Opening Statement to the Oireachtas Health Committee
in relation to
Concerns for the operation of Section 38/39 organisations
Wednesday, 10 July 2019

Peter Murphy, CEO, Epilepsy Ireland
Niamh Jones, Community Resource Officer, Epilepsy Ireland

Thank you to the committee for the opportunity to speak on this important issue.

For over 50 years, Epilepsy Ireland has been supporting and representing people with epilepsy and their families. Epilepsy is one of the most common neurological conditions, affecting 37,000 people in Ireland, including ten to fifteen thousand people who live with uncontrolled, recurrent seizures.

It can be a source of major long-term, often hidden and stigmatised disability, affecting a person's employment, education, independence and psychological functioning.

Epilepsy Ireland receives Section 39 funding under seven HSE Service Arrangements to provide a range of community-based services. These are delivered by a team of 11 Community Resource Officers, all of whom work part time. My colleague Niamh Jones, one of our Community Resource Officers based in Cork, will speak about our service in a few moments.

In terms of funding challenges, it is important to say that the difficulties we face are not unique. They are replicated across the spectrum of small and medium sized community-based organisations.

In our case, while the service in each HSE region is almost identical, the SLA funding varies significantly from region to region. In no area does the funding cover the full cost of delivering the service.

In CHO 2 for example, which is Galway, Mayo, Roscommon, the cost of providing our service is approximately €50,000 per annum but the SLA is for just €3,800. In 2018, the total national cost of providing HSE-funded services was €926,000 but total HSE income was €784,000.

As with other organisations, the SLA amounts are not negotiable. A series of annual cuts were implemented a decade ago and these were followed by a long period of static funding. Today, it is 12% lower than it was in 2010.

This has been compounded by growing pressures in terms of costs. In recent years, we have worked to innovate and expand our services in response to evolving service-user needs. As a result, the total number of service user contacts has increased from 14,000 in 2014 to 20,000 in 2018.
This, along with economic factors generally, has led to increases in virtually all direct and indirect operating costs, with the notable exception of pay, which remains at similar levels to 2009. The cost of maintaining quality assurance and governance standards such as the ‘Triple Lock’, vital to funders and all our stakeholders also have significant resource implications that did not exist a decade ago.

Epilepsy Ireland, like other charities, actively fundraises to support our work, which extends well beyond SLA-funded services, to include research funding, awareness activities, training programmes and advocacy.

We expect and embrace the need to fundraise but in recent years, greater demands are being placed on fundraising to cover HSE deficits while also maintaining wider organisational objectives.

SLA deficits are averaging €160,000 per annum. Driven by this, and despite tight cost control, over €600,000 of reserves were utilised between 2013 and 2017 to cover overall organisational deficits. For an organisation that operates on a total budget of €1.7m per annum, this is not sustainable. What happens when the reserves run dry?

There has been no recognition of these issues by the HSE and no willingness or ability to address them in the annual SLA process. Deficits are reported in detail on the HSE’s Annual Financial Monitoring Return, which ties directly to audited accounts. However, some CHOs do not allow deficits to be recorded on SLAs, giving the false impression that services are provided at break-even.

The current funding relationship between HSE and voluntary sector organisations does not reflect the economic realities of operating high quality, needs-based community services. Rather than continuing to innovate and deliver greater outcomes for people living with epilepsy, our primary focus in the current environment is on protecting existing services and ensuring that resources are available annually to meet SLA deficits.

A fundamental shift in the relationship between the State and the voluntary sector, as detailed by the IRG, is needed if smaller, community-based organisations like Epilepsy Ireland are to deliver on our missions.

This must begin with a recognition of the problems and a commitment to resolving them. Two IRG recommendations are becoming increasingly urgent – the need to jointly review the broken SLA process and the need to move towards full-cost, multi-annual funding. Non-profit should not mean ‘loss-making’.

Thank you for your time and I would now like to hand over to Niamh Jones.
Good morning.

I am one of eleven HSE-funded Community Resource Officers supporting people with epilepsy and their families across the country. Our aim is to empower people to become experts in their own condition and learn to self-manage their epilepsy in their day to day lives. My role has evolved and expanded greatly over the past 10 years becoming more varied, flexible and tailored to individual needs.

I’d like to give you an example of a recent case, which I hope will demonstrate this and the impact that we make on-the-ground. I received a referral from the epilepsy team at CUH regarding a man who had just been diagnosed. I immediately arranged to meet with him and his wife to start our ‘Living Well with Epilepsy’ programme, designed specifically to meet the needs of people with a new diagnosis. We discussed epilepsy-related issues including employment, driving, entitlements, safety and risk, lifestyle and triggers and we jointly worked out personalised plans to address these issues.

We arranged a full family meeting as the children were worried about looking after Dad if he had seizures when alone with them. The family were able to speak openly about their concerns and I went through all the do’s and don’ts of seizure first aid. Not long after, the children had to put their new-found knowledge into use when Dad had a seizure at home.

Since then, I have provided talks in the children’s schools and the couple have attended several support group meetings, engaging in important peer support and learning with others in similar situations. His employer has also asked for epilepsy training for staff.

