

Resilience
Healthcare

The Development of a PWS Specific Respite Service

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Ait Shona



Introduction & Objectives

The purpose of this presentation is to look at the development of our PWS Specific Respite Home.

We will look at the following headings:

- Development
- Strategic Collaboration
- The need for specialised respite
- How the service is designed and operates
- Outcomes and Impacts
- Challenges
- Future directions





What is Respite?

Respite care is the provision of alternative care for a person with a disability in order to enable the family carer to take a short break, holiday or rest.

For individuals with PWS, respite that is residential in nature should be available as endorsed by Irelands Rare Diseases Plan (A Report on the Joint National Pilot of the Health Service Executive and the Prader Willi Syndrome Association of Ireland, 2024)

What is Respite?

Respite is recognised, both nationally and internationally, as a necessary support for families of people with PWS (Akindola et al., 2015; National Clinical Programme for Rare Diseases, 2013; Gallagher et al., 2017).

Gallagher et al. highlighted the ‘critical need for appropriate, PWS-specific respite services in Ireland’ and stated, ‘provision should be PWS-specific for consistency in management’



Early Stages of Development

In 2017, at the request of the Minister for Health, Simon Harris, the Health Service Executive (HSE), in partnership with Prader-Willi Syndrome Association Ireland (PWSAI), established a National Working Group to develop, implement and test positive models of intervention and practice in supporting people living with Prader-Willi Syndrome and their families.

The Working Group brought together parents in collaboration with professionals, both national and international, in order to lead and drive an agreed work programme.

Arising from the Working Group submissions, a PWS respite service was identified as a top priority for both adults and children.

Early Stages of Development

In early 2021, a Task Group was set up, consisting of Mac McLachlan, NCPPD, Clinical Lead, Michael Walsh, NCPPD, Programme Lead, Dr. Michael Byrne, HSE, PWSAI, members of the Working Group and other key professionals, with a focus on developing a model of care and appropriate supports for people with PWS and their families.

The key areas for consideration were, The Joint National Report, PWS appropriate residential and respite and access to mental health supports.

In 2021, the Task Group entered a submission into the estimates process for a PWS appropriate respite service and in 2022, we were provided with part funding for the service.



Resilience Healthcare & PWS

Resilience Healthcare is a private Healthcare company who provide Residential, Respite, Day Service and Outreach supports to adults and children who have autism, intellectual disability and PWS.

Former CEO Laura Keane was linked in with members of PWSAI and through her experiences saw the need for PWS specific care.

In 2017 Laura and key staff from Resilience and members of PWSAI travelled to Germany, Denmark and UK to research best practice in PWS specific care. Must be described as emergent rather than resultant.

They brought back the best of what they learned and developed a PWS specific model of care for a residential service.


2011
Resilience
launch


2019
Opened first PWS
specific Residential
Home to support 6
adults


2023
Opened second PWS
specific Residential Home
to support 4 adults


2023
Development of new role
within the company;
Regional Operations Role.

This person would lead and
coordinate all of the PWS
services and contribute to
ongoing strategic planning
and development.


2024
Opened the Respite
Home 'Ait Shona'


2025
Opened third PWS
specific Residential
Home to support 4
adults and 1 teenager

Plans to open fourth
PWS specific Residential
Home to support 4 adults
by the end of 2025





Strategic Collaboration & Commitment



- Throughout their PWS journey Resilience Healthcare have worked closely with PWSAI, Health Service Executive (HSE) and government officials to promote the necessity for PWS specific services.
- The close collaboration between Resilience Healthcare and PWSAI has been instrumental in driving home the need for PWS specific care and ongoing development of PWS specific services.

- Lemongrove was instrumental in convincing the task group that PWS specific care was essential.
- Laura Keane (CEO) and I hosted Mac and Michael for an afternoon in Lemongrove where we were able to demonstrate why the PWS Specific model worked so well.
- The feedback from the task group to PWSAI following this visit was extremely positive. They saw for themselves why a PWS specific Respite Service was what would work best.
- Finally, the tireless efforts of PWSAI resulted in the great news that the HSE were going to award partial funding for a PWS Specific Respite Service



Ait Shona = Happy Place

- Once the tender was awarded, Resilience purchased a house and commenced renovations.
- The house consists of 5 ensuite bedrooms, a dining room, 2 living rooms, a kitchen that is not accessible to the attendees, an office, a laundry room and a medication room.
- The house is set in the countryside and has a lovely garden and play area outside.
- Competition within PWSAI to chose the name.



