



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

Oifig an Cheannaire Oibríochtaí,  
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,  
31-33 Sráid Chaitríona, Luimneach.

Office of the Head of Operations,  
Disability Services/Community Operations,  
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369  
Suíomh Gréasáin/Website: <http://www.hse.ie>

4<sup>th</sup> May 2021

Deputy Steven Matthews,  
Dail Eireann,  
Leinster House, Kildare Street,  
Dublin 2.  
e-mail: [steven.matthews@oireachtas.ie](mailto:steven.matthews@oireachtas.ie)

Dear Deputy Matthews,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary questions, which were submitted to this department for response.

#### **PQ 20541/21**

*To ask the Minister for Health the resources he is providing to assist persons with Prader-Willi syndrome and their carers; and if he will make a statement on the matter.*

#### **PQ 20543/21**

*To ask the Minister for Health the position regarding Departmental reviews of existing services available for those with Prader-Willi syndrome; and if he will make a statement on the matter.*

#### **HSE Response**

The HSE acknowledges the work of the Prader Willi Syndrome Association of Ireland in raising awareness and understanding of PWS and the needs of persons with this syndrome. The Association provides information services, including seminars and conferences and promotes best practice standards of care for persons with PWS.

Prader Willi Syndrome Association of Ireland is based in Carmichael Centre for Voluntary Groups, which was established in 1988 as a community services project with the principal objective to nurture and support the development of small, national voluntary groups. The Centre provides a shared service facility for its member organisations, including office space; administrative services including payroll and accounting; training, support and consultancy in organisational management and development; conference and meeting facilities; ICT support; community employment; access to information, conferences and seminars on sectoral issues; representation and policy input and support to local organisations.

Since its inception, funding for the Carmichael Centre has come from a number of sources including the HSE, which provided funding of €47,098 in 2020 under Section 39 of the Health Act 2004.

The HSE has agreed to continue funding the position of Development Officer for Prader Willi Syndrome Association and will be allocating €75,590.5 to PWSAI in 2021 and beyond as a grant aid agreement. PWSAI informs that the position of the Development Officer will allow the Association to increase capacity to spread awareness of the unique nature of PWS and assist with the development of specific services tailored to the condition. Having successfully bid for the IPWSO International Conference in 2022, PWSAI want to plan and deliver a Conference that highlights best practice in caring for PWS through collaboration with all relevant stakeholders. Other objectives of the role include:

- Increase the knowledge and understanding of PWS with relevant stakeholders across a life time of care.
- Publication and promotion of the recommendations agreed in the joint work group report between HSE and PWSAI.
- Increase the supports available to families with PWS across a life time of care.
- Liaise with and support families
- Understand the Impact on siblings in a family with a member that has PWS.
- Develop a clinical pathway for individuals with PWS within a centre of expertise where a seamless transition of care is provided from birth through childhood, adolescence and adulthood.
- Develop PWS specific training material tailored for Clinicians, Medical Professionals, Educators, Carers, Service Providers etc

### **Graifin House – PWS Service**

In addition the HSE provides funding to Rehab Group to run a dedicated community residential service in Dublin, which offers residential care to 5 young adults with PWS.

Graifin House was opened by RehabCare in 2003 with funding from HSE and is Ireland's only dedicated PWS service. Graifin House was developed by RehabCare and funded by the HSE in response to a request from families of adults with PWS who identified the need for their family members to have access to specialised PWS residential care. The service offered at Graifin while similar in many facets to a typical adult residential service has a number of critical defining features. A key feature of the model is its rights based approach, service users are supported by staff to control the urge to eat and to build their capacity to make appropriate decisions. The defining features of the service are:

#### ***Weight Management***

Significant weight loss has been achieved and sustained. This has been achieved by close monitoring of the calorie intake of the service users by staff under the direction of a dietician. Food and making choices in relation to food are a major cause of stress for adults with PWS, routine and structure in this regard can offer a mechanism to reduce and control this stress. Significant improvements in service users' health have been sustained as a result of the weight loss, including two service users reversing the diagnosis of Type 2 Diabetes. Within Graifin there is an onsite gym and exercise programmes are facilitated for service users. Living with others with the condition has helped to motivate service users to lose and maintain weight loss.

