

# DÁIL ÉIREANN

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## AN COMHCHOISTE UM SHLÁINTE AGUS LEANAÍ

## JOINT COMMITTEE ON HEALTH AND CHILDREN

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*Déardaoin, 26 Samhain 2015*

*Thursday, 26 November 2015*

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The Joint Committee met at 9.30 a.m.

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### MEMBERS PRESENT:

Deputy Catherine Byrne,	Senator Colm Burke,
Deputy Seamus Healy,	Senator Thomas Byrne,
Deputy Billy Kelleher,	Senator John Crown,
Deputy Sandra McLellan,	Senator Jillian van Turnhout.
Deputy Dan Neville,	
Deputy Caoimhghín Ó Caoláin,	
Deputy Robert Troy,	

In attendance: Senator Kathryn Reilly..

DEPUTY JERRY BUTTIMER IN THE CHAIR.

*The joint committee sat in private session until 9.50 a.m.*

### **Independent Advocacy Services for Health Service Users: Discussion**

**Chairman:** Apologies have been received from Senators Imelda Henry, Jillian van Turnhout and Colm Burke. On my own behalf and on behalf of members of the committee and the secretariat, I offer our sympathies to the van Turnhout family on the death of Jillian's father, Mr. Hassett. I know members will all agree with me sending our sympathies to her mother and her family. Ar dheis Dé go raibh a anam.

I remind those present about the use of mobile phones. They should be switched off or put in airplane mode as they interfere with the broadcasting of the proceedings. Our meeting is a very important one on the area of advocacy. As members know, we have been raising this issue at the committee for some time. I welcome our witnesses who will give us their insight on advocacy, which is not just about handling patients' complaints or providing information or advice but is about support to patients and users of the health service, their rights and entitlements and how to make their wishes known. Our meeting coincides with the announcement by the Minister on 12 November of the setting up of a national patient safety office, which includes a patient advocacy service. The purpose of this meeting is to hear from some of the most respected national stakeholders and their views on what the office will mean for the health service. Mr. Tony O'Brien hoped to attend at 9.30 a.m. but, unfortunately, he had commitments that he could not change and he will join us in a separate session at 11.30 a.m.

I welcome Mr. Mervyn Taylor of Support and Advocacy Service for Older People, Sage; Ms Louise Loughlin, regional manager of the National Advocacy Service for People with Disabilities; Ms Eileen Fitzgerald, senior manager, regional services of the Citizens Information Board; Mr. Peter Tyndall, Ombudsman and Information Commissioner; Mr. Paddy Connolly, CEO of Inclusion Ireland, who is accompanied by Mr. Cormac Cahill, communications and information officer; and Ms Angela Black, CEO of the Citizens Information Board. They are all very welcome and I thank them for being here.

By virtue of section 17(2)(l) of the Defamation Act 2009, witnesses are protected by absolute privilege in respect of the evidence they are to give this committee. However, if witnesses are directed by the committee to cease giving evidence in relation to a particular matter and they continue to so do, they are entitled thereafter only to a qualified privilege in respect of their evidence. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given and asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any persons or entity by name or in such a way as to make him, her or it identifiable.

Members are reminded of the long-standing ruling of the Chair to the effect that they should not comment on, criticise or make charges against a person outside the House or any official by name or in such a way as to make him or her identifiable. I invite Mr. Taylor to make his opening remarks.

**Mr. Mervyn Taylor:** Thank you, Chairman, and members of the committee for inviting us here for what I believe is the first dedicated discussion on the wider issues of advocacy. I acknowledge the presence of the chair of our national advisory committee, Patricia Rickard-Clarke, and of the co-ordinator of our legal and financial team, Mary Condell. Sage has its

origins in the Leas Cross scandal of 2005. It is ten years ago in May since that dreadful scandal broke in an RTE story. We have had a number of other events since then, such as Áras Attracta, the events in Portlaoise hospital, the investigation of home help abuses in 2011 and other abuses which were highlighted in 2014. We have had reports from HIQA and the Ombudsman's office, both of which have recommended the development of advocacy services in hospitals.

The redevelopment of a support and advocacy service for older people in the last year has coincided with commitments by the HSE to develop a national volunteer advocacy programme as part of a wider response to the Áras Attracta scandal, a recent commitment by the Minister for Health, to which the Chairman referred, to develop a national patient advocacy service and a recommendation by the Ombudsman for the development of independent advocacy services, involving volunteers, in hospitals. There are a number of other organisations, some of which are represented here today, notably the Citizens Information Board and Inclusion Ireland. Together there is a very rich picture of what exists and what is promised to emerge but we now need to take stock and find direction and a framework for development. In some ways, we are dealing with the law of the 46A bus; one waits a long time for one bus and then three come along. We are at the stage of three buses coming along. The question is whether we can get on any of them and if they are going in the right direction.

Fundamentally, advocacy is about voice. It is about the right of a person to have support in expressing their wishes and preferences or to have another person act independently of service providers, family members and systems interests to advocate on their behalf. That is widely recognised in the developed world. Independent advocacy must be distinguished from the work of staff responsible for complaints and from the day-to-day work of professionals and health and social care providers who can advocate on behalf of an individual up to a certain point but beyond that, a conflict of interest can arise.

I will focus on the framework for development, which we have set out in great detail in our opening submission, in short points in this statement. The framework must address some key issues. The first of those is the fragmented and sometimes reactive nature of developments to date and the need for collaboration and co-ordination. There is a need for standards, training, support, recording and monitoring of activities and assessment of outcomes. The latter area is of particular importance. There is a need for a clearly stated rationale for the development of support and advocacy services as part of the wider pattern of response to the health and social care needs of citizens. I stress that advocacy on its own is not a solution. It is part of a wider approach. There is a need for an assessment of the likely resources required to provide effective independent advocacy in the health and social care sector. I say that in particular in the context of the emerging capacity legislation, which in many ways will bring us forward but it will be very challenging for many people.

