

Opening Statement

An Saol Foundation

Members of the Joint Committee on Disability Matters:

Thank you for the invitation to speak to you today.

My name is Reinhard Schaler and I am the CEO and Founder of the An Saol Foundation: *Life and Living with a severe Acquired Brain Injury (sABI)*. I am accompanied today by Mr. Odhrán Ó hUallacháin, Senior Physiotherapist and Interim Clinical Lead, An Saol Foundation, and Mr. Joe Grogan from Galway, Trustee of the An Saol Foundation and father of Shane Grogan who suffered a severe Acquired Brain Injury in an unprovoked attack in 2012 when he was 22 years old.

We will be speaking to you on behalf of a group of people who because of their injuries can no longer speak for themselves. They have been left behind as hopeless cases, not curable, not worth the effort.

But they have a passion for life, a passion to be active, to seek new experiences and a healthy living.

They would rather live.

This is why we established the An Saol Foundation in 2014.

The An Saol Foundation

The Foundation is inspired by our son Pádraig Schaler who was hit by a truck in 2013 when he was cycling to work on Cape Cod. Nobody was ever prosecuted.

The An Saol Foundation Centre opened its doors in January 2020 for its three-year Pilot Demonstrator Phase. In January 2022, we presented a midterm review of the Pilot Demonstrator Phase and proposed a fully specified and costed Implementation Phase 2023-2027 with a National Centre and country-wide Satellite Centres to the HSE.

The HSE commissioned a review by three independent international experts who published their Report and Recommendations in February 2023. This report found that the service was necessary, that it was effectively delivered by the An Saol Foundation, that it should be expanded in terms of scope and geography, and that it could position Ireland internationally as a leader in the delivery of this kind of disability services.

In its Santry-based Centre, the An Saol Foundation offers a holistic service for the body, mind, and soul of its clients. Total funding for the three-year pilot demonstrator project aimed at 3-5 families was 1.5 million euro. In 2023, total running costs were 570,000 euro for 28 clients, with a current weekly delivery of a total of just over 140 hours by 4.7 WTE practitioners and 2.2 WTE support staff. The Foundation requested a budget of 880,000 euro for 2024 to allow it to *start* implementing *some* of the recommendations of the 2023 HSE Report. It was offered 600,000 euro by the HSE, in effect a decrease in funding. To

date, the 2024 Service Arrangement has not been signed as there have been ongoing discussions about the budget allocation since May 2023.

Lived Experience

In our first discussion about the lack of services for people with a severe Acquired Brain Injury on RTÉ Radio One's Late Debate in March 2014, one of Ireland's leading neurologists said to us: *I understand your personal tragedy, but you need to understand that a health system with limited resources has to invest these resources in patients who have a reasonable chance of a meaningful recovery.*

A rehabilitation nurse who had asked about our son's accident, concluded, standing right beside his bed, *it might have been better had he died.*

The first question by a Neuro Nurse was, *which nursing home is he going to go to?*

When Pádraig started to move his legs more actively but with little control in October 2018, we brought him to the A&E as we suspected that he was pushing the ball at the end of his femur out of the socket. In 2019, he was suffering so much pain that he couldn't sleep and was rapidly losing weight. He was referred to an Orthopaedic Consultant. This appointment finally came through in May 2022.

In the meantime, fearing for his life, we desperately pleaded for help. No help was offered. Eventually, at the height of the first COVID lockdown, in June 2020, we drove to Germany where Pádraig was admitted to and successfully treated in an orthopaedic clinic in Munich using a minimally invasive procedure called Percutaneous Myofasciotomy, followed by a period in a specialised Therapy Centre. The consultants who treated Pádraig in 2020 are now philanthropically involved in developing our services. They have seen and helped several of our clients both in Germany and in Ireland.

Teach An Saol

It is national policy to cease admission of under 65s to nursing homes. In continuing to do so Ireland is failing in its obligations under the UNCRPD (Article 26) to *"maintain maximum independence"* and to *"support participation and inclusion in the community and all aspects of society,... as close as possible to their own communities, including in rural areas."*

An Saol, as a Day Service, provides the supports and services to enable Ireland to fulfil these human rights obligations.

Services should start with the most in need, not end before they get to them.

Encouraged by the HSE, we proposed Teach An Saol, the National Centre for Life and Living with a severe Acquired Brain Injury, and submitted the proposal to the HSE and the Minister for Disability in June 2023.

We propose six regional services and the national hub to support these. The Sustainable Development Goals calls on governments to *"Leave No One Behind"* - An Saol services is how we can fulfil this obligation for people with sABI.

So far, we have received and established:

- Enthusiastic support by Minister of State Anne Rabbitte.
- A letter of Comfort by Dublin City Council, DCC, for land in Ballymun.
- Expression of support for, sadly, only two hubs of the Centre from the Chief Officer of CHO9 DNCC, with qualified support for the remaining two hubs and no satellite centres.
- A strong philanthropic Planning and Design Group with six of Ireland's largest architectural, planning, engineering, and legal firms who aim to submit planning permission and tenders for a design built of the proposed development.
- A high profile international Clinical Governance Committee to guarantee regulatory compliance of Teach An Saol's current and planned services, temporary assisted living and respite in particular.

This project offers a golden opportunity to the HSE and the nation to create a long overdue National Centre with international visibility for people who have so far been left behind.

Call For Action

Current national, EU, and international legislation and conventions, including Article 26 of the UNCRPD, as well as new and emerging scientific and medical evidence, and, not least, plain human decency demand that they do.

Ireland can fulfil its obligations under Article 26 of the UNCRPD by providing the An Saol Foundation with:

- An adequate 2024 budget in support of its expanding services as recommended in the 2023 HSE Report;
- Funding for Teach An Saol in the HSE 2025 capital plan;
- New revenue funding for the delivery of additional services, including respite, transitional living, social, clinical, and regional (satellite centres).

In summary, the HSE supported us to pilot the An Saol Foundation service. Through difficult times, including Covid, we provided a service addressing an unmet need for perhaps the most marginalised group of people in the country. The HSE commissioned an independent evaluation of the service and subsequently recommended expansion.

You have heard our plans for expansion.

Please support us now by adding your strong voices to those of the independent evaluators.

Please support our request for the necessary funding, to do what is necessary, and what Article 26 of the UNCRPD calls for.

This is the time for deputies and, especially, Ministers and the Taoiseach to take decisive leadership and act.

We cannot allow this opportunity to lose momentum and die a slow death.

Because for our injured family members this is, literally, a matter of life and death.