

DÁIL ÉIREANN

AN COMHCHOISTE UM SHLÁINTE

JOINT COMMITTEE ON HEALTH

Dé Céadaoin, 10 Iúil 2019

Wednesday, 10 July 2019

The Joint Committee met at 9 a.m.

Comhaltaí a bhí i láthair / Members present:

Bernard J. Durkan,	Colm Burke,
Alan Kelly,	John Dolan,
Margaret Murphy O'Mahony,	Keith Swanick.
Kate O'Connell.	

I láthair / In attendance: Deputy Jim O'Callaghan and Senator Pádraig Mac Lochlainn.

Teachta / Deputy Louise O'Reilly sa Chathaoir / in the Chair.

The joint committee met in private session until 9.14 a.m.

Voluntary Organisations in the Health Sector: Discussion (Resumed)

Vice Chairman: This morning, we are meeting representatives of section 38 and section 39 voluntary organisations. The purpose of this meeting is to examine the role of voluntary organisations in the delivery of health services. This is our second meeting on this topic. Our first meeting on it was held last month. On behalf of the joint committee, I welcome Mr. Ivan Cooper, who is director of policy with The Wheel, which is the national association of community and voluntary organisations, charities and social enterprises; Mr. Austin O’Sullivan, who is director of resources with the WALK organisation, which supports adults with intellectual disabilities; Dr. Joanne McCarthy of the Disability Federation of Ireland and Mr. Gary Lee, who is the federation’s chairperson; and Mr. Peter Murphy and Ms Niamh Jones of Epilepsy Ireland. They are all very welcome. I thank them for being here.

I draw the attention of witnesses to the fact that by virtue of section 17(2)(l) of the Defamation Act 2009, they are protected by absolute privilege in respect of their evidence to the joint committee. However, if they are directed by the committee to cease giving evidence on a particular matter and they continue to do so, they are entitled thereafter only to a qualified privilege in respect of their evidence. They are directed that only evidence connected with the subject matter of these proceedings is to be given. They are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person, persons or entity by name or in such a way as to make him, her or it identifiable. I wish to advise the witnesses that any opening statements they have submitted to the committee may be published on the committee’s website after this meeting. Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside the House or an official by name or in such a way as to make him or her identifiable. Now that I have got the formalities out of the way, I welcome the witnesses and invite Mr. Ivan Cooper to make an opening statement on behalf of The Wheel.

Mr. Ivan Cooper: I thank the Chairman and members of the committee for the invitation to speak about the review of the role of voluntary organisations in health and social services. As director of public policy for The Wheel, I am delighted to have an opportunity to present our position on the subject. I am joined by Mr. Austin O’Sullivan, who is director of resources with WALK, which is a long-standing member of The Wheel. Before I introduce the members of the committee to The Wheel, I want to make it clear at the outset that The Wheel strongly supports the recommendations made in the independent review group report. We believe the implementation of these recommendations will bring us closer to an optimised health service that focuses on maximising individual and community health. When the recommendations are implemented, they will enable community and voluntary organisations to work in partnership with statutory funders to maximise the responsiveness and innovation they can bring to services.

The Wheel is Ireland’s national association of community and voluntary organisations, charities and social enterprises. It has more than 1,600 member organisations, which employ over 35,000 people and involve over 45,000 volunteers in delivering services and supports across the country every day. At least 150 of our member organisations are funded by the HSE under the provisions of sections 38 and 39 of the Health Act 2004, with which members of the committee will be familiar. They are among more than 800 organisations in total that are funded by the

HSE to deliver services, thereby forming a key part of our national health and personal social service infrastructure. These organisations support people, including people with disabilities and medical conditions, older people and children, to live independent lives and to realise their potential. Many of these organisations were established through the initiative and advocacy of self-organising communities when no statutory services were provided.

Despite the long-standing role many of these organisations have played, they are facing challenges which limit or in some cases prevent them from carrying out their vital work. Inadequate budgets and annual funding structures do not facilitate long-term service development. The increasingly demanding general regulatory environment is diverting time and resources away from front-line services. The compliance and reporting system is increasingly oriented towards financial compliance rather than effective service outcomes. Relationships with the HSE are becoming increasingly contract-determined rather than collaborative. Commissioning and contracting processes put community and voluntary providers at an inherent disadvantage compared to private sector providers. In many cases, these trends are resulting in our member organisations being unable to meet service demands and maintain the responsive, innovative and person-centred approach that has characterised the sector.

The report proposes a range of practical and urgently needed solutions which would address these issues while improving the relationship between the State and the sector to ensure better outcomes for all. The authors listened attentively and took a great deal of care in reaching balanced conclusions. In addition to addressing the issues I have identified, those conclusions identified many areas for improvement in the practice of community and voluntary organisations. Although these changes will present challenges, I can assure the committee that the sector will not shrink from implementing them. We would like to bring some key recommendations in the report to the attention of the committee. Key recommendations include that a forum for regular dialogue between relevant Departments and the sector be implemented; that a charter for a new relationship between the sector and the State focused on collaboratively developing world-class services be produced; that an agreement be reached on essential services to be fully funded and mapped throughout the country; that service agreements be simplified and duplication in reporting avoided; that multi-annual budgeting be introduced to enable organisations to plan for the long term; that a system to manage deficits be established; and that governance training and supports for smaller organisations be provided.

Finally, the Wheel believes that the forum on the independent review group's report, which is now in the initial stages of planning, offers a very valuable structure to advance and implement the report's recommendations. This will be a key means to renew trust and improve collaborative working between all stakeholders. The terms of reference for the forum should be transparent and open to consultation from representatives of organisations delivering services. I will now pass to my colleague, Mr. O'Sullivan, director of resources for WALK.

Mr. Austin O'Sullivan: WALK, founded in 1967, is a section 39 HSE-funded charity based in Dublin, providing community-based supports to 370 adults with intellectual disabilities and autism. WALK employs 205 staff. WALK receives an annual grant from the HSE to provide its essential core services. In addition to this core grant, up to 2008 WALK also received additional grants for salary increments and staff pensions. Commencing in 2008 WALK has had cumulative cuts of €3.2 million to its core funding and no increment or pension payments have been made since 2009. In addition to this, WALK faces the additional costs of HIQA compliance, comprising €187,270 in capital costs and annual operational costs of €227,923.

What is the impact of these cuts to funding? They primarily revolve around service-user

safety and quality of life. Due to this lack of funding, we have been unable to adequately staff support services and this has resulted in risks to service-user safety. These risks have been fully documented and communicated to the HSE. WALK continues to operate with high levels of risk in its front-line services. In addition to these risks, WALK is aware that the lack of funding has had a direct impact on service-user quality of life. This is most noticeable in incompatible placements of people in residential services and the lack of personalised supports to enable people to achieve their life goals. The issue of changing needs is also relevant and poses a risk to the individual and the organisation.

WALK staff earn, on average, 23% less than similar staff in section 38 and HSE-funded services. Attrition of experienced staff was running at 18% in 2018. This has had a further impact on the quality of services provided. In 2014, the Labour Court ruled that St. Aidan's, a similar agency funded under section 39, was liable to pay increments to staff backdated to 2009. On the back of this, WALK staff have commenced industrial action. WALK's unsustainable organisation deficit since 2009, caused by funding cuts, has left it in a precarious financial position.

Mr. Ivan Cooper: To conclude, the experience detailed by Mr. O'Sullivan in respect of WALK is typical of the challenges facing HSE-funded members of the Wheel. The recommendations in the independent review group report, which we are here to discuss and explore this morning, would go some way towards addressing some, but not all, of those challenges. We look forward to working in partnership with the Oireachtas, the Government, the Department of Health, the HSE, and other Departments and agencies to ensure the very positive recommendations of the report are implemented and can play their part in achieving the health and social services Ireland deserves.

Vice Chairman: Before we move on, I welcome our visitors in the Gallery and those who are watching the meeting from outside. I know that there are people who follow this issue very closely. I welcome them on behalf of the committee. I invite Ms McCarthy to make her statement.

Dr. Joanne McCarthy: Mr. Murphy will speak next, if that is okay.

Vice Chairman: There is no difficulty with that.

Mr. Peter Murphy: I thank the committee for the opportunity to speak on this important issue. For more than 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 10,000 to 15,000 people who live with uncontrolled, recurrent seizures. It can be a source of major and long-term disability, which is often hidden and stigmatised. It affects 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, Ms Jones, is one of our community resource officers based in Cork and will speak about our services in a moment. As the committee will see, these services are closely aligned with the goals of Sláintecare.

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 service

level agreement, SLA, funding varies significantly from region to region. In no area does the funding cover the full cost of delivering the service. For example, in community healthcare organisation, CHO, area 2, which comprises Galway, Mayo, and Roscommon, the cost of providing our services 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 just €784,000. As with other organisations, the SLA amounts are not negotiable. A series of annual cuts were implemented in the early part of this decade and these were followed by a long period of static funding. Today, this funding is 12% lower than it was in 2010.