We have made some specific suggestions. The first is that there should be a process of stakeholder and public consultation to inform the development of future legislation which would guide the development and provision of advocacy services. Things that are really important, which will be stressed by other colleagues during the meeting, include the right of an advocate to have access to people, premises, information and meetings. They exist and are supposedly allowed for in the HIQA regulation, for example, in nursing homes, but they are not in many cases allowed by the care provider.

Services funded from public sources should have, as a clear requirement of that funding, an obligation to provide and promote access to independent advocacy for the benefit of service users. Services funded from public sources should be clear on the requirement to provide and

promote access to independent advocacy for the benefit of service users. Those who receive funds should be required to engage in formal structures of co-ordination and collaboration. A process of collaboration and co-ordination could be started by the formation of a liaison group for relevant support and advocacy services in the context of the formation by the HSE of the new inter-sectoral committee for safeguarding vulnerable adults. That is currently at the formation stage. There needs to be an assessment of the desirability of the separate development of support and advocacy services for people with disabilities and for older people. A small piece of independent research should be commissioned to assess the likely resource implications of developing support and advocacy services to an adequate level of provision. We need to address the resource issue. There is a need to develop a public sector volunteering policy and guidelines to ensure that people who wish to make a contribution can do so but, equally, to reassure those who are professionals in their area that there is no attempt to impinge on their role. If we wish to add value by involving citizens in advocacy, we must be clear and have a public sector volunteering policy and guidelines.

As the Minister alluded to earlier in the month, we seek the extension of the jurisdiction of the Ombudsman to include administrative and organisational aspects of clinical care and the simplification and further development of existing complaints system. We are particularly conscious of the fact that a decision support service will be established under the Assisted Decision-Making (Capacity) Bill. That agency will have considerable potential to act as a catalyst for developing standards and promoting good practice. As part of its brief, it will play a role in developing codes of practice. Therefore, we need to factor in a new entity which is emerging but is not yet there. I hope that it will be in the legislation by the end of the year.

We need some clarification on the role of the recently announced national patient advocacy service because a service was announced last year by the former Minister for Health, Deputy James Reilly. It will now be established by the national patient safety office and the talk is that it will be about information and signposting. It may be a very useful development but it could also be another layer that might make things more complicated.

People should be able to advocate for themselves in advance. Therefore, we need a major public campaign to promote the advantages of advance planning for future life events involving advance health care directives, an enduring power of attorney and the Think Ahead resource which enables people to record key information, wishes and preferences in the event of an emergency, serious illness or death. Financial incentives of different forms, such as tax credits or free legal aid, should be developed to support the initiative. In effect, the State would promote pre-planned self-advocacy for when people are no longer able to speak for themselves.

We believe that the development of an oversight and accountability mechanism, chaired by the Ombudsman, would link the work of independent providers of support and advocacy with the work of the Oireachtas Joint Committee on Health and Children. There is a need for providers to be accountable to the publicly elected representatives of Ireland and, in turn, they should have an opportunity to hear what the issues are for the independent support and advocacy sector.

**Chairman:** I thank Mr. Taylor and call Mr. Peter Tyndall to make his opening statement.

**Mr. Peter Tyndall:** The situation in Ireland in terms of health complaints is an interesting one. They are very much lower than they are in comparable jurisdictions. We all know that health complaints are one way of driving improvement in the health service. If one does not know what is going wrong, then one cannot know how to put it right and, therefore, we under-

took our first own initiative investigation into health complaints earlier this year. In doing so, we tried to establish why people were not prepared to bring their complaints forward. We did not believe that it was because the quality of health care in Ireland was so much better than elsewhere and that people did not have things to complain about. We felt it was much more likely that there were structural reasons for people not complaining. We found a number of reasons. I will mention a couple of them but more have been documented in the statement I have provided to the committee. One of the reasons people were afraid to complain was that they were concerned about the impact a complaint might have on themselves, as patients, or, more usually, on their family members. They felt, particularly for people in vulnerable long-term care situations, that they would put them at risk by complaining.

The second reason that people often advance is that the complaints system is so complex and arduous to pursue a complaint to its conclusion that people simply lose the will to continue with a complaint even when they start. When one finds situations, as we did, where it is almost impossible to find on the website where one might lodge a complaint, and where it is not obvious on the hospital's premises where one might go to complain, then one starts to wonder why it is that we are not taking complaints more seriously. One might ask what has this got to do with advocacy. In my previous life, I was used to working in a context where hospital patients had access to independent professional advocacy. That meant there was somebody to stand beside patients when it came to making a complaint and very often, he or she could focus a complaint. Sometimes the advocate nipped complaints in the bud because he or she raised the issue of concern on the spot with health professionals and the matter was dealt with there and then. On other occasions, he or she was able to provide explanations to individuals which meant that the patient did not have cause to complain. When a patient did want to complain, an advocate was able to help him or her articulate a complaint in such a way and helped him or her pursue it through what was often a labyrinthine process until a reasonable outcome was reached.

One must ask why there is such a labyrinthine process. The answer is that at the moment, the HSE's Your Service, Your Say guidelines are very high level and it is not spelled out in detail how a person can make a complaint. That means there is a different process in place in virtually every health setting in Ireland.

