



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
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4th May 2021

Deputy Holly Cairns,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: holly.cairns@oireachtas.ie

Dear Deputy Cairns,

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 20873/21

To ask the Minister for Health the status of the cross-Departmental report on Prader-Willi syndrome; when it is expected that the report will be published; the reason for the delay; and if he will make a statement on the matter.

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 (NCPD) 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 NCPD 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