This has been compounded by growing cost pressures. In recent years, we have worked to innovate and expand our services in response to changing service-user needs. As a result, the total number of service-user contacts nationally increased from 14,000 in 2014 to 20,000 last year. 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, which is 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 activities. This work includes funding research, awareness activities, training programmes and advocacy. We accept and embrace the need to fundraise but, in recent years, greater demands have been placed on fundraising to cover HSE deficits while we also struggle to maintain wider organisational objectives. SLA deficits are averaging €160,000 per annum. Driven by this, and despite tight cost control, more than €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 €1.7 million per annum, this is not sustainable. What will happen 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 CHO areas 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 the 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 resources are available annually to meet service level agreement deficits. A fundamental shift in the relationship between the State and the voluntary sector, as detailed by the independent review group, is needed if smaller, community-based organisations like Epilepsy Ireland are to deliver on our mission. That shift must begin with a recognition of the problems and a commitment to resolving them. Two IRG recommendations are becoming increasingly urgent, namely, the need to review jointly the broken SLA process and, second, the requirement to move towards full-cost, multi-annual funding. In short, non-profit should not mean loss-making.

I will now hand over to my colleague, Ms Niamh Jones.

Ms Niamh Jones: I am one of 11 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 it

on a day-to-day basis. In the past ten years, my role has evolved and expanded greatly, be-

coming more varied and flexible as we work to tailor our services to meet individual needs. I will use my time to outline a recent case, which I hope will demonstrate

the impact we are having on the welfare of people with epilepsy and their families.

I received a referral from the epilepsy team at Cork University Hospital of a man who had just been diagnosed. I immediately arranged to meet him and his wife to start our Living Well with Epilepsy programme, which is designed specifically to meet the needs of people with a new diagnosis. We discussed the relevant issues, including employment, driving, entitlements, safety and risk, lifestyle and triggers, and jointly worked out a plan and strategies to manage those issues. We subsequently arranged a full family meeting as the couple's two children are likely at some point to find themselves alone with their father when he is having a tonic-clonic seizure. The family members were enabled to express their concerns in a safe environment and I went through all the "dos and don'ts" of seizure first aid. At a subsequent meeting, the man's children were happy to report that they had been at home with their father when he had a seizure and the knowledge they had gained meant they did very well looking after him. Since then, I have delivered epilepsy awareness talks in both children's schools, and the man and his wife have attended our support group meetings, which take place in the evening, where they have received peer support from people in similar situations. The man's employer called me recently asking for epilepsy training for staff, which is another service we provide. This client will soon be attending our six-week STEPS self-management programme, which provides a learning environment where people can gain skills and knowledge to achieve the best health and quality of life that they can by managing their epilepsy in an active and positive way. He may later avail of our Innerwise service, a more advanced personal development and well-being programme.

These innovative services were developed in response to unmet needs, and evaluations have shown very positive outcomes. Our programmes also strongly complement the HSE's Sláintecare objectives, such as the promotion of patient-centred,

self-management interventions for chronic conditions. In the near future, community and patient organisations like Epilepsy Ireland will play a key role in making Sláintecare a reality. This is only one example of my day-to-day work, 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 for the individual with epilepsy but also for all those who are impacted by the diagnosis in their daily lives.

Chairman: I thank Mr. Murphy and Ms Jones for their presentations. I now invite Dr. McCarthy to make her opening statement.

Dr. Joanne McCarthy: I thank the Chairman and members for giving us the opportunity to participate in today's discussion. We acknowledge that this is the second of two days of discussions with voluntary organisations in the health sector, which shows a welcome commitment on the part of the committee to get under the skin of this issue. The Disability Federation of Ireland, DFI, is a national support organisation comprising more than 120 member organisations. We work to create an Ireland that is fully inclusive of people with disabilities. It is important to note that we are not distinctive in the work that we do; in fact, there are huge interlinkages with Epilepsy Ireland, for instance, which is a member of DFI, and we are a founding member of The Wheel. We all work well together to create a strong community infrastructure which supports people with disabilities and those at risk. Members can find more information about DFI on our website.

Like our colleagues, we fully endorse the recommendations contained in the independent review group report, notwithstanding the reality that our member organisations will face significant challenges in implementing them. One of the most important recommendations is the commitment the IRG is seeking to resetting the relationship between the voluntary sector, on the one hand, and the HSE and the Department of the Health, on the other, in the delivery of services. We have heard stark evidence, both today and at the meeting of this committee on 19 June, of the need for that to happen. It is one of the issues I hope members will take away and reflect upon following these meetings. The reality is that the relationship between the State and the community and voluntary sector is broken. There are significant failures in the process of agreeing on and delivering necessary supports and services to people with disabilities, whether in acute settings such as day services, respite and 24-7 residential services, as members heard on 19 June, or in the types of community-based services we are talking about today. There is no planning mechanism in place to respond to changing needs, no effective costing mechanism, no clarity on what the State is willing to fund, and no agreement to fund services to their full cost. These are core issues that go to the heart of the ability of organisations to provide high-quality services to some of the most vulnerable people in society.

Having noted the interlinkages between organisations in the sector, it is important to consider the complexity that underlies that commonality. Members heard at the meeting on 19 June and again today that while we have agreement around the issues and recommendations in the IRG report, experiences vary greatly depending on the organisation. We all agree on certain points, namely, that the nature of the HSE relationship is broken, there are chronic funding deficit issues that must be addressed, there is a difficulty in recruiting staff and there are pay issues and issues to do with the service level agreement as the mechanism for agreeing contractual relationships. However, those issues are experienced differently depending on whether an organisation is community-based or one that delivers what are seen as core disability services in the context of residential or day services. We all know there is a funding crisis. Most organisations took cuts during the recession and, in most cases, there was no attempt to secure agreement on how those cuts would be implemented and the impact they would have on service users. There may have been that type of engagement with some of the larger organisations but not generally. Fifty organisations are now in a process to achieve pay restoration, but most organisations in the sector, including the ones we represent, are not included in that process. In other words, funding is a general problem, but how it is being experienced is not equitable across the system.

At the meeting on 19 June, we heard that the sector is facing a deficit of between €30 million and €40 million. In fact, that estimate needs to include the types of things we have been discussing today, where organisations are running down their savings and using important fund-raising money to supplement the cost of delivering core disability services. This goes to the heart of the need to secure a multi-annual investment programme and, in addition, an agreement on the types of services we wish to deliver into the future. I take this opportunity, before the Oireachtas goes into recess, to remind members of the importance of agreeing a list of essential services. We are all agreed that the first thing that must be done is to establish a forum and agree on its charter, that is, the work it will be tasked to do. After that, the next big challenge will be agreeing the list of essential services. One option might be to seek to continue to deliver the services we currently deliver into the future. If we do that we will be missing a significant opportunity to actually use something like the forum to deliver on Sláintecare.

I will offer an example of how the money for disability in the 2019 budget is used. A total of €1.9 billion is going into disability services. That is a significant amount of money - we all have to acknowledge that. Decisions have been made around how that money was to be applied.

Fully 90% of that funding goes to fund residential respite and day services. I am not suggesting these are not needed - in fact, we heard on 19 June that more is needed - but it means only 10% of €1.9 billion is used to resource and fund centre and community-based services. Day services and respite services respond to the need of approximately 30,000 people with disabilities and their families. Yet, there are over 600,000 people with disabilities living in Ireland today. Most of those are struggling in their own homes with changing needs and conditions. The community-based organisations offering the types of services we have heard about today help to keep these people living in their own homes, staying as well as possible and away from heavy expensive services. If that is not value for money, then we have to ask questions about what is.

Before coming in today we did a quick *tour de la table* with some of our member organisations to ensure we were still on the pulse of the issues being experienced by them. I will offer a quick snapshot. These are small organisations that help those with epilepsy, multiple sclerosis and post-polio. They have family names. Committee members will know them because they are in the local communities. Most carry a service arrangement with between two and nine HSE community healthcare organisations. We need to consider the administrative burden of this on a small organisation. None of these organisations is fully funded. We heard the example of how the epilepsy organisation gets €3,500 but it costs €50,000 to deliver the service. There is no engagement to discuss how or what type of services will be delivered and how this will be funded. That is a common experience across the board. Some organisations have been feeling the pressure to use and divert existing resources to deal with increasing health demands. A person from the Blanchardstown Centre for Independent Living explained that the centre has a bus that it had been using to support its members for social outings and engagements. We all know the social isolation that people with disability experience. That service is really important to maintain people's mental health and to create connections in communities. Increasingly, because of the increasing health needs of that particular cohort of service users - I hate that term - or people with disabilities who use the services, the centre now has to use the bus to ferry people to and from medical appointments. They are doing core health business but that has never been acknowledged in the service arrangement. Again, at issue is the fact that the organisations are not allowed to record deficit and this causes major problems. Oftentimes, the organisations not have a formal face-to-face relationship or even a meeting once a year with the HSE to agree the service plan. These are core basic issues that need to be addressed to support the network of vital community services that support people. I will hand over to the chair of the Disability Federation of Ireland who will make some further comments.

Mr. Gary Lee: I thank the committee for the invite this morning. I wish to associate the Disability Federation of Ireland with the comments of the previous speakers from the other organisations. I will follow on from what Dr. McCarthy said. It is imperative that community-based supports serving 95% of people with a disability are recognised as essential services. The list must be sector-specific and be respectful of the needs of people with disabilities. The majority of people with a disability would identify measures such as respite, personal assistance hours or community programmes as essential services. The importance of community based services is clear when we see the first-hand impact it can have on service users. Some examples were given and there are more examples in our submission to the committee.