He will soon be attending our six-week STEPS self-management programme. The programme provides a learning environment where people can gain skills and knowledge to achieve the best health and quality of life that they can by living with their epilepsy in an active and positive way. He may later avail of our Innerwise service, a more advanced personal development and wellbeing programme.

These innovative services have been developed in response to unmet needs and evaluations have shown very positive outcomes. Our programmes also strongly complement HSE’s Slaintecare objectives such as the promotion of patient-centred, self-management interventions in chronic conditions. In the near future it is community and patient organisations like Epilepsy Ireland who will play a key role in making Slaintecare a reality.

This is only one example but I hope it shows how accessible, valuable and complementary our service is in providing a person-centred approach to support and education - not just to the individual with epilepsy but also to all those who are impacted by the diagnosis.

Thank you.
APPENDIX: EPILEPSY IRELAND

About Epilepsy

Epilepsy is one of the most common neurological conditions, affecting at least 37,000 people in Ireland today. The condition is characterised by recurrent seizures associated with abnormal electrical activity in the brain. An estimated 1,300 – 2,100 people are diagnosed with epilepsy each year. While it is very much a treatable condition for many, there are 10,000 – 15,000 people with uncontrolled epilepsy in Ireland.

For this group in particular, the condition can be a source of major long-term, yet often hidden disability. A diagnosis will involve learning to cope with the physical impact of seizures, the often significant medication side-effects and impaired psychological functioning. Epilepsy can also affect a person’s employment, education and relationships and can lead to the loss of independence and self-esteem. Stigma is also commonly experienced by many people. People with epilepsy also have a higher risk of mortality, a risk that can be reduced through effective education and supported self-management. Currently, there are an estimated 130 epilepsy-related deaths each year in Ireland.

These are just some of the reasons why the World Health Organisation last month termed epilepsy as a “global health imperative” and called on governments to increase investment in reducing its burden.

Epilepsy Ireland

Epilepsy Ireland was established in 1966 with the goal of improving the quality of life of people living with epilepsy in Ireland. Today the organisation provides a range of support, training and educational services for people with epilepsy, their families and their carers from our head office in Dublin and 9 regional offices around Ireland.

Our vision is to achieve a society where no person’s life is limited by epilepsy.

We aim to achieve this by:

- Providing support, training and education services to people with epilepsy, their families and carers (see below).
- Providing training and education services to people with epilepsy and healthcare professionals.
- Raising public awareness and understanding of the condition
- Advocating for and representing the needs of people with epilepsy and their families.
- Supporting Irish epilepsy research
- Raising the necessary funds for our work, and maintaining best-practice standards of governance and quality.

Our Support & Education Services:

Epilepsy Ireland offers a broad range of services all aimed at supporting people with epilepsy to live complete and independent lives. These include:

One-to-One Support:
Epilepsy Ireland provides one-to-one support and advice for people with epilepsy and their families and carers through a network of community resource officers around the country

Living Well with Epilepsy Toolkit programme
This service is available to anyone newly diagnosed with epilepsy and parents of children
recently diagnosed. The programme consists of one or more training and support sessions, supported by a comprehensive ‘Toolkit’. The programme covers topics such as Seizure Management, Medication Management, Seizure Diary, Safety Action Planning and more.

**Self-Management Programmes**
The STEPS training programme was created to help people with epilepsy learn about managing epilepsy and broader health & wellness issues. The programme also offers the opportunity for participants to meet other people with epilepsy and learn from shared experiences. The programmes are carried out over 6 weekly sessions and are facilitated in a number of locations around the country. A more advanced self-management programme called Innerwise was launched in 2017, utilising tools such as mindfulness and meditation to achieve wellbeing.

**Emergency medication training**
Epilepsy Ireland provides training in Epilepsy Awareness and the administration of Buccal Midazolam to health care professionals, teachers and SNAs. We also provide demonstrations for parents and carers.

**Training for Success**
The Training for Success programme is a one year QQI Level 5 access programme based in IT Sligo and funded by the Mayo Sligo Leitrim ETB. Managed by Epilepsy Ireland, TFS provides practical and inspirational experiences for people with epilepsy who, due to their condition have experienced difficulties in the progression of their educational and career aspirations.

**Epilepsy Specialist Nursing**
Epilepsy Ireland has funded an Epilepsy Specialist Nursing post at Beaumont Hospital since 2002. The post has recently been upgraded to that of an Advanced Nurse Practitioner.

**Events, Seminars & Support Groups**
Epilepsy Ireland runs events in all regions of the country, ranging from information sessions, workshops and seminars to family fun days out and support groups. We also run awareness raising events for National Epilepsy Week and International Epilepsy Day.

**Other Services**
Other services include free safety pillows and epilepsy ID for members, our Epilepsy Management App, a comprehensive library of information resources and outreach activities in the community and in hospital clinics.

**Service User Contact statistics 2018**

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<th>Region</th>
<th>Total</th>
<th>Individual</th>
<th>Group</th>
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<td>North-West</td>
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<td>683</td>
<td>894</td>
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<tr>
<td>Mid-West</td>
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<td>South (Killarney)</td>
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<td>984</td>
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<td>South (Cork)</td>
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<tr>
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<tr>
<td>East</td>
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<td><strong>Total</strong></td>
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