS going to extraordinary lengths to obtain food, including criminal behaviour such as stealing. International best practice residential models recommend the locking of the kitchen, fridges, freezers and rubbish bins. This can be achieved through applying for restrictive practices authorisation through the NSW Guardianship Tribunal. Food and diet management is an essential component to providing support to individuals with PWS, due to their slow metabolism, excessive weight gain and lethargic activity levels.</p> <p>The kitchen will be located in the centre of the house. The kitchen will contain glazing for supervision at meal times, substantial fridge space for the storage of fresh fruit and vegetables and ample bench space for meal preparation. Individuals with PWS need to adhere to a low calorie diet to ensure positive health outcomes and increased life expectancy. All meals consist of unprocessed ingredients and are prepared by staff from menus designed and negotiated with the Royal Prince Alfred Hospital's PWS Clinic Dietician.</p>
Laundry	<p>The laundry will house two washing machines, tumble dryer, sink and storage area. Through house meetings between staff and the residents, a routine will be negotiated regarding the equitable use of the laundry. Individuals with PWS can be resistant to change and thrive in an environment of structure and stability. The individuals will be taught by staff through task analysis how to wash their own clothes and linen. Staff will monitor the use of laundry chemicals as there have been reported incidents of individuals with PWS ingesting non-food items to alleviate their feelings of hunger.</p>
Living area	<p>The living area will be at the front of the house. The living area will contain a television, DVD player, interactive activity and routine board and heavy lounge suite. All furniture contained within the house will be heavy to ensure they cannot be used as projectiles in critical incidents or conflicts. The living area will promote peer and social interaction for the residents and in line with community standards.</p>
Dining area	<p>The dining area will be located at the back of the house, next to the kitchen. The dining area will contain a heavy seven piece dining table and chairs. All furniture contained within the house will be heavy to ensure they cannot be used as projectiles in critical incidents or conflicts. The dining area will be in line with community standards.</p>
Exercise area	<p>Regular exercise is essential for individuals with PWS and is part of the holistic best practice approach to promoting positive health outcomes and well-being. Exercise is built into each resident's routine to ensure the building of muscle mass; calorie burning to offset weight gain leading to obesity; the boosting of their metabolism and as a distraction to the pervasive food seeking thoughts. Exercise areas are well-documented in international best practice residential models for supporting individuals with PWS. If weight is controlled, life</p>

	<p>expectancy may be similar to the non-PWS population, and the individual's health and functioning can be maximised.</p> <p>The exercise area will be located at the back of the house in an open plan design. This allows for staff to monitor resident's exercise without appearing to be overly intrusive of their structured daily exercise program.</p>
Garage	<p>The garage will be used as a resident storage area and to park the house vehicle. The garage will provide additional storage for each resident. The purpose of the storage is to minimise the hoarding behaviours, increased sense of privacy and security of their belongings, and related anxiety characteristic of PWS. The use of the storage will be negotiated under the service agreement with each resident. The garage will be in line with community standards.</p>
Calming, relaxation area, alfresco area and sensory garden	<p>The calming, relaxation area, alfresco area and sensory garden will be accessed through the dining room and exercise area. The alfresco area will be undercover and have a table and chairs for visitor, peer and familial interactions, as well as leisure activities such as craft.</p>
Landscaping	<p>The landscaping of the front and backyard will be low maintenance. This is to promote the involvement of the residents in making their house feel like a home. The residents will be taught gardening skills by staff through task analysis and to promote a sense of belonging within the home. Staff will research the type of plants and monitor the use of garden chemicals as there have been reported incidents of individuals with PWS ingesting non-food items to alleviate their feelings of hunger. A flat driveway will provide access to the garage and staff parking when required. A pergola will increase the residents' sense of privacy and security at the front of the house.</p>
Flooring	<p>The floor will have underfloor heating covered by flooring which assists in temperature regulation. Individuals with PWS have difficulty regulating their body temperature, related to their hypothalamus. In addition, this requires staff to be vigilant in ensuring residents do not overheat or under dress related to the weather and temperature conditions. Stability in the environmental temperature also assists in regulating their behaviour, in particular in times of physical or emotional stress and anxiety.</p>
Safety features	<p>The property will have secure fencing and side gates in line with community standards. The internal walls will be reinforced with stud wall frames at 300mm centres and impact grade plasterboard to minimise property damage in periods of critical incidents. Doorways will have steel frames and solid timber doors. All windows will have laminated safety glass installed to minimise property damage and personal injury in periods of critical incidents. External bins will be contained within a secure area to reduce opportunities for food foraging. A secondary fuse box will be located in the staff sleepover room for emergency response where required. A ceiling sprinkler system will be installed to meet fire safety concerns.</p>

**Interaction's PWS Purpose-built Concept Design**