We have put forward quite a large number of recommendations but I will focus on a couple of them. One of my recommendations is the introduction of an advocacy service that would be available to patients in all health care settings. Given the difficulties people face when trying to lodge a complaint and the fears that they have about complaining-----

**Chairman:** Does Mr. Tyndall have a phone or an iPad near his microphone?

**Mr. Peter Tyndall:** I possibly have but I will get rid of them.

**Chairman:** The microphones are so sensitive that they can pick up interference no matter where it comes from.

**Mr. Peter Tyndall:** It is somebody else. I did not think it was me.

**Chairman:** The joys of modern technology.

**Mr. Peter Tyndall:** It is wonderful. One of my recommendations is that an advocacy service should be put in place. We are pleased that such a service has been announced. What we have in mind is something that is accessible to patients and is not a national advocacy service. We want something that individual patients can access. Within the general hospitals, we want



such a service it to have a relatively high profile so that it is easy for a person to see where to go. We are anxious to see what is delivered in the context of the commitment to provide an advocacy service.

In terms of our report, our recommendations were agreed by the HSE. We had very good co-operation from the HSE once we identified what the issues were. We are also working with the HSE as it produces action plans to implement the report. We have made it very clear, in this instance, that we will reassess in 18 months' time to see what has happened on the ground because sometimes recommendations can get lost in a welter of recommendations. Although there is a commitment to implement them, a central commitment to implement them does not always lead to changes in practice for individual patients throughout Ireland. We will go back to make sure the changes happen not just at a national level and on paper. We will send people to see what is happening on the ground to make sure the change has been put in place, as agreed.

I refer to a simplified health complaints system. The system, as it currently stands, has two stages - one of which is sometimes observed and one is not. The issue of whether there is a review stage before complaints come to my office is an important one. If complaints are looked at locally and there is a delay and if they are then looked at by the HSE centrally and there is a delay, by the time they reach my office, the detail in the complaint has been lost in the minds of many of the people engaged in it. For the person who is making the complaint, the issue is most important and he or she is very clear in their mind about what happened. The staff who may have been involved in the complaint - doctors and nurses - may well have long forgotten the particular incident. Therefore, it is very difficult for us to understand what may or may not have happened at the time.

We want to see a streamlined complaints system introduced and to see the same system used across the health service. In order to move this forward, when we took on jurisdiction for private nursing homes, we introduced a simplified streamlined model complaints policy which we rolled out to the proprietors at that time. We held workshops and seminars across Ireland for the proprietors of private nursing homes and we issued them with a standard complaints policy that we expect them to use. The advantage of that is that we will see whether they have complied with best practice when dealing with complaints. In addition, everyone will see that the same standards are applied across the sector rather than have the huge variety of standards that exist at the moment. We have removed the second stage because we think people should attempt to resolve a matter informally at the point the incident happens and have one investigation. If the issue is a serious one, then there should be an investigation by an independent person or persons. Some of the complaints will be about food or whatever, so one does not need an independent person. For more serious complaints, it is best that one engages an independent person to investigate. We say investigate once and investigate well and if the issue cannot be resolved at that point, the complaints should come to the Office of the Ombudsman and not to another third party. It is a simple, streamlined, effective complaints service, which applies across the health sector. We have taken the first steps to putting that in place.

One of the complexities people face when complaining is that they can only complain about part of their care to the HSE and to my office. Technically the issues around clinical judgment often are only part of a complaint. Let us say that somebody is complaining about the care of their loved one - they may have issues around care and compassion, or issues around whether a treatment regime that was put in place was followed but they may also have issues around diagnosis. Currently some of the clinical judgment issues cannot be dealt with within the existing complaints system. That is clearly wrong. If a person is unhappy about the care, it should

be possible to make one complaint to one body. Because of a recent Supreme Court judgment, the person must complain to the professional body of the individuals concerned which has to apply a very high threshold before it can look at complaints. There is a large number of complaints that nobody can look at. Clearly that must be fixed. I was delighted when the Minister for Health, Deputy Varadkar indicated that he intends fixing that. I hope that can be done. I do not think it will be a speedy process, but at least we seem to have embarked on the correct path at this point.

I hope that has been helpful. There is more in the statement, but I am happy to take questions.

**Chairman:** I thank Mr. Tyndall. I invite Ms Eileen Fitzgerald, senior manager, regional services of the Citizens Information Board to make a presentation.

**Ms Eileen Fitzgerald:** I thank the Chairman and members for the opportunity to address the joint committee today. I will speak from the experience of the Citizens Information Board on the establishment of an independent advocacy service for people with disabilities and I hope our experience will inform this discussion.

There are approximately 400,000 people with disabilities in Ireland and from time to time some people need access to an advocacy service, but most do not, or would not if services were offered and delivered differently. While advocacy services are undoubtedly required, it is important not to lose sight of the requirement that public services be designed and delivered in an accessible manner which facilitates people in using those services and minimises the need to seek help from others to understand and use the services.

The current experience for many people with disabilities living in the community or residential services is one of marginalisation in terms of health, housing, employment and social participation.

There are still more than 3,000 people living in congregated settings. Research has demonstrated that the quality of life for people in residential settings is often compromised and there may be restrictions on their rights and choice; decision making is often taken away from the individual. Many people with disabilities have limited support from family and community and need to access an advocate who is independent of all service providers to ensure they are included in decisions about their lives.

During the past four years the National Advocacy Service, NAS, for people with disabilities has worked intensively with more than 2,000 people, supporting them to have their voices heard. In addition, NAS has engaged with significantly more people by phone, linking them to other services if their service need was other than advocacy or if their inquiry did not correspond with the access criteria to NAS. NAS targets its service offer to people with disabilities who are isolated from their community and services, have communication difficulties, are inappropriately accommodated, live in residential services, attend day services and have limited or no natural supports.