It is crucial to recognise that voluntary organisations are businesses. To function they must have an open dialogue with the State, in particular, the Department of Health and the HSE, that can be facilitated through the establishment of the forum, as recommended in the independent review group report. We need contracts that are fit for purpose and specific to the services we provide. Voluntary organisations must be provided with the opportunity to plan for the future

through multi-annual budgeting. To allow for equity across the sector, the services that benefit all people with disabilities must be recognised as essential.

We recognise that the disability voluntary sector has issues that must be tackled and the implementation of the recommendations in the report will be a challenge to both the sector and the State. However, it is of paramount importance that action is taken and that real change occurs in the relationship between the State and the voluntary sector. A healthy working relationship stands only to better the lives of service users.

The independent review group report was an evidence-based report. The committee was chaired by Catherine Day, as we know. It is February since the report was issued. Yet, we have not seen any progress on the report in that time. Our concern is that it will be shelved. It cannot be shelved. The State needs the voluntary sector. The voluntary sector provides essential services to people the State should be providing services to. From our experience, the relationship between the State and the voluntary disability sector is broken. I echo the comments of previous speakers on that point. Something needs to be done about it.

Vice Chairman: I have two brief questions. The first relates to what Dr. McCarthy said about not being allowed to record deficits. We had some discussion at the meeting on 19 June with regard to the impact this has. As Dr. McCarthy said, the organisations are businesses. In business terms, there is a name for that. I have no wish to be throwing it around but we know what it is. I wish to be clear. The HSE prohibits the organisations from recording a deficit but the executive expect services to be delivered. Can you confirm that the organisations effectively take referrals from the HSE, Dr. McCarthy? People in the community are told where they can access these support services. Ms Jones illustrated well exactly how that works. It strikes me that there is an attitude of wanting it but not being prepared to pay for it on the part of the HSE. Can you expand on that and explain how the relationship works, Dr. McCarthy? Perhaps I am wrong but I am hearing that on the one hand the HSE says it desperately needs the organisations but on the other hand the HSE is not prepared to pay for them.

Dr. Joanne McCarthy: Perhaps I will start but I imagine some of my colleagues will be able to better illuminate the experience of design and service delivery. In the case of many of the community-based organisations the HSE does not even say it desperately wants them and that is part of the problem. Let us consider SláinteCare. We recently had Ms Magahy in with us. There is an interpretation of what a core disability service amounts to. As we heard on 19 June, even those core services are being significantly challenged in terms of how they agree to deliver services. The term “auxiliary services” is often used to describe community-based services. There is probably a lack of understanding or appreciation of the value of those services because organisations do not necessarily have face-to-face meetings ever with the HSE to agree on the service. There is no discussion even around what the HSE is willing to fund. I reckon we need to take a step back. There is a historical funding relationship that gets delivered through the service arrangement. I am unsure whether there is a contemporary understanding of what these organisations are doing or the fact that this is the future model. It is about delivering person-centred community services as close to the person’s home as possible. This is being put into operation by these organisations. We fund a particular model and that is where 90% of the funding goes. That is where the relationship is being driven. I do not know if my colleagues want to talk about a particular point.

Vice Chairman: I would like to direct one question to Ms Jones. She gave us an example. Could she describe what would have happened if Epilepsy Ireland’s service was not there? What services exist for that gentleman? Ms Jones’s service is right there with him. He is deal-

ing with a fairly traumatic event in his life and Epilepsy Ireland is giving him practical support. If it was not doing so, who in the HSE would step in to meet his needs?

Ms Niamh Jones: We have wonderful neurology teams in all our hospitals and we have very strong links with them. However, we are the only organisation in the country representing people with epilepsy. Once the epilepsy team has provided its education and support within the hospital environment, a patient is then out in the community. We now have a direct referral link with the HSE epilepsy team. We get the referrals, immediately contact them and tailor the response to the person's needs. No other organisation exists to deal specifically with epilepsy.

Vice Chairman: As such the HSE would have nowhere to refer him. He would be in community without Epilepsy Ireland's support.

Ms Niamh Jones: Some of our people have links to other organisations. There could be some additional help.

Vice Chairman: The voluntary sector is where the help comes from.

Ms Niamh Jones: In the case of epilepsy specifically, the help comes from Epilepsy Ireland.

Dr. Joanne McCarthy: It is really important to say that this is quite common. That is not to undermine what has been said. This level of expertise is quite common around the neurological bodies and it is usually undervalued. Motor neurone disease is another example. Voluntary bodies shadow affected families. Approximately 400 families, give or take, are addressing the issue of neurology at any one time. Voluntary bodies will shadow an affected family. They know that in six months that family will need a hoist for the patient to get downstairs. These organisations are able to predict needs and provide a wraparound service in the community that really sustains the capacity of those families to live with those conditions.

Mr. Austin O'Sullivan: A question was asked about how service level agreements, SLAs, operate. They are fundamentally divided into three parts. The first part is very straightforward; it is the quantum of service an organisation is to provide on behalf of the HSE. That arrangement pertains either to a number of people or a number of hours. The second part is the cost, that is, how much it costs the organisation to provide those services. The third part concerns the amount the HSE will actually pay. In the vast majority of cases there is a fundamental difference between the cost of providing those services and the amount the HSE pays. The HSE does not allow voluntary bodies to put the actual cost of providing services into their SLAs. They have to manipulate things to show the costs as equal to the amount the HSE is paying. It is very difficult for most organisations to get the chairperson of their board to sign off on that because it is not really true.

Deputy Margaret Murphy O'Mahony: I welcome all the witnesses and thank them for the Trojan work they do. It was great to listen to them. I am glad that everybody is here together and we are all singing from the same hymn sheet. This meeting should be very productive.

I very much agree with Mr. Lee about the report launched five months ago. We are now facing into a quiet summer period. I sincerely hope it will not be shelved, but I am concerned that nothing has been done. Have the voluntary bodies approached Ministers? With respect, are they pushing for implementation of the report or just waiting for it to happen?

Mr. Ivan Cooper: If I may jump in, we are taking every opportunity available to us to raise it with officials, political parties and politicians. It is very well known that the voluntary sector

is-----

Deputy Margaret Murphy O'Mahony: Ready?

Mr. Ivan Cooper: -----enthusiastic about the recommendations in the report and very concerned to ensure it is brought to the attention of policymakers, understood in its entirety and there is a commitment to implementing it. We are delighted to be here today for that very reason.

Deputy Margaret Murphy O'Mahony: Mr. Murphy noted that funding varies between different areas. Offhand, does he have figures for community healthcare organisation, CHO, 4?

Mr. Peter Murphy: Not off the top of my head.

Deputy Margaret Murphy O'Mahony: Why do they vary?

Mr. Peter Murphy: It is a historical issue that goes back to the old health boards. I do not necessarily have access to the history. I can certainly comment on it on the basis of the documents available in our case. In the pre-HSE era so-called section 65 funding under the Health Act 1953 was individually negotiated with each local health board. There seems to have been a system for several years under which service plans were submitted locally for each region around the country. Again, they grew up individually in each region. Around the turn of the century a process called the Harmon review introduced funding arrangements for several smaller community organisations like ourselves. These things all happened piecemeal and led over the years to individual funding amounts. When the HSE was set up and the SLA process began, those amounts transferred over and they have been stationary ever since.

Deputy Margaret Murphy O'Mahony: It is a pity that every area does not have the same funding *pro rata*-----

Mr. Peter Murphy: CHO 4 is the south east, is that correct?

Deputy Margaret Murphy O'Mahony: It is the south, including Cork.

Mr. Peter Murphy: I beg the Deputy's pardon.

Vice Chairman: All politics is local.

Mr. Peter Murphy: It is not the north of the country, anyway.

Deputy Alan Kelly: That is completely random.

Deputy Margaret Murphy O'Mahony: Yes, it was a random choice.

Mr. Peter Murphy: Cork and Kerry together make up the south area.

Deputy Margaret Murphy O'Mahony: It is a very important area.

Mr. Peter Murphy: It is not the worst-funded area, but funding is nowhere near the full cost.

Deputy Margaret Murphy O'Mahony: It has the best people.

Mr. Peter Murphy: We have an extremely good service in the area. I am not just saying that because Ms Jones is here. There is only one area, the south east area, where funding is

anywhere near 100%. It is normally somewhere in the region of 90%, up to 95% in our case.

Deputy Margaret Murphy O'Mahony: It is worrying that no area has full funding. More luck to the people who have.

Mr. Peter Murphy: It is most extreme in CHO 2, the west. I do not say that to single the west out. To be fair, funding is not given to each CHO area to distribute as we would like. That is an important point as well. It is often not very easy to understand the decision-making processes behind the scenes. I do not know if "transparency" is the right word. We have good relationships with our contacts in every region, but the decision-making process is not very clear.

Deputy Margaret Murphy O'Mahony: I thank the witness. I will finish up with Mr. O'Sullivan. Along with KARE, WALK is part of the Oireachtas work and learn, OWL, programme.

