Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

**Oifig an Cheannaire Oibríochtaí,**
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21st September 2021

Deputy Éamon Ó Cuív,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: eamon.ocuiv@oireachtas.ie

Dear Deputy Ó Cuív,

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

**PQ: 42316/21**

*To ask the Minister for Health his plans to provide funding for appropriate respite services for persons affected by Prader Willi Syndrome in view of the ultimate cost savings of such a services due to it allowing families and communities retain persons affected by this syndrome in families and in the community longer thus reducing the requirement for full-time residential care and also reducing incidences of crises for families and so on; and if he will make a statement on the matter.*

**HSE Response**

The HSE and its funded Agencies provide respite care to children and adults with disabilities. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user and their family or carer, and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential 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 persons affected by Prader Willi Syndrome, and is acutely aware of the impact the absence of respite service provision can have on family life.

Prior to the public health emergency with regard to COVID-19 and in accordance with the National Service Plan 2020, the HSE was committed to provide 33,712 day only respite sessions and 166,183 nights (with or without day respite) to people with disabilities in 2020.

The delivery of Respite Services continued to operate during the pandemic, albeit at a reduced capacity; some centres remained open, while others were temporarily re-purposed as isolation facilities. The number of respite overnights operated at just over 50% of the NSP target for 2020; while the number of day only sessions operated at 62% of 2020 target. This was mainly due to necessary precautions to maintain physical distancing and to adhere to infection prevention and control requirements. Throughout the pandemic, staff and resources associated with closed or curtailed services were redeployed where possible to support residential provision and to provide for targeted in-home, community and tele-/online supports for service users and families based on prioritised needs.

### *Targeted actions to improve supply*

In 2018, the Minister for Health announced an additional €10 million for the HSE, specifically to enhance respite care in the disability sector. The funding provided for the equivalent of 12 new houses, 1 in each CHO, and 3 in the Greater Dublin area together with the development of alternative models of respite such as summer camps, evening and Saturday clubs.

### In-home Supports

In addition, the HSE committed to provide 144 intensive transitional support packages for children and young people with complex / high support needs, to include planned residential respite interventions and access to planned extended day / weekend and summer day based activities. However, at end of December 2020, a total of 857 intensive home support packages were developed across the 9 CHOs. The significant increase on the NSP target is indicative of the requirement for additional in-home services to compensate for the reduction in the delivery of traditional respite services. Children with special needs also benefitted from traditional Home Support Services, the provision of which remained steady during 2020.

### 2021 Developments

The need for increased respite facilities for people with disabilities including those with Prader Willi Syndrome is acknowledged and the HSE continues to work with agencies to explore various ways of responding to this need. In accordance with the National Service Plan 2021, the HSE will provide nine additional centre-based respite services, providing some 10,400 additional respite nights along with a range of alternative respite projects including Saturday clubs, breakaway schemes, and summer schemes. In addition, the HSE will provide 214 intensive respite support packages to children and young adults.

In addition, to address the growing requirement for respite services, the current estimates process is proposing €10million in investment and targeted alternative models of respite provision such as extended days, weekends, in-home and overnight respite (away from home). This investment proposal includes the development of a Prader Willi-appropriate respite service.

### Prader Willi Syndrome Association of Ireland

The HSE acknowledges the work of the Prader Willi Syndrome Association of Ireland (PWAI) 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.

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. 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 includes:

- 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 Residential Service**

Graifin house was opened by RehabCare in 2003 with funding from HSE and is a dedicated PWS service, supporting 5 adults with PWS. 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.

Yours sincerely,

Cathal J. Morgan

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