In 2014, more than 35% of people supported by NAS had an intellectual disability, 20% had a physical disability and nearly 20% had mental health issues. Issues addressed include moving out of institutional care, inappropriate accommodation, income support and access to personal finances, and quality of life issues, which would be a significant part of the work.

The Citizens Information Board, CIB, has incrementally developed mainstream advocacy

provision in Citizen Information Services to enable people to access their rights and entitlements. Under the National Disability Strategy 2005, the Citizens Information Board was designated as the organisation to provide advocacy for people with disabilities, with the terms of the proposed personal advocacy service, PAS, set out in the Citizen Information Act 2007. In anticipation of these responsibilities, CIB undertook and published research on international models of advocacy intervention.

We set up 46 pilot advocacy projects for people with disabilities in collaboration with a range of community based organisations around the country. In 2008, when the implementation of personal advocacy service, PAS, was placed on hold and the sections of the Act were not implemented, we started to look at the various stages of development of the national advocacy service, which has been restructured a number of times and is now one national organisation, the National Advocacy Service for People with Disabilities, NAS.

In terms of its remit, the National Advocacy Service for People with Disabilities, NAS, provides an independent, confidential and free, representative advocacy service that works exclusively for the person using the service and adheres to standards as set out in NAS code of practice. It is staffed by 28 advocates, eight senior advocates and managed by four regional managers and a national manager, supported by five administrative staff. There are 45 staff. Given the remit and resources of NAS, it is inevitable that it reaches only a small number of people who could benefit from the support of a representative advocate. Representative advocacy is a relatively new service in Ireland, and drawing on experience over the past decade, CIB and NAS have developed standards, policies and procedures in line with international best practice, to ensure that the representative advocacy service we provide operates to high standards.

Independence is absolutely central to the work of the National Advocacy Service, NAS, in that the advocate will not share information with third parties unless directed by the person. Of particular importance is that the NAS advocates are not influenced or compromised in carrying out their independent, representative advocacy role by any other party. This ensures robust advocacy practice and places the will and preference of the person at the centre of the situation.

Issues to be addressed can be about any aspect of the person's life, and may be directed by the person, or where the person's will and preference cannot be ascertained, the advocate approaches the matter using the four internationally recognised methods, namely, witness observer, person centeredness, rights based approach and ordinary life principles. In that context an experienced advocate can and does represent the will and preference of people who communicate differently and who cannot articulate their wishes. This requires time and skill, support and supervision, as this is complex work and the advocate must earn the respect of both the person they are representing and the service provider.

NAS has experienced a wide range of expectations and misunderstandings as to what representative advocacy is and should be. This is a very important issue in the context of the new service being set up. Representative Advocacy is a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf. It is not about making decisions for someone, mediation, counselling, care and support work or consultation.

I welcome the developments the Ombudsman is talking about. NAS assists people in making complaints. NAS tries very hard to work to seek an early resolution prior to people having to go into the complaints procedure because of the complexities of the complaints process. NAS also supports people to make complaints to the Office of the Ombudsman and we try to



support people right through that process.

A key issue for the National Advocacy Service is the need for statutory powers. That is very important to consider in the context of all advocacy work. NAS frequently experiences issues with service providers when seeking information and meaningful engagement with the advocacy process. There continues to be misunderstanding about what advocacy is. The services may engage with advocates but this can be experienced as tokenistic. This is hugely time consuming for advocates and can take time away from working with other people who need the service.

Although NAS continues to engage in extensive relationship building with services, the lack of statutory powers means that issues can arise in the following areas: Access to services – where providers do not facilitate NAS’s presence *in situ*; access to information – where an individual cannot give written consent, NAS may not be able to obtain access to documents; decision making – as services slowly begin a cultural shift away from “best interests” to the will and preference of people, many decisions are still being made on behalf of individuals without reference to the person, their will and preference and-or their advocate; and, there is obfuscation through delays, that is, delays in replying to the National Advocacy Service, delays in replying to correspondence and delays in giving access to key decision makers. The NAS has welcomed the incorporation of advocacy into HSE and service provider service level agreements, but it is essential that there is training and capacity building for service provider staff about advocacy and that this is included as part of staff training and development. On some occasions when an advocate presents, the front-line staff and local manager are unaware of the inclusion of advocacy in service agreements and do not understand why an advocate has been requested or what their role is. Sometimes they think advocates are inspectors and therefore can be circumspect about the advocate’s involvement. Senior professionals and management can be equally so. The NAS provides information sessions on advocacy and training for staff, but it does not have the resources to deliver all of this. A joined-up approach to training and awareness-raising is required. All services should be obliged to train their staff on working with advocates. This will assist in breaking down barriers so people with disabilities and others can be recognised as equal citizens and their voices can be heard. Currently, the CIB is in discussion with the Department of Social Protection to seek statutory powers for the NAS to overcome these barriers.

With regard to the recommendations the CIB and the NAS wish to make, one relates to statutory powers to ensure a right of access and information and for meaningful engagement with the NAS and other advocacy service providers. In terms of an over-arching framework for advocacy, I share the views of my colleagues that there are many different forms of advocacy and many different providers in Ireland, all playing valuable roles. However, there is a need for the establishment of a framework of advocacy which would identify the different advocacy models and different advocacy providers; provide a co-ordinated approach across services and linkages; establish accessible information on advocacy, including a dedicated website; establish national standards and quality assurance in advocacy and mechanisms to ensure these standards are met; and, provide a co-ordinated approach to advocacy services that would cover people with disabilities, those who need support with decision-making and patients within the health services who need help in establishing their rights. There is a need for training and capacity building around the range of service providers involved in both health and social care with regard to person centeredness and advocacy to enable a cultural shift. Advocacy should be incorporated into service level agreements and other contractual and policy documents. There must be a continuation and strengthening of advocacy in HIQA standards and a review of those. These standards should be used as an assessment tool by regulators and inspectorates.