Mr. Austin O'Sullivan: Yes.

Deputy Margaret Murphy O'Mahony: I was a bit dubious when this was first mooted, but having gotten to know the lads and the girls it has been fantastic to see their confidence growing. They have become very much a part of the Oireachtas.

Mr. Austin O'Sullivan: Excellent.

Deputy Margaret Murphy O'Mahony: I know some of them are finishing up today. I want to wish them well. It was an excellent initiative. Well done. Did WALK find it to be good?

Mr. Austin O'Sullivan: It was absolutely fantastic. Our purpose is to create opportunities for people with disabilities to have normal experiences that we take for granted. The Irish Parliament is the first parliament in the world to have such a programme. It is absolutely fantastic.

Deputy Margaret Murphy O'Mahony: That is great. Well done. It is an excellent initiative.

Vice Chairman: It is. I wish to join Deputy Murphy O'Mahony on that and to particularly acknowledge the Ceann Comhairle, who really drove this. It is a fantastic programme.

Deputy Margaret Murphy O'Mahony: He also sold it to us.

Vice Chairman: The whole committee wishes everyone who participated in it well. Given that we have had some talk of Cork and that there is a match coming up, I will say "Up the Dubs" and call our next contributor, Deputy Kelly.

Deputy Alan Kelly: I am not next.

Vice Chairman: Deputy O'Connell and Senator Colm Burke indicated.

Senator Colm Burke: I thank the witnesses for their presentations and for all the work they are doing. In addition to raising awareness and trying to source grants from the agency, in some cases they are also trying to raise money voluntarily. Every organisation is involved in that.

I raise an issue in respect of healthcare. We seem to be continually increasing the expenditure going into healthcare and I am not sure whether we are doing it in the right way. I raised that issue previously with the HSE. People here may not be aware that an additional 16,000

staff are working in the HSE now compared with the number four years ago. I am not sure whether the witnesses are aware of that. I do not believe there has been any growth in the numbers of people working in the organisations the witnesses represent. Funding has not been given to increase the number of people in their organisations to the same extent as that which has occurred in the HSE.

In examining all these issues I have to consider the area of budget. According to the 2018 annual report of the HSE, more than €4.4 billion was paid out to the various section 38 and 39 organisations. That is a very large slice of the HSE budget. We seem to be reliant now on a range of organisations to deliver care in many areas. For instance, we are very reliant on Epilepsy Ireland to deliver care for people with epilepsy. Is there a need for a more co-ordinated approach? It must be the case that some organisations are delivering the same services. Should we consider if we can deliver better services by more co-ordination among existing organisations and the HSE? The HSE has looked at the way its funding is being used, but I am not sure if the organisations have considered if a better service can be delivered by them working together rather than independently. That is one area we need to examine.

More than 3,000 organisations get funding from the HSE. That is a very large number and is a huge amount of the HSE budget, but is that funding being used wisely? I am not convinced that the budget the HSE retains is being used wisely. As I said, 16,000 additional staff have been recruited over four years. I am mesmerised how that number has grown in such a short time.

Have the organisations considered doing a five-year or a ten-year programme? We have talked about Sláintecare, which is a ten-year programme. In terms of forward planning, have the organisations looked at whether a merger or amalgamation would be beneficial in some cases or the possibility of delegating work one organisation is doing where another organisation is also providing the same service? Have they examined that entire reorganisation issue? It happened in the trade union movement 25 or 30 years ago. It had a large number of different unions and they came to the conclusion that they would gain much more by amalgamating and working together rather than working independently. Has that issue been examined?

I have the list from the HSE's 2018 annual report and there are a very large number of organisations. I am aware that some of them are getting very large amounts of funding. Some of the voluntary hospitals are included in that €4.4 billion but it is still a major slice of the entire health budget. It is about whether we can deliver services in a more co-ordinated way in certain areas. I am not taking from the work of Epilepsy Ireland. No other organisation can replace it because the work it does is comprehensive, but there is duplication in other areas and I wonder if we can do a better job in that regard.

Dr. Joanne McCarthy: I will start and others can come in if they wish. That is a question people always ask. We hear of these large numbers of organisations. To reply to the Senator I will go back to go forward. The first point to remember is that 90% of the funding goes to a very small cohort of service delivery organisations. The number the Senator is talking about is not that large. Some €1.9 million goes into the voluntary sector part of the disability programme and 90% of that goes in one particular way.

There are opportunities for looking at service design. For example, a new rehabilitation strategy was published a year or two ago focusing on the clinical side of rehabilitation. Part of it refers to the community side, which would bring organisations such as Epilepsy Ireland and others together to examine ways of sharing services, planning for the need for community-

based services and then going to the HSE for funding of that need. There is opportunity for that but the Senator should not forget that most of these organisations are bringing in significant resources. First, they are co-funding services so how do we build that into the mix? We cannot afford not to let Epilepsy Ireland use its own resources to deliver services. Second, they have a significant amount of expertise that will not be in the system if we do not protect it. All these organisations have major links with the European associations and research groups. That level of expertise and added value must be valued and brought into the system.

Without a doubt, that conversation needs to start but not just at the point of amalgamations because we would lose the co-funded nature of many of these services and their significant added value in terms of expertise, specialism and the touching base with families and communities. When we have that conversation it needs to be in that much broader context. That is where I would start. I do not know if anybody else wishes to contribute.

Mr. Austin O’Sullivan: There is no research showing that bigger is better in people services. In fact, the research we have done shows that when organisations get to a certain size, the person gets lost, so to speak. Our experience and the experiences of other community and voluntary organisations is that they arose out of the community to meet the needs of the community they serve. When organisations are disassociated from the people, there are far fewer outcomes for those people. It is a stated objective of the HSE to deal with far fewer organisations but I have yet to receive any evidence from it on the reason it believes that makes sense.

Senator Colm Burke: People do get lost in big organisations. Is that not exactly what the HSE is now dealing with in that I presume many of the organisations find it difficult to tie down one individual in the HSE to make a decision? Mr. O’Sullivan might talk about that experience where his organisation meets one person in the HSE only to find that he or she must go up along the line for a decision to be made. One of the problems I find with the HSE is that I can make representations on a particular issue, and while I might make it to person A, I find that A passes it on to B, B onto C and C onto D before I can get a decision. Are the voluntary organisations experiencing the same problem?

Mr. Austin O’Sullivan: From our experience there had been a very collaborative relationship with the HSE and every area had its own development committee where each organisation met its HSE people to discuss issues being faced by its region and how best to deal with those issues. The relationship with the HSE is now purely a transactional one. There is no partnership and no coming together to solve the needs of the cohort. We find that the person we meet face to face has no power to decide on even the smallest thing. Everything has to be sent up and we could be waiting for years before the answer comes back down. The efficiency of communication between the sector and the HSE certainly has an impact on the ability of organisations to do their day-to-day work.

Senator Colm Burke: Does that lead to a situation where a substantial amount of time is given over by the organisations in trying to follow up and get decisions?

Mr. Austin O’Sullivan: Absolutely.

Mr. Ivan Cooper: Dr. McCarthy referred to taking a step back from it. The role played by the voluntary and community organisations in health and social services is well understood by this committee and it is in every community in the country. It is inextricably intertwined and bound up in our core health and social services. The two are no longer separable and they need to be understood to be part of a system that needs to be re-understood and properly resourced.

The independent review group report published by Dr. Catherine Day and her team engaged very deeply with this particular issue and made a strong, central core recommendation - to which Dr. McCarthy alluded earlier - on the idea of essential services. We are never going to escape this kind of circular conversation we are having currently.

In fairness to the folk who work in health services administration in the various departments, they are all under intense pressure in delivering outcomes and scrutiny around budgets, which of course is all right and proper. Everybody is under pressure, but a core recommendation is to agree and identify the essential services people should have available to them in their day-to-day lives in their communities and that we should work backwards from that. It is kind of like the old idea - most of us are familiar with the terminology - of outcomes-based working. There is some theory there. Inside the HSE there are people who think about this, and in the Department of Health, the Sláintecare office is established now. Maybe we can look more towards ideas of commissioning services where we look at the outcomes and then agree if the outcomes are going to be sufficient to meet the community need. Ultimately, however, it starts off with having a clear sense of the need we are trying to serve within communities. Then we can have a conversation about the types of resources and services that are necessary.

This plays back to Senator Burke's point about optimal ways for organisations to do things. Of course, inevitably there are optimal ways of doing things. If reform is to be structured around making central administrators' lives easier, the problem will be administration-led services that will come increasingly distant from communities. If the reform is designed to make services more flexible, innovative and responsive at ground level, then it will be the other way around and we will end up with a devolution and delegation inside the system to the closest possible place where accountability should be experienced by individuals who require services.

Viewed that way, our community and voluntary sector being present in every community is in fact an asset that is already there, if we can find a way of connecting it up better with itself and integrating it in a more cohesive way into our health services' strategic thinking. I would call today for the Department of Health and the HSE to engage the community and voluntary sector more in strategic thinking about the future of the health and social services. The sector will not be found wanting ultimately in understanding the part it needs to play in well-designed services.

