

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

> Office of the Head of Operations, Disability Services/Social Care Division, 31-33 Catherine Street, Limerick.

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

15th May 2023

Deputy Carol Nolan, Dail Eireann, Leinster House, Kildare Street, Dublin 2. E-mail: <u>carol.nolan@oireachtas.ie</u>

Dear Deputy Nolan,

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 20525/22

To ask the Minister for Children; Equality; Disability; Integration and Youth if Irlen syndrome is a recognised disability within the HSE; if not, if there are plans to recognise it as such; and if he will make a statement on the matter.

HSE Response

Disability services are provided based on the presenting needs of an individual rather than by the diagnosis of the individual or the actual type of disability. Services are provided following individual assessment according to the person's individual requirements and service needs.

It is reported that Irlen Syndrome is a problem with the brain's ability to process visual information. Described signs and symptoms include light sensitivity, reading problems, headaches and migraines, attention and concentration problems, fatigue, problems with depth perception and print or environmental distortions. It is not currently identified by standardized educational, psychological, optometric, or medical tests. The signs and symptoms manifest differently for each individual.

The National Rare Diseases Office based at the Mater Misericordiae Hospital inform that Irlen syndrome is not listed as a Rare Disease/Disorder on the International Rare Diseases Database Orphanet. This office has also provided some useful links to the medical literature as follows;

Irlen syndrome: systematic review and level of evidence analysis - PubMed (nih.gov)

The conclusion of this analysis suggests that the syndrome as described, as well as its treatments, require further strong evidence.

Other links provided include:

Irlen-Syndrome-Position-Statement-May-2018-1.pdf (ranzco.edu)

No scientific evidence that Irlen Syndrome exists, say ophthalmologists | RANZCO

Irlen Ireland is an Irish based organisation which provides supports in the form of information, useful links and YouTube videos. This organisation is not in receipt of funding from HSE Disability Services See link: <u>https://irlen.ie/</u>

Due to the unique presentation of each individual who presents with symptoms analogous to Irlen Syndrome, the role of the HSE, following individual assessment according to the person's individual requirements and service needs, is to provide a multi-disciplinary team approach, which includes the provision of health and personal supports which may incorporate acute services, primary care community services and disability services in the case of complex disabilities.

A wide range of disability services are provided to those with physical, sensory, intellectual disability and autism. Disability services focus on supporting and enabling people with disabilities to maximise their full potential, as independently as possible. Current policies are based on the principles of person-centredness to ensure insofar as possible that the supports for a person are based on individual assessed need, will and preference and to support people to remain as close to home and connected to their community as possible. Services provided include Residential Services, Respite Services, Day Services, PA and Home Support Services and Therapeutic Supports.

Yours sincerely,

Bernard O'Regan

Bernard O'Regan Head of Operations - Disability Services, Community Operations