To conclude, measuring the impact of advocacy provision is an important piece of work and requires more attention. In the CIB, we have seen how effective the NAS independent advocacy can be. Changes in the quality of life for one person in a residential setting can influence change for many others in that service. However, advocacy is not the panacea to resolve service gaps. It gives voice, highlights need and highlights gaps and inadequacies. It means that those who cannot shout the loudest have somebody to speak up for them. We are all entitled to be heard but the responsibility to provide the relevant service to the proper standards lies with the service provider. As service providers improve the quality of the service they deliver, over time the requirement for advocacy services should lessen.

The NAS looks forward to continuing to support people with disabilities and to working with a range of service providers, including our colleagues here, to ensure the upholding of the individual's will and preference.

**Mr. Paddy Connolly:** I thank the Chairman and members of the committee for the opportunity to make an input. As I address the committee, children with a disability are being restrained and secluded in schools, children have been waiting years for essential speech and language therapy and persons with a disability are living in residential settings which in many cases provide little in terms of a good quality of life and are often neglectful, demeaning and sometimes brutal, where physical and sexual assault are most likely significantly under-reported. The number of adverse events recorded by Irish hospitals and health care facilities in 2011 included 10,000 incidents of violence, harassment, aggression or abuse of patients. Over 4,300 of these incidents involved a physical assault on patients, including persons with disabilities.

It is the experience of Inclusion Ireland, based on over five decades of work, that persons with an intellectual disability require advocacy support in a broad range of areas throughout their life cycle. I am particularly conscious that the language of "patient" and "patient safety" is not in most cases appropriate to persons with a disability who need advocacy support to express their will and preference. It is a different argument, although the patient safety argument dominates this sphere. There are issues in education and employment, obtaining or changing other public services, when they are victims of crime because they are invisible in the criminal justice system, in family law where they are represented disproportionately in child care proceedings and when making health care decisions because consent is rarely obtained.

The issue of congregated settings has come to the forefront of popular and political debate. This is, however, an issue that stretches beyond one institution in one location. I was in an institution last Saturday and a family member told me that in the 60 years her son has been in the centre he has never left the complex. Another family member told me that in the 52 years her son has been in the complex they have never been called together as a group of families to discuss their issues. The neglect and abuse in these institutions is not acceptable and many of the community group homes that people are being moved into offer little more in quality of life.

The HIQA has shown this over a long period of time. Recent coverage has shown that only 7% of the centres inspected by the HIQA managed to comply fully with the HIQA process. Inspectors found that there was a high level of restrictive practice and restraint, that centres did not safeguard people's civil and legal rights and there was a lack of adequate safeguards and external scrutiny to ensure residents' rights were vindicated. This is all covered in the HIQA reports.

I am conscious of the time so I am summarising the document I provided to the committee. The Ombudsman correctly referred to the issue of people suffering in silence. We are told all

the time by family members that they are afraid to complain or to raise their heads because they are concerned that if they complain it will affect the service they will get. In many instances, and this has been said to us many times, the services have instructed families that if they make a complaint they can go elsewhere. That is a common theme that arises for families - if they are not happy with a service, they should find a service elsewhere. Of course, there is no other service to be found.

To cut to the chase, the landscape of advocacy services for persons in receipt of health and personal social services is characterised by a lack of co-ordination, consistency or oversight. A range of advocacy services are currently being funded, including Inclusion Ireland, Sage - the Support and Advocacy Service for Older People, Patient Focus, Empowering People in Care or EPIC advocacy for children and young people in care, and others. Despite the investment in advocacy services in the voluntary sector certain things remain the same. There is currently no co-ordinating or oversight body for advocacy, there is no central funding stream as funding is only provided on an *ad hoc* basis, no public body has responsibility for developing standards or codes of practice and there are no national standards or codes of practice for organisations providing advocacy services.

Obviously, advocacy services operate alongside other public bodies, including the Office of the Ombudsman, the Office of the Ombudsman for Children, the Irish Human Rights and Equality Commission and the Citizens Information Board. Again, there is a lack of co-ordination and connection between these bodies and voluntary advocacy services. An important new development will be the decision support service which is provided for in the Assisted Decision-Making (Capacity) Bill and will operate under the aegis of the Courts Service. The decision support service will have a role in providing information and guidance, the development of codes of practice and powers of investigation in respect of decision-making arrangements under the legislation. There is a need for this body, as it develops, and advocacy in a broader sense to be co-ordinated.

Inclusion Ireland believes there is a need for a broad spectrum of advocacy supports, as was first recommended by the Commission on the Status of People with Disabilities in 1996. Building on the recommendations of the commission's report, the Goodbody report in 2003 recommended a programme of support for organisations providing advocacy services, an independent advocacy service with statutory powers and a community visitors' programme for persons in long-term residential care. However, none of these recommendations has been implemented. Funding for community and voluntary organisations providing advocacy services and supports has been cut. The relevant section of the Citizens Information Act that would afford legislative powers to an independent advocacy service has not been commenced, and this is important because this is an action that could be taken immediately. The community visitors' programme for persons in long-term residential care has not been introduced.

I will not repeat what has been said, but there is a lack of co-ordination. The National Advocacy Service is grossly under-resourced. There are 35 advocates nationwide while there are 3,500 people in congregated settings and a further 4,000 in community group homes. Even getting to that group of people is absolutely impossible for the NAS.