Senator John Dolan: I welcome all of the witnesses. I have had a long connection with all of them in my involvement with the Disability Federation of Ireland. We were very core, which goes to the very idea of co-operation, to the importance of the establishment of The Wheel as something that was bigger and for the whole community and voluntary sector. It is an example of understanding that it is beyond oneself. WALK and Epilepsy Ireland and many others have been part of the movement for a long time.

This report gives our committee a strong basis for focusing its work over the next year or two around the disability issue. It raises some of the critical strategic issues and brings it down to brass tacks. The independent review group report referred to owing a debt of gratitude to the people who work in the voluntary sector. It did not say the people who were employed. It referred to those who work in it, which takes in both. There is a high dependency in that regard as an integral part of the whole sector. The report's authors were struck by the need of the organisations with which they engaged to be listened to and their willingness to find a new basis for co-operation. The last part of that is a challenge to the voluntary organisations as well as just saying that they are great.

The report stated that Ireland benefits from a strong public service commitment in both the statutory and voluntary sectors. Perhaps this is the place to start engagement between the HSE, the statutory health services and the voluntary services. The report reads, “If the voluntary sector is to be retained, as we believe it should, there is a need to give public recognition to its legally separate nature”. This may be a soft way of putting it that they are not subcontractors of the HSE. It goes to the heart of how we respectfully engage. The report goes on that the voluntary sector must also recognise “its dependence on the State”. It is a two-way street.

I will move on to the witnesses, as I realise we are stuck for time. We have been here before. There was the White Paper in 2000 on supporting voluntary activity. That was nearly 20 years ago. It was a whole-of-government thing with all of the Departments, an implementation group and the whole works for a policy that came out in 1999. That has withered on the vine and it withered fairly quickly. In the context of this report and all of the things that would give us hope, how do we put that statement against the fact of what has happened previously and the difficulty of making things stick?

Is there actual respect for the public benefit these organisations bring? This is the term used in our charity legislation. They cannot become charities unless they are adjudged to bring public benefit. Is there actual respect for that?

The disability services programme of €1.9 billion is built on an old administrative structure that perhaps goes back to the foundation of the State. Will the witnesses comment on or make an input into the amount of support and engagement that takes place outside of the disability health services but within the health services? Much of the epilepsy support for people is neurologist teams and so on and is not funded through the disability services programme. Perhaps the witnesses could give some sense of the importance of the broader picture. How relevant do the representatives believe Sláintecare is? Is it another process that is going in parallel or in a similar direction?

Much of the disability services programme is about delivering reactive services, which must be provided because people have got to a certain situation. Should we be getting to the point of delivering more of a proactive service? Last week we had a meeting with the new chairman of the HSE. He talked about the demographics and said we are trying to chase him at the wrong end of the spectrum. I put that to the witnesses. He says we must invest in prevention, amelioration and measures that prevent and-or slow down the impact of conditions. He referred to medicines and other things.

Then there is the advocacy role and the work that is done outside of the specific disability. Ms Jones spoke about schools, family and employment, and other witnesses made similar references.

That is it in a nutshell.

Ms Niamh Jones: I will give my opinion from my work on the ground. I am not a figures or administration person. With regard to Sláintecare, we are already there. We take a very person-centred approach. We are flexible and work out of hours. I work at night and on Saturdays to provide our service. That is very important to the public reaction and its appreciation of what we provide. We are accessible. We work everywhere - in the south, south west and up to the north. I am saying that it should not just be on paper, but on the ground. It should be looking at what I am doing. My 11 colleagues and I are the people who are out providing a service that is recommended. There is much talk about being person-centred and accessible, but how many

of us can do that without the resources? We need the resources to do it.

The Senator mentioned that the funding is going into main sources, whereas much of ours has to come from fundraising and other areas to provide these formalised programmes. We provide a continuum of care outside the hospital environment from new diagnosis right through the person's life. It might be a parent at the beginning. I am now meeting young adults who were children who have come through it. I am going with them into colleges and providing epilepsy awareness in colleges throughout the country. They are going into employment. I belong to a single very small organisation in the group to which Dr. McCarthy referred. Let us look at what we are doing on the ground.

I wish to get rid of a misconception that we do not work with other organisations. We need to go there and examine that. As the Senator said, ours is a very specialised organisation but we link on the ground. We have very strong links. It is not appreciated how much we link with the neurology teams, but outside those teams and in the community, we could not exist without networking with each other, education centres, acquired brain injury organisations and mental health organisations. We are linking continually. How one formalises that is the way to go forward. We are not all working in isolation. We work with people on the ground. Look at what is happening on the ground and not just on paper. Let it not be the words but the work on the ground. This is all about the person with the condition and the people it impacts in the community.

Dr. Joanne McCarthy: With regard to the €1.9 billion, it is interesting that 90% of it is for core specialist disability services. That is what the Senator was talking about on the 19th. It is for the day services, 24-7 residential services and the respite care. There is 10% which relates to much of what we are discussing today. They are funded through disability services, but they equally could be funded through primary care. They are a significant resource to primary care because they provide a specialist network of resources that enable people to live with conditions. They do self-management courses, specialist yoga and so forth. They provide core primary care services that have a specialist interest.

That goes back, perhaps, to what Senator Dolan said. We are almost stuck to delivering disability services in an historical way when the reality of disability has changed over time. One in four people now acquires a disability at working age. That is all neurological. Many of them are, for example, people with acquired brain injury and people with MS. They are not planned for within disability services. That is the 1,400 people who acquired a disability at working age and are now living in nursing homes because they are not planned for and there is no service for them. We must think differently about what type of service we are willing to offer people with disabilities. That includes better demographic planning for the 30,000 people who are in core disability services but it equally means we must plan the value of community-based disability organisations into the delivery of generic primary care community-based services at local level. Where one will ring for the epilepsy, MS or motor neurone person, the HSE offices should know who the person in the region is and it plans in a coherent way the delivery of community services to people, whether it is through primary care or disability support services.

In that way one can see how critical it is for Sláintecare to fully understand what community disability services do when it is beginning to plan its services. The DFI had a seminar to which we invited Ms Magahy. She acknowledged that and she said she recognises how critical it is for Sláintecare to look at the recommendations from the Dr. Catherine Day report in this context. We know that. She also acknowledged that perhaps disability in its entirety had not been planned into Sláintecare in its current position but that she was open to it and, hopefully,

following our seminar, will begin to do that. Undoubtedly, Sláintecare should offer a way to create threading between specialist and disability services in the mainstream and then specialist community services and core disability residential or wraparound services. It should allow us to thread those and see them as a tapestry of opportunity so people can come into and out of different types of services depending on what their need is.

Mr. Ivan Cooper: I will engage on a few of the points the Senator Dolan. With regard to respect for public benefit, this respect is articulated at senior leadership level in Departments and agencies and exists formally on paper in strategies and documents. The system knows that it is reliant in many respects on organisations and the work they do on the ground. It is articulated in that way.

There is a danger that the words do not move from that leadership level into practical application in terms of daily realities between funders and organisations. The system, organisations and funding agencies are under stress, as I indicated. Many of our members will report, for example, that they experience this double type of attitude to them. Formally they are respected, but when it comes to the nuts and bolts of the contracts, the service arrangements and the annual negotiations on budgets the relationship is not like that. It is felt more as a relationship that is moving in the direction of control via service contract. Some members will use stronger language, such as “manipulation”. Very strong language is used sometimes, so there are mixed messages. It is like the relationship between the funded organisations and their statutory funding partners. It is a marriage that is under intense stress at present and is in danger of coming apart at the seams. One member of the marriage appears to hold all the power in the form of the pay cheque, if members understand what I mean. This is the reality. They are putting a brave face on it in public when they are out and about but that is starting to wear off, to stretch the metaphor. There is an issue in that regard. To answer Senator Dolan’s question directly, is it respect if one says one respects somebody but one’s actions do not appear to be read by others as being respectful? That issue is coming to a head.

Another point made by the Senator was about whether we have been in this situation previously; we have been. It relates to the same issue. It is the positive language. Something happened ten years ago and everybody in the voluntary sector is awake to the stresses and strains, but Austin O’Sullivan articulated the extent of the cuts that were made. They were never reinstated and demand is continuing to rise.

My final remark comes back to the idea of essential services. We are going to be in a groundhog day conversation until we can get this issue nailed. We have an opportunity to do it through Sláintecare and this report. It is important for us, given the forum we are in now, to signal very strongly to the officials in the Department, to politicians and to everybody that the sector does not want an adversarial relationship but a relationship of partnership and collaboration. That is what we stand for in terms of our work. Partnership work is difficult. It is like a marriage under stress, it will come apart if positive action is not taken.

Vice Chairman: Mr. Murphy wants to contribute.

Mr. Peter Murphy: Essentially, I wish to make the same point about respect. This is one of the key words I picked up from what Senator Dolan said. It is difficult to state that there is a culture of respect when, as we have heard from others, we operate in an environment whereby the contract is king and governs the entire relationship. It is very rare, if at all, that we will be questioned about the quality of the service we deliver, our plans for the future or anything that relates to the outcomes we deliver. Any or all of the relationship interactions seem to be based

on observing the timeline, meeting the deadline or informing us that we forgot to enter data in a particular column. It is a technical relationship, as Mr. Cooper stated. Everybody wants to move to a position whereby our work in the future will be evaluated not just in the context of the financial numbers but on the basis of the actual outcomes we can deliver. We try to deliver actual outcome information and data, but this is not necessarily something that is ever valued by the contracting partner.