Service Development

- At the development stage an Operational group was set up consisting of Gary Brennan (National Development Manager PWSAI), Gerry Malley (HSE), Sinead Butler (Director of Services), Lynsey Moorehouse (Regional Operations Manager PWS)
- The PWSAI wanted a Respite that facilitated equal access and not crisis allocations based on need.
- They were clear that their members wanted a holiday with their friends and the opportunity to enjoy social activities while being supported with their PWS needs.





- We looked at our existing model of care within our PWS Residential services and adapted it to reflect the needs of Respite
- Developed referral and expression of interest forms
- Assessment of need and care plan
- Support requirements
- Adults/Children
- Food Security – Locked Kitchen
- Meal Plans – Family input
- Anxiety
- Routine
- Preferences

Challenges and Barriers

- Geography and accessibility
- Sharing of information and changing needs
- Compatibility
- Limited capacity based on partial funding



Outcomes & Impacts

- ✓ We are currently providing Respite support to 25 individuals and their families.
- ✓ 2 adults have successfully transitioned into a residential placement within Resilience after attending Respite. Knowledge of Resilience made transition easier for the person and their families.



Testimonials



Regarding the respite at Ait Shona I can't begin to tell you how much Christina loves it. She had been attending another respite before Ait Shona opened, and she is so happy at Ait Shona she no longer wishes to attend the other respite. She feels so happy and safe being in the PWS specific setting and the staff are so wonderful. As a parent this gives me great comfort. Christina can't wait for her next stay!





I would like to compliment Ait Shona on providing such a fantastic service. As a parent it very consoling to know that my child is being cared for in a place where she feels safe, with staff that understand her needs. The staff are excellent and have a good understanding of the different aspects of PWS. This is very reassuring to both Mya and us as parents.

Mya has said that Ait Shona 'is like a home from home'. She has really enjoyed spending time with other people who have PWS and making new friends.

She said, 'I don't feel so alone'.

We just wanted to thank you from the bottom of our hearts for such an incredible weekend for Oisín last month – his first stay at Áit Shona.

The whole experience was a huge success from start to finish. I think the video call we did with you and Kayleigh a few days beforehand really helped Oisín as he was able to put a face to the names. When we arrived, Oisín got such a beautiful warm welcome that he instantly felt at home. For the first trip I prepared all the food and the meal plan, so Oisín knew exactly what he was having, and I think this really helped Oisín to relax. The outing to the open farm in Kildare was a huge hit as was being there at the same time as someone he knew. Having said that, he was so comfortable, I think he would happily go along without knowing anyone there! The carers were such good fun, and Oisín really enjoyed every moment. From the moment we arrived to pick him up he was asking when he could go back and this time he wants to go back for 3 days! He loved his time with you, Florence and Kayleigh and a huge highlight was the trip to Kildare Open Farm on the minibus, singing songs and having a great laugh ... he has mentioned this many times!!!

I think the fact that he didn't want to come home when myself and Mark came to pick him up is a true testament to what a wonderful time he had and what a truly fabulous and unique experience you offer at Áit Shona.



Resilience PWS Respite

Expression of Interest



Date: _____

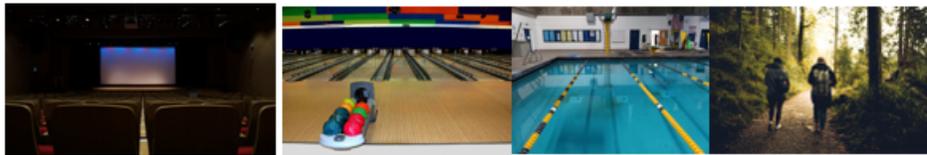
Name: _____

Address: _____

Age: _____



Gender: _____



Activities I enjoy:

1. _____
2. _____
3. _____
4. _____
5. _____



Friends I would like to attend with if possible

1. _____
2. _____



Please tick if you are happy for us to contact you in relation to our Respite service

Signed: _____



AÍT SHONA

Resilience
Healthcare

**The Power
of Possible**