Finally, Ms Ita Mangan, chairperson of the Citizens Information Board, in her presentation to the social protection committee in June 2015, called for "a co-ordinated approach to advocacy services across a number of areas but particularly in the context of the implementation of the assisted decision-making legislation...". Inclusion Ireland suggests an immediate action which could be taken is the introduction of a personal advocacy service, as provided for in the

Citizens Information Act 2007. Inclusion Ireland is proposing the establishment of a national advocacy authority. This new body would have responsibility for co-ordinating and overseeing the provision of all advocacy services for persons in receipt of public services. It would work alongside existing bodies such as the Office of the Ombudsman, the Office of the Ombudsman for Children and the Irish Human Rights and Equality Commission. Inclusion Ireland recommends that such an authority be responsible for setting standards and developing codes of practice and that one of its first tasks be to develop a national strategy for advocacy. We also recommend the introduction of a national signposting service, as mentioned, to guide people on how to make complaints and access advocacy services.

**Chairman:** As Deputy Caoimhghín Ó Caoláin has to attend another meeting, I invite him to speak first.

**Deputy Caoimhghín Ó Caoláin:** Go raibh maith agat, a Chathaoirligh. I also thank Deputy Billy Kelleher for allowing me to lead off.

I thank each of the groupings that has come before us. I thank them for their detailed presentations on what I emphasise is a hugely important area. I have always regarded my role in public life as one of representation and advocacy. In that context, I empathise greatly with what has been shared by each of the delegates. I thank Ms Fitzgerald, in particular. I am not seeking to make a distinction between one group and the rest, but on the basis of my experience in my community the role played by the Citizens Information Board merits particular recognition.

I wish to ask Mr. Taylor about a point made at the end of page 2 of the presentation made by SAGE. I ask him to elaborate on the point that advocacy services funded from public sources “should be required to engage in formal structures of co-ordination and collaboration”. How all-encompassing would this be? How does he envisage such a requirement being worked out? I concur absolutely with the emphasis placed on the point that advocacy services funded from public sources should be “required” to act in this way. That is critical. Of what would the component parts of the “formal structures of co-ordination and collaboration” be comprised? How wide would the net be cast?

A point made a little further on in Mr. Taylor’s statement is almost like a natural addendum. He refers to the need for “an assessment of the desirability” of whether advocacy services should be all-encompassing. Should the same services advocate on behalf of people with disabilities, people in the later years of their lives and those represented by Inclusion Ireland? Does he believe we are looking at separate advocacy services or a single all-encompassing service? When he asks for “an assessment”, does this suggest there is uncertainty from the point of view of SAGE about how progress should be made in this regard? Perhaps he might give us a little indication in that regard.

I would also like Mr. Taylor to elaborate on something interesting he said. I would welcome ongoing engagement between his organisation and the committee. He seemed to allude to such engagement in his concluding remarks when he referred to “the work of the Oireachtas Joint Committee on Health and Children”. I am neither challenging him nor teasing the matter out further. I want to know a little more about the vision he is presenting in the points he has shared with us.

I welcome Mr. Tyndall and wish him every success in his role and responsibilities. I think this is the first opportunity an Oireachtas committee has had to meet him in his new role. I found one aspect of his presentation very interesting. Last June I marked 30 years as an elected

representative. Mr. Tyndall has said he has examined how public hospitals handle complaints. Having spent many of my 30 years in politics as a health spokesperson, I feel I could write a little book about that subject and it might not be complimentary. There used to be a common position in this regard which Ms Fitzgerald reflected to some extent. Mr. Connolly certainly did so.

I would like to make a link between something interesting that was said by Mr. Tyndall and Mr. Connolly's statement that "despite the investment in advocacy services in the voluntary sector certain things remain the same". Mr. Connolly was alluding to the fact that "there is currently no co-ordinating or oversight body for advocacy, there is no central funding stream as funding is only provided on an *ad hoc* basis, no public body has responsibility for developing standards or codes of practice and there are no national standards or codes of practice". As I was listening to him, I thought of something that could be added to the list. It is reflective of what has been said by others. There is no statutory obligation on hospital or other care setting management to accept the input of advocates, including elected representatives and the organisations represented here.

**Chairman:** The Deputy's time is up.

**Deputy Caoimhghín Ó Caoláin:** Have my minutes been used already?

**Chairman:** Yes, the Deputy had six minutes.

**Deputy Caoimhghín Ó Caoláin:** I ask the Chairman to be patient with me.

I am talking about what I have experienced in my role as an advocate. I would like to know whether each of the delegates agrees that there is a need for this form of advocacy. We cannot work on the sole basis of the goodwill that may be present. There should be a statutory obligation on people in positions of responsibility across hospital, health care and other care settings to be respectful of and open to the essential roles played by advocates. As a national spokesperson on health, I was absolutely astonished in the recent past to receive a communication from a hospital site telling me that in future representations - for example, when I might make an intervention - I would need the written consent of the patient and photographic identification of the individual concerned. In many of the cases in which I am asked to intervene, I am in Leinster House and the patient is not in a position to provide written consent. I refer to persons who might be in difficulty in accessing a transfer or whatever the case might be. It is bizarre, outrageous and totally unworkable to expect me to secure photographic identification in order that my representations can be considered. While this is an indication of the difficulties and obstacles that can be encountered, I must acknowledge that in most cases my experience has been good. People are generally respectful and co-operative, but there are instances of what I regard as extreme obstructionism.