We have heard a great deal about Sláintecare. As already stated, it is organisations such as Epilepsy Ireland that will play a key role in the delivery of Sláintecare. We are looking to move from a hospital-centric model to the timely provision of services locally. All of the neurological organisations and groups have a major role to play in this regard.

When one talks about the HSE, there is a significant difference between how organisations such as ours are viewed by our clinical partners. In our case, these are the neurologists, the epilepsy specialist nurses and the wider services. Those who work with us on a day-to-day basis see the value in how we supplement their services and, in certain instances, how we actually fill in the gaps, particularly in respect of epilepsy nursing and so on. They see the real value of our service, but one does not form the impression that there is any form of partnership approach. I wish that there could be a communications channel whereby our funders could engage with the staff of the HSE with whom we work day to day.

Senator Dolan referred to advocacy and the significant role that organisations such as ours play in that. Ms Jones referred to speaking to employers and various others regarding rights, entitlements and all the rest. Another key aspect of advocacy is highlighting the deficiencies that are out there. It is organisation such as ours that highlight these issues. A recent example that this committee would be familiar with would be that of sodium valproate, a drug used to treat epilepsy that was brought to the attention of the Oireachtas through patient advocacy efforts.

Vice Chairman: I thank Mr. Murphy and call Dr. McCarthy.

Dr. Joanne McCarthy: I have been trying to find a way to make this point. I will focus on Senator Dolan's concept of value. We know that what is counted is valued. One can hear a great deal from the HSE regarding outputs. Often, in the context of the types of services we are talking about today, there is no counting of unmet need. The number of PA hours that are not being delivered in a particular region are not counted. They are not looking at the number of respite services that are required in a particular region for families that are trying to support loved ones at home but just need that extra support. That is not counted. That the community services and supports available are not valued can often be seen in the fact that they are not counted. Once it is counted, one must acknowledge the increasing level of demand and the inability of the system, as it stands, to meet it. I want to use this opportunity to allow people to understand that it is not just about the funding, it is also about not gathering the evidence of the need that is there. It is also about how organisations at community level are being stretched in terms of trying to fill the gaps regarding something that is not actually been acknowledged or counted.

Vice Chairman: I call Deputy O'Connell. She will be Senators Swanick and Mac Lochlainn.

Deputy Kate O'Connell: I thank our guests for all they do and for attending this meeting.

On her final point, is Dr. McCarthy is really stating that if one cannot quantify the need in

the community or the work that is being done, one cannot put a value on it and, as a result, it cannot be budgeted for and that bedding it into the base is a cost?

In terms of respect, it is disappointing to hear that there is a gap between organisations such as those represented here and the medical professions. I have used the services of Epilepsy Ireland in my professional life in the context of people with new diagnoses. There is always a void if someone, especially a young person, receives a diagnosis of epilepsy and needs support. Epilepsy Ireland is the only organisation to which to refer people. There is no one else to call. The value of that support for an individual or a family who have never dealt with such a condition cannot be underestimated, particularly, as Ms Jones noted, in the context of working through the process as the person gets older and the changes in his or her life become more significant. It is very concerning that there is very little value placed on or respect for this support.

In terms of Sláintecare, would I be correct in stating that this is a contract-and-service based approach and that one would nearly be afraid it would be whittled down into a monetary contract and that the years of work, the years of relationships and the natural networks that have been built up would not be taken into consideration? In other words, it would almost become an inanimate figure rather than comprising an evaluation and a qualitative analysis of all that our guests' organisations bring to the table. I am concerned about whether, if it becomes a contractual, box-ticking, deadline-meeting exercise, that the core value of the voluntary bodies represented here will be destroyed.

Reference was made to sodium valproate. Epilepsy Ireland, along with its international counterparts, has done significant work to help the people who need this drug but also to bring information on it to the attention of the medical professions and this committee. It has done significant work in informing us and I do not know where we would have gone if it had not been for Epilepsy Ireland. It also contributed greatly when we were considering the medicinal cannabis legislation and, as a professional body, had huge value to add in that regard. This committee knows the value of Epilepsy Ireland and has respect for it. We have benefited from its expertise.

I was not exactly sure what Dr. McCarthy was saying when she stated that 10% of what is budgeted for could through community services?

Dr. Joanne McCarthy: There is €1.9 billion in the budget for disability services in 2019. Of that €1.9 billion, 90% funds residential respite and day services. It is often respite care that is linked to the day services programme. That allocation is for 30,000 people give or take.

Deputy Kate O'Connell: So we are talking about people who might be in St. John of God's and those with Down's syndrome who may get three weeks of respite.

Dr. Joanne McCarthy: Yes, and those who have a nine-to-five, five-days-a-week day service or a residential place. Some 90% of the funding goes to fund that model of service and the remaining 10% is used for all the other community-based services. It is crude, but it works off the value for money working group 1 report for 2017 and, as such, is quite accurate.

Deputy Kate O'Connell: It was mentioned that the groups had arisen from the community in order to meet its needs. Would any dissociation from their connection with people be an erosion of their work? There seems to be a dissociation between the HSE and their work, with the Disability Federation of Ireland being an essential link in that regard.

Dr. Joanne McCarthy: Yes.

Deputy Kate O’Connell: On policy, how is the relationship between the delegates’ organisations and the Department in coming up with policy initiatives for people engaging with the services they offer when one takes the money and contracts out of the equation? I refer specifically to people with epilepsy who may not drive. Epilepsy Ireland previously contacted me on this issue. Such persons do not receive a travel pass. Particularly in rural Ireland, people often take the risk of driving a car because they cannot otherwise go to work, operate their tractor, etc. As a medical professional, I am concerned that it could have serious consequences if the person has a seizure. When the delegates go to the Department about an issue such as this, for people with epilepsy who have a long-term illness card and, as such, receive their medication for free, how are such initiatives responded to? Leaving aside the money and contract and, rather, focusing on their expertise, how does the Department and the HSE engage with the delegates? Are they just dismissed?

Mr. Peter Murphy: In many cases, such contact takes the form of formal or written submissions as part of a bigger process. On the specific issue of free travel, a campaign we have fought for more than ten years, approximately a year and a half ago we met the Minister of State, Deputy McGrath, to discuss the issue. He considered it fair that people who essentially were stopped from driving by the State should be compensated in some way by it.

Deputy Kate O’Connell: It would also be in the public interest.

Mr. Peter Murphy: Yes, absolutely. If a person has active seizures, it goes without saying he or she should exercise caution. It would make sense in terms of their independence and ability to function economically for people to automatically qualify for free travel on diagnosis of epilepsy or for as long as they cannot drive because of seizures. The Minister of State was very enthusiastic about this idea. Several weeks later we were put in touch with officials within the Department and every aspect of our plan was hit back to us. We were given six or seven reasons it could not happen.

Deputy Kate O’Connell: It is unlikely to affect a significant number of people.

Mr. Peter Murphy: We estimate that approximately 5,000 people are affected. Although I cannot remember the exact cost of extending the free travel scheme to them, it would not be particularly significant. The proposal has gone into hibernation based on some of the feedback we received from the Department which did not take the issue particularly seriously at the time. It is one on which we hope to revert to the committee. We recently sought to speak to the Deputy about the matter.

Deputy Kate O’Connell: On outcomes and their engagement with the workforce, it would be very useful for those who might be diagnosed in their teens and then go to university not to meet that barrier. It is very difficult to explain to an 18 year old lad with epilepsy that he may not drive. Perhaps as a result of this meeting the committee will write to the Minister to remind him of the correspondence in that regard.

Vice Chairman: That is a very helpful suggestion.

Deputy Kate O’Connell: If the issue affects 5,000 people, there is a public good. In recognition of what Mr. Murphy and his organisation have worked towards, it would be helpful if the committee were to do so.

Vice Chairman: Absolutely. It is a very good suggestion which we will take on board.

Mr. Peter Murphy: A maximum of 5,000 people are affected. Many of them already qualify for free travel under other schemes and so on. The document to which I refer is very short and we are more than happy to share it with the committee.

Vice Chairman: That is helpful. We will write to the Minister.

Senator Keith Swanick: I thank the delegates for their attendance. I agree with the comments of Deputy O'Connell. As someone who works on the ground, I often wonder whether the figure of 5,000 is accurate because people may under-report or diminish their symptoms. I know of certain patients who are almost afraid to say they have had a seizure because their livelihood may depend on driving or working with farm machinery, etc., especially in a rural setting.

There is significant disjointed thinking when it comes to this sector, particularly in the funding model and primary care services. I have repeatedly stated it is not really about the primary care building but about the activity that happens within it and the connectedness of primary care, the GP, neurology services and voluntary bodies such as those of the delegates. The services provided by the delegates' organisations are not valued to the degree they ought to be. From a neurology point of view, they are nearly treated as add-on services. My doctor colleagues will give out to me for saying this, but sometimes one must say what one thinks. The organisations do not carry the weight they deserve to carry and that upsets me. One may sometimes perceive passiveness in the medical profession about the services they provide and that upsets me. Doctors and the medical profession need to do more to value the role played by the organisations on a day-to-day basis for people who suffer from epilepsy.