#### ***Expert Staff***

Key to providing support to adults with PWS is ensuring staff involved truly understanding the condition, experience has shown that where this does not exist placements do not produce the best possible outcomes and in some cases break down. RehabCare staff in Graifin House have received specific training in PWS and have gained hands on experience of supporting adults with PWS.

#### ***Controlled Environment & Structure***

The service offers an environment where access to food is restricted to pre arranged times agreed with the service users. At other times the kitchen is locked and staff implement a consistent approach to requests for food, a key feature of the service is consistent limits that are consistently enforced. Routine and structure are critical to the lives of adults with PWS, Graifin House supports each of the service users to develop routines that offer them predictability and structure. This structure not only focuses on food but also on social, leisure and educational activities.

#### ***Behavioural Support***

Support delivered in the service is done in a manner which is in compliance with best practice in terms of Restrictive Practices. With the support of a Behaviour Therapist the service users have behaviour support plans to enable staff to support them with behaviours that challenge. These focus on supporting individuals to manage their behaviours and provide staff with guidelines that are implemented consistently amongst support staff.

### **Respite Services**

The HSE and its funded agencies provide respite care to children and adults with disabilities. Respite can occur in a variety of settings for any length of time, depending on the needs of the family and available resources. It is not always centre-based and can be provided in a number of ways, e.g. Out-of-Home; In-Home; Home-to-Home;

Home Support; Family Support etc. As a vital part of the continuum of services for families, respite helps prevent out-of-home placements, preserves the family unit, and supports family stability.

The HSE is very much aware of the importance of respite service provision for the families of both children and adults with disabilities, including the impact the absence of respite service provision can have on other services.

### **Therapy Supports**

In addition, people with Prader Willi Syndrome can benefit from therapeutic assistance, including Physiotherapy, Occupational Therapy and Speech and Language therapy as well as a range of medical interventions.

Therapy services for adults and children are generally delivered through Primary Care Teams or community therapy services; through specialist disability providers or Early Intervention and Children's Teams for 0-18 years, which are continually being developed under *Progressing Disability Services for Children and Young People (0-18s) Programme*.

In 2013, additional funding of €20m was provided to strengthen Primary Care services. This comprised over €18.5m for the recruitment of over 260 Primary Care Team posts and over €1.4m to support community intervention team development. There was also a €4m allocation within the 2016 Service Plan to facilitate the recruitment of Speech and Language Therapists to address waiting lists as part of the overall Speech and Language Therapy waiting list initiative within Primary Care and Social Care. The allocation provides for an additional 83 posts. In addition, a further 40 posts in Occupational Therapy (OT) was allocated to Primary Care Services.

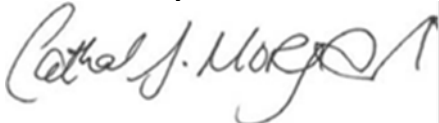
The level of increase underlines the commitment of the HSE and Government to ongoing therapy provision. These measures will have a positive impact on the provision of clinical services for all people requiring access to health related supports.

It must be noted however that therapy service provision has been impacted due to the Covid -19 pandemic.

### **HSE/PWSAI Draft Joint Report**

The HSE, in collaboration with the Prader-Willi Syndrome Association of Ireland (PWSAI), have developed a draft report on Prader-Willi Syndrome (PWS). As agreed at a meeting on February 4th 2021 hosted by Minister Rabbitte (Minister of State for Disability) and Minister Butler (Minister of State for Mental Health and Older People), and attended by PWSAI, this draft report is now being reviewed by a wider stakeholder task group to identify what aspects of this report may be implementable, and the most expedient means of implementing same. This will include consideration of the need for, and the feasibility of, a respite centre for persons with PWS. This process is being overseen by the National Clinical Programme for People with Disability (NCPPD) by establishing a new Model of Service for PWS. The incorporation of reports into a Model of Service is the mechanism used in disability services to ensure that appropriate recommendations are actioned either within existing structures, or through the development of new structures. In the case of the proposed Model of Service for PWS, it is likely that some additional funding will be required but the amount is yet to be determined. The NCPPD are working with PWSAI to develop and then publish the Model of Service.

Yours sincerely,



**Dr. Cathal Morgan,**  
**Head of Operations - Disability Services,**  
**Community Operations**