**Deputy Sandra McLellan:** Yes.

**Deputy Caoimhghín Ó Caoláin:** This has to be confronted. As we cannot assume goodwill will always be present, I suggest we must place certain requirements on those in these roles.

**Deputy Billy Kelleher:** I welcome the delegates. Having listened to the points made by Deputy Caoimhghín Ó Caoláin about the presentations, I want to focus on the issue of patient confidentiality.

The protection of information is obviously very necessary, particularly when one is deal-



ing with medically sensitive files, etc. Like Deputy Caoimhghín Ó Caoláin, I sometimes find that it is used as a guise to obstruct public representatives making representations on behalf of citizens. While we do not parade around the country looking for problems, they come to us, for example, via family members or concerned neighbours. The idea that I cannot act on such representations in any way has to be revisited very quickly. This attitude is becoming more prevalent in the health sector and across many other areas of public administration. It is simply to close down representation and accountability and to sideline advocacy by a public representative. This is regrettable and in some areas people are becoming more obstructive in this regard. As I stated, it still is limited within the system but is becoming more prevalent. I perceive it almost to be getting to the point where representations of public representatives are no longer being entertained unless they have written consent signed by somebody who witnessed it, etc., which I do not consider to be good. To be clear, I would be much happier were I not obliged to make any representation, as it would make my life a lot easier. Clearly, however, there is a fundamental role for a public representative and it should be considered by all advocacy groups as being complementary to advocacy, as opposed to being in the way of professional advocacy. Equally, the system should be cognisant that public representatives are aware of what is happening. This trend is limited but is growing.

The hint in all the presentations is the term “public service”. It is a service to the public and therefore efforts should be made to provide as good a service as is possible with the resources made available to it by the executive or by the health service provider itself. There is an obligation on people who work in public service to provide it. This is merely an observation but they often are in a monopoly in that there is only one hospital in one’s area and one cannot walk down the road to go to another hospital. Similarly, there may be only one school, one bus service and so on and consequently, they often operate as a monopoly. One could then argue that because of this less notice is taken of a customer’s complaint; it is just a natural instinct. I am in favour of retention of the public services as they are by and large in respect of health care for example, but there is an underlying view that if people complain, they cannot go anywhere else and consequently, one simply listens to them but does not act. The opposite should be the case and there should be a full embracing of complaints. It should be part and parcel of any modern system, as it is the cheapest form of research one ever will be obliged to do to find out what one’s service is or is not doing. Most private companies or companies that deal with the public on a continual basis in a private capacity embrace complaint. They actively seek to find complaints because it is the best form of research into how they can improve their services and often it is free because people will make that complaint. It will be necessary to change this mindset and as I stated, this goes back to the original idea of public service.

To be clear, these are observations, rather than casting aspersions widely on people who work in the public service. However, and this may be because of under-resourcing, understaffing or simply pressure on people trying to deliver a service, I find there is some harshness in the system in respect of palliative and end-of-life care that perhaps should be revisited. In particular, this is because people are highly vulnerable at that time when a loved one is at the end of life. I acknowledge we have some wonderful facilities, some wonderful hospices and so on, but for people who are not in those good facilities but are in hospitals, for example, it can be a harsh environment for families. I believe much work must be done in this regard. The staff are so busy in trying to maintain life and in trying to keep people healthy and are working with people under huge pressure that it is questionable whether enough support is being put in place. The system is a little harsh in the area of end-of-life and palliative care.

Overall, a big difficulty is that there should be a single citizens’ point for many things.

Members have discussed this for a long time. We have the Ombudsman, the Ombudsman for Children and some other ombudsmen, as well as advocacy groups and citizens' information services. I am sometimes concerned that an individual does not know where to go or how to start a complaint. I will stick with the health services for the moment and the first thing we should have is open disclosure. Open disclosure would help the entire system in making people feel confident they can complain, either in administrative areas or in clinical areas. Again, the system will try to resist this because once one starts admitting open disclosure, one also starts to admit liabilities and that clearly is an issue that also must be addressed. If a system is expected to be open, it cannot be allowed to be perceived as being easy in respect of liability. These are observations.

Finally, I had written down a point I wished to raise. It goes back to what I was going to say on the issue of fear and people being afraid to make a complaint. I will tell the witnesses why this is. They are not only afraid for themselves but often are afraid for the staff as well, that is, the people who actually provided the service. This may be because the complaint involved one person only or because people simply do not wish to create difficulty. For most Irish people, we are a live-and-let-live type of nation, we all know one another and are fairly interconnected in smaller communities in particular. However, I find there is fear both for people themselves and often for the staff as well. One must be conscious that people will go to the ends of the earth to avoid making a comment. While the system does not encourage it, equally as a nation we are not great. It goes back to the old example of restaurants whereby people will spend all day bad-mouthing a restaurant but will never tell the chef it was a bad meal. One must be conscious of this.

**Chairman:** I welcome Senator van Turnhout and reiterate what was said in her absence, which was to sympathise with her and her family on their bereavement and to welcome her back.

**Senator Jillian van Turnhout:** I thank the Chairman and that issue probably motivates me in this regard because the issues of end-of-life care and independent advocacy are my entry point into this issue and are why I wished to be present today. During the end-of-life hearings, members discussed these issues and I came up with three Cs about consent, choice and control. One issue I do not believe has arisen today is that while one talks about independent advocacy, individuals often do not know what choices they have and are rarely given that list of choices. It is felt that, somehow telepathically, they will know for what they must ask or what they need. There must be greater exploration of how this can be ensured. There has been good work, such as that raised by Mr. Mervyn Taylor in respect of the Think Ahead resource and advance planning, part of which is to help people to equip themselves with knowledge regarding the language, because it is very different. However, there must be discussion on ensuring the individual is aware of what he or she can ask for, rather than thinking after the event that perhaps he or she should have asked for it.

In addition, as a children's rights advocate, I often talk about the best interests of the child and the need always to act in the child's best interests. However, in this area, one must discuss best interests versus preference and sometimes, preference must win. This is what must be and an issue that must be discussed is how does one ensure this is balanced in order that one does not always act in the medical best interests of an individual if so doing actually neglects the strong preference the individual may have. At the heart of this issue is the question of how to ensure a proactive, timely and appropriate response before even getting to a complaints mechanism. It is a question of how to ensure, within each setting, that the response is there.

The issue of statutory powers has arisen and I believe Mr. Paddy Connolly mentioned the personal advocacy service. That was established under the Citizens Information Act 2007 but has not been commenced. A question I have, in particular for the National Advocacy Service for People with Disabilities, is whether it is prevented from accessing people or from acting on their behalf because of the lack of statutory powers for advocacy. This is an issue for the Joint Committee on Health and Children and I would ask the question of all the representatives present because they all have raised the issue of statutory powers. Do the witnesses believe this has prevented them from acting on behalf of people? I believe it has but that belief is based on anecdotal evidence acquired from sitting in a nursing home and looking at the situation around me, where I have seen many individuals who have no visitors and for whom nobody comes in to act on their behalf. If somebody does come in, it is only for a friendly chat and is not an advocacy service. How can we ensure that such an advocacy service is in place?

As for particular questions, how does the Citizens Information Board know the advocates from the National Advocacy Service for People with Disabilities are reaching the people with disabilities who require advocacy the most? How can we ensure those people who are in the community are being reached? As we are trying to move away from congregated settings in some cases, how can we ensure these services really are reaching everybody? The HIQA standards require advocates to be available for those living in community houses. However, the inspection reports very often look only at whether an advocacy service was well advertised. How do we know, beyond being well advertised, that a service is really engaging with people and that individuals have access to it? Deputy Kelleher has raised the issue of where to go. I would add to this by asking whether, when they go there, people's expectations will be achieved. We have these great posters saying "Come and talk to us," but if the organisations and the advocacy service do not have any statutory powers, is it fair on the individual? Should we beef it up?

Does the National Advocacy Service report its findings to the HSE? Perhaps we could prevent further cases if some of the lessons learned achieved at local, regional and national levels were reported on. That would be a big issue for me.

Another important issue is holding people accountable for their actions or inaction. In issues of child protection, I often say I would only hold people accountable for doing nothing. When people take action, if they can account for the action they are taking I will give them that. We do not always know how things are going to pan out. We need to ensure that the HSE and individual facilities can be held accountable, that there is transparency and that they will respond in a timely manner to all types of complaints and representations. I would be particularly concerned about lower-level complaints, concerns or representations that an individual may have.

The role of the family is extremely important in advocating for those who cannot speak up. On the other hand, I would suggest a little caution based on anecdotal evidence. I have witnessed family members who do not regularly visit but will come in and feel they need to create a bit of a storm, maybe to assuage their own guilt. We have to have that balance, and that is where regular visiting and understanding the individual are important. I would go back to the issue of consent, choice and control for the individual. It is his or her life and, as much as possible, anything we do should be focused on that individual, whether he or she is in a nursing home, a hospital, a congregated setting or his or her own home.

**Senator Colm Burke:** I thank all the witnesses for their presentations and for the work they are doing. I wish to raise the issue of enduring power of attorney, which I have raised previously. I do not think we have done enough in setting out its advantages. As a practising

solicitor, I find I am being asked to complete enduring power of attorney forms when there is a question mark as to whether the person is competent to even sign it. It is a huge problem. The doctors have to sign off on it and there is hesitation, as people are coming to us too late. We need to do a big sales effort on the issue to communicate the advantages of allocating enduring power of attorney when people are in full health and not when their health is failing.

On the way our health services deal with issues, I know of an example in which the management of a patient went wrong, doctors accepted that it had gone wrong, an internal inquiry was set up and everyone was happy with that, and then the internal reviewers decided that there should be an external reviewer to keep everyone happy and make sure it was independent and everything else. Seven months later, someone in administration has decided they are not happy with the external reviewer who was appointed. The family has been looking for answers for seven or eight months and the inquiry is not even happening. That is the kind of thing that is so frustrating. Now everyone is convinced that people within the hospital are trying to hide something, which is not the case. The people within the hospital want answers just as everyone else does. Nevertheless, that impression has been created because of the delays in dealing with the issue. These matters need to be prioritised. If there is a review to be done, it should be done as quickly and efficiently as possible.

In respect of local authorities in particular, I wish to raise the failure to ensure that there is one person in charge of a file. I have two complaints on this issue, one with the Ombudsman and one with the Ombudsman for Children. For children with disabilities, I know of cases in which work needed to be done on local authority houses, yet seven or eight years later no work has been done. It causes great frustration that there is no one person taking charge of the issue within the local authority. I would say that the offices of the Ombudsman and the Ombudsman for Children are having the same problem. I do not understand why people cannot take responsibility. I recently spent an hour on the phone on one problem, going from one department to another - four departments altogether - only to be referred back to the first one. No one person in any of them was responsible for the file, yet the issue has been ongoing for seven years. Surely we can do something about that. If we had a proper procedure within the authorities, we would not have half the complaints we do. Mr. Tyndall might outline his own frustration with that issue. I am sure he is having the same problem pinning down who is in charge. We need a radical change. At European level - in the health section of the European Commission, for example - there are perhaps 80 different departments, but there is a