As Dr. McCarthy stated, there is a tapestry of opportunities. She hit the nail on the head in that respect. The only way we will achieve things is by speaking about the role played by the organisations with positivity and engaging. There is significant disjointed thinking when it comes to health. Everyone seems to work in his or her own little box, including GPs such as me, the epilepsy nurse I contact occasionally in UCHG, the organisations represented today and neurologists. We need to break down the barriers and concentrate less on the infrastructure of primary care services. The delegates' organisations need to be funded through a proper funding model and there should be more communication. We used to have many primary care meetings in the community some years ago, but they are no longer held. It would be of benefit for the delegates to present more frequently to bring their message home to clinicians in the community.

Vice Chairman: I call Senator Mac Lochlainn and thank him for his patience.

Senator Pádraig Mac Lochlainn: I am not a member of the committee and the protocol is non-members ask their questions last, as is right and proper. I appreciate the opportunity to contribute to the discussion.

I was asked by the Inishowen Childrens Autism Related Education, iCARE, organisation in Buncrana, County Donegal, from where I come, to attend the meeting and tell its story as part of this dialogue. The issues with the HSE are often to do with what are referred to as silos. There is no communication between its various parts. It appears the HSE wants to extend this approach to the community and voluntary sector so it has the same lack of professionalism and joined-up approach. This is why the recommendations of the independent review group are welcome, particularly recommendations 8.1 to 8.4, inclusive, which deal with the list of essential services.

It is critical that we define the essential services in partnership with the community and voluntary sector. Then we get into mapping where they are, the charter, which is a framework, and, of course, the forum. This has been referred to today. It is essential the recommendations are implemented. It is self-evident that these must be done. As has been said, in February it was welcomed by the Minister but here we are. Everybody who lives in the State understands that if it were not for the community and voluntary sector, people with disabilities, the elderly and young people in their communities would be left behind. All sectors would be left behind if it were not for the community and voluntary sector.

iCARE was established 18 years ago in my home town of Buncrana. It is a groundbreaking organisation for children on the autism spectrum, which works with schools and the local community. The service has grown and grown with no money from the State over all of those years. Last year, it teamed up with Bluestack Special Needs Foundation in south Donegal, which has been in existence for 17 years, again with no funding from the State. Both organisations, one at the top of Donegal and one in the south of the county, provide essential services, respite and support to children with disabilities in both areas with no State funding. They came together, along with Extern, to make a professional application for funding under the ability programme. It should have been a no-brainer but it was turned down.

They decided enough was enough and put together a map of disability services. I am sorry to be somewhat parochial about this but it is a reality where I am from in Donegal. If, on a map, a line is drawn from Dublin to Galway in so many respects, the services above that line are absolutely appalling. There is an out of sight, out of mind mentality. These organisations decided to do something about it, stood up and found their voice. Significant political pressure then followed from the physical manifestation of the map where we could see the absolute discrimination and failure. Both organisations received approximately €35,000. We thought this was a breakthrough. The HSE found the money somehow. Then we got to the beginning of this year, and again the money was found with another €35,000. Bluestack Special Needs Foundation needs €150,000 per annum - this has been costed by the HSE - just to keep basic services going. iCARE needs €100,000 per annum. What has been happening is that the parents, who are already carers and under ferocious pressure, must hold fundraiser after fundraiser and they are totally exhausted. They are dead on their feet. They were about to close the doors of both organisations, which would have been a disaster for the communities.

iCARE got one third of what it asked for and Bluestack Special Needs Foundation received approximately one quarter. I am angry about something I recently found out. Last year, we met the Minister for Health and Minister of State with responsibility for disabilities and we thought the Government had intervened and sorted this out but it had not. The HSE, under political pressure, found money from somewhere, and God knows somebody else must have lost out, to solve the problem. It was not resolved by the Department or the HSE at national level. It was a local solution to a local problem. No one in the senior echelons of the HSE is listening. Nobody is listening in the Department of Health. This is about respect and the democratisation of how we spend our money.

I always say to community groups, and particularly to disability groups, that if they were to knock on every door in their communities and ask how people would like their taxes to be spent, who would say they do not want them to be spent on disability organisations or on young people with disabilities so they can have dignity and achieve their potential in life. It does not happen because we have an organisation called the HSE that tries to replicate its silo approach in the community and voluntary sector.

This is about respect. I have sat here to have the opportunity to speak and I appreciate the committee giving me this platform to say on the record that the report from Dr. Catherine Day must be implemented. We have to get beyond the approach that has been there.

If we talk to citizens and ask them how much value they put on community and voluntary organisations, particularly those organisations working with people with disabilities, they would absolutely demand that those organisations receive the resources they need because they save the State money through supporting carers and families and giving respite to people who are everyday heroes. I urge the committee to put as much pressure as possible on the Minister for Health to ensure the review is fully implemented and that the HSE treats these organisations with respect and partnership in a democratic fashion using the resources of the State to deliver services to people who need them the most.

These are my comments. They are not questions. I just wanted to tell the story of iCARE and Bluestack Special Needs Foundation, what is going badly wrong in the State and why people do not want this to happen but the State and its apparatus allow it to happen.

Vice Chairman: The depth of the feeling expressed by the Senator is common throughout both Houses. When we are in our constituencies and advice clinics we are the people saying there is some support. I will invite a speaker from each group to make concluding remarks and we will close the session.

Mr. Ivan Cooper: I thank the committee. I will not repeat or summarise what has been said. I will add that the members of The Whee, which are HSE funded under sections 38 and 39, understand we live in the context of limited resources and significant unmet need. We need to transition away from piecemeal *ad hoc* responses as we go along to a more strategic approach based on identifying the essential needs in communities. I draw attention to a potent observation made by Dr. McCarthy that this has to do with establishing the actual need in communities because unless we live in a perfect world, there will always be a quantum of unmet need. We need to have the courage to identify that there is unmet need in order to design services to meet the actual need that is there. The sector is enthusiastic about the opportunity to work in partnership that is presented by the independent review group's report and Sláintecare. We hope we will be invited to work in partnership with the Department and the HSE on understanding the need that is there and playing our part in delivering a much more effective service and advocacy role for voluntary organisations and the people they support.

Dr. Joanne McCarthy: I thank everybody for the engagement and how people have come to the table to discuss the issue. I will pick up on something said by Senators Burke and Dolan. One of the greatest challenges we will face is taking the independent review group's report down off the shelf. It is already gathering dust. That is the biggest threat. The independent review group's report is essential for delivering Sláintecare. We can pull at the heartstrings on the value of these organisations. We could have 20 people with disabilities telling us the level of their need for personal assistance, which they are not getting. There are core essential services they do not get. That level of need is not being recorded. We have to ensure that this committee understands how important it is to ensure that the report is taken off the shelf and stitched into Sláintecare and that it is not just used to respond to existing deficits. I am not saying there are no deficits. We heard that at a recent meeting of the committee on 19 June and we have heard it today. There are deficits in the delivery of the existing quantum of service. It needs to reshape our understanding of what is a really valuable service to people with disabilities, considering how to expand the role of community services and make them link seamlessly with primary and acute services so that the person with a disability, that horrendous diagnosis of some condition,

can be confident that the resources will be there to support them and their family. I acknowledge the work of the committee in highlighting this and I encourage it to take the report off the shelf, get the forum established and the charter agreed and find a way to truly sketch out the list of essential services.

Mr. Peter Murphy: I thank the committee for both of the sessions it has held on this issue and its enthusiasm for seeing this through. My colleagues have highlighted the importance of the forum's being set up and the development of a charter. There are urgent practical day-to-day needs. There is a crisis now. Our organisation will have four years at the current rate before we run out of reserves. What happens then? We have been hearing for years that charities should not hold reserves or have money in their back pockets but what has happened in recent years has shown why organisations like ours planned for a rainy day. That broken process needs to be fixed.

We need to have a full review of how service level agreement, SLA, negotiations are conducted. We need to consider urgently a mechanism whereby full cost recovery is introduced. There is already a system there for it. All these deficits are highlighted in the annual financial monitoring return, AFMR, document which is sent annually to the HSE. The information is there to be examined on an individual organisation basis. It can be compiled pretty easily by any statistician or Excel specialist to understand the extent of those deficits. That needs to be addressed from 2020. Issues around reporting and the suitability of contracts need to be examined urgently. The forum that is proposed is probably the best way to ensure that happens.

A couple of other issues did not come up today, for example, while many compliance and governance activities have been introduced in recent years, everybody would like to see the introduction of supports for the sector to maintain those standards. Board training has been mentioned and I think it is in the independent review group, IRG, report, and there is a really positive recommendation to establish an innovation fund. Organisations like ours drive innovation in service delivery. I could give the committee five examples of things that we want to do that we know would improve service outcomes. That would be an extremely well-subscribed scheme if it was set up because there would be many good projects from the community and voluntary sector.

Vice Chairman: I know I had signalled that we had concluded but Deputy Durkan has re-joined us. Does he have any questions for the witnesses?

Deputy Bernard J. Durkan: I apologise for having to absent myself but I had to put questions in the Dáil Chamber.

I hope my questions for the witnesses have not been covered already and apologise if they have been. Everybody is trying to rebuild and go back to where we were between 2005 and 2007. I wonder if everybody is aware that we were broke then. That is the problem. We need to be careful about where we go from here and make sure we do not have another crash. If we do, unfortunately, it will be more severe than the last one. That is just a rider in the background to what I say now.

Mr. Cooper or Mr. O'Sullivan referred to the private sector and competition between it and the voluntary sector. Could they expand on how the private sector may be competing with them in the delivery of services?

To what extent are the organisations reliant on direct funding from the State versus vol-

untary fundraising? We need the voluntary sector and at the same time it should get a reward from the State to encourage, augment and help in the delivery of services. Could they perhaps comment on those two points first?

Mr. Ivan Cooper: This is in our submission. The competition issue is related to the fact that funding Departments are increasingly putting services out to tender. There are several cases where services traditionally delivered by community and voluntary organisations at local level over decades were put out to tender and contracts were awarded to private firms to deliver those services. The funding is lost to the public benefit community. The assets move from the public into the private sector. If community and voluntary organisations receive funding to deliver those services, they must sign a very detailed service level agreement and contract that are highly specific about what they can and cannot do with the resources, whereas private sector firms are simply awarded a commercial contract that is much more straightforward. The playing field is considered to be uneven and community and voluntary organisations are put at a disadvantage in taking part in the process. The assets, volunteerism and community connectedness that they bring to services are lost if services are awarded to private firms to deliver contracts. If, for example, a private firm decides that it is not interested in renewing a contract at some point in the future, the capacity of the community to ensure that a service continues to be available locally is removed. There is a series of strategic questions that we need to consider before making a wholesale rush to put everything up for competitive tendering without adequate consideration of the long-run consequences for communities.

Deputy Bernard J. Durkan: Are the voluntary organisations allowed to tender or are they excluded from that tendering process?

Mr. Ivan Cooper: Community and voluntary organisations can tender if they choose to.

Deputy Bernard J. Durkan: Do they tender?

Mr. Ivan Cooper: Some do.

Deputy Bernard J. Durkan: Now they are tendering against the private sector.

Mr. Ivan Cooper: Correct.

Deputy Bernard J. Durkan: They are *in situ* delivering services, they have experience and they appear to me to be in a better position to deliver the service.

Mr. Ivan Cooper: Correct.

Deputy Bernard J. Durkan: How can they be beaten in a tender?

Mr. Ivan Cooper: Locally based community organisations cannot bring the same kind of economies of scale to services. There is a price potentially paid in respect of services offered in communities because voluntary organisations will go the extra mile. They will respond to need, raise additional resources to provide the necessary service and all of that will be brought to bear, whereas the private firm will operate strictly within the resources it secured through the contract. It is certainly not going to be out fundraising to bring additional resources to bear in relation to the service.

Deputy Bernard J. Durkan: There is a question that needs to be answered somewhere along the way. Given that the organisation is *in situ* and is specialising in the delivery of the services, it appears that if all things were equal, the private tenderer should not be able to get

into the marketplace at all. The national amorphous organisation that is dealing with larger organisations is a little like the HSE, which we complain about from time to time-----

Mr. Ivan Cooper: I would be happy to have a one-on-one discussion with the Deputy on the finer detail. I would like to make a point about the scale of the contract that is awarded. It is important that contracts are kept at a scale that enables voluntary organisations with an existing capacity to bid for them. If the contract award is designed for too great an area, smaller organisations will be excluded from being able to compete because they do not have the capacity to deliver the service at the specified level.

Deputy Bernard J. Durkan: Okay. My other question related to the balance between fundraising in the voluntary sector and the State subventions.

Dr. Joanne McCarthy: I will take this question. Some of the organisations we are talking about today, including some of our member organisations, receive absolutely no funding from the State. Some of them receive 5% or 10% funding. This means there is an enforced marriage or relationship between the funding side of an organisation and the service delivery side of the organisation through the service arrangements. This is an ongoing challenge for organisations like Epilepsy Ireland. Mr. Murphy may have more to say about this.

Deputy Durkan also referred to the concept of rebuilding. Perhaps we were not clear enough. I would like to take this opportunity to restate a point that was made earlier. I do not think anybody is asking for things to go back to how they were in 2006 or 2007. Sláintecare has redefined what our expectations of a health service should be. We are asking for people to be guided by the IRG report in understanding the role and value of community-based disability service organisations as core deliverers of health services - not just disability services - that are embedded in primary care and are auxiliary resources in acute services. Fundamentally, we are not asking to go back to 2006. We are looking for a way forward that sees the value of community services as a roadmap for delivering personalised and person-centred services into the future. We are asking for them to be included in the list of essential services. I am using their language. They have to be identified in the list of essential services. They need to be costed appropriately. The State needs to be honest about what it is willing to fund in order that we all know what the quantum is.

Demographics must also be used in this context. We know that at any one time, approximately 400 families are affected by motor neurone disease. I am using them as an example because I was going through some stuff relating to them recently. The relevant organisations will not provide the names of the families or the geographical regions in question, but they will confirm that they support approximately 400 families at any one time. They can set out the percentage of those involved who are in care, the percentage of those involved who are at the early diagnosis stage, and everything in between. This allows them to plan demographically for bringing these people into the system and to ensure sufficient resources are in place to support community services as they seek to respond. These organisations are really good at being responsive, listening to what people with disabilities and their families want, and developing appropriate services at the appropriate time to support people in their own homes and communities. I suppose that is where we are looking to go. I ask Mr. Murphy to pick up on the point that was made earlier with regard to fundraising.

Mr. Peter Murphy: It is important to bear in mind that the services provided under the HSE agreements are not the only activities in which most organisations are involved. As stated earlier, over the past ten years we have invested more than €1 million in epilepsy research.

We do a great deal of fundraising for those purposes. We apply the income we accrue through fundraising to other things like public awareness and public education activities. As indicated, we have a particular advocacy role that is not necessarily funded by the HSE. There are many other activities. There are ongoing operational costs associated with administration and governance. It is understandable that nobody really wants to pay for such costs, but they have to be paid for. Fundraising is currently supplementing what appears to be an actual contract for services. The HSE contracts particular services which cost X, but it pays just 80% or 85% of X. A commercial operator would have walked away from such an agreement many years ago. One of the big advantages of this sector is that our organisations will not walk away from their missions and objectives just because 10% or 15% of funding is missing. We will find ways. We will get rid of non-essential costs. We will slash things that are more essential, such as staff training. We will raise funds. I will mention a great example that relates to CHO 2 in the west, which is funded to a very low extent. For a number of years, a large and popular cycling event was very successful in raising funds that helped to supplement the services provided in CHO 2. The money from that event was used to support something that, in theory, the State is paying for through the HSE. Regardless of whether a body is 5%-funded or 95%-funded under its contract, its obligations remain the same. It is important to point out that under our service level agreement, we have the same obligations in respect of €3,800 that a much larger organisation might have in respect of €20 million. The key point is that our organisations are not going to walk away from meeting the needs of our service users. I am not sure that could necessarily be said of a private operator in a similar position.

Mr. Austin O’Sullivan: As Deputy Durkan indicated, the State does not have an unlimited pot of money to spend. The Deputy mentioned that the private sector has come in to take business from the community and volunteer sector. I can talk about our experience in that regard. In our dealings with the HSE, we are not looking for anything extra. We are looking for a better way for funding to be spent. I will give an example. We proposed to the HSE that if it invested €1.2 million in our residential services, we could create €4 million worth of capacity for CHO 7, which spends an average of €16 million each year on essential respite services. The authorities in CHO 7 have told us that they cannot plan for these emergency placements, but they know they will spend an average of €16 million each year. When we came up with a plan that involved the HSE investing €1.5 million with us, thereby enabling us to create €4 million of capacity, the HSE was not interested. Approximately 90% of the €16 million spent by CHO 7 in this area goes to the private sector because the private sector has the resources to invest in buying the properties. It takes six months from the time a property is bought to get HIQA approval to open it as a residential service. The community and voluntary sector is not sitting on resources that would enable it to buy houses to be used six months later. We believe that with a little bit of planning, money that is already being spent could be spent in a far better way.

Deputy Bernard J. Durkan: That is an interesting answer. I think we should come back to this matter again. There is competition-----

Vice Chairman: We had more or less agreed to pursue this issue as a committee. I thank Mr. Cooper, Mr. O’Sullivan, Dr. McCarthy, Mr. Lee, Mr. Murphy and Ms Jones sincerely for attending and for the work their organisations do, which we see at first hand. We know that the organisations in question are providing invaluable lifelines to people in their communities. The witnesses can be assured that this committee has heard what they have said today. As a committee, we will not let go of this issue any time soon. I thank the witnesses again for their attendance.

10 JULY 2019

The joint committee adjourned at 11.20 a.m. until 9 a.m. on Wednesday, 18 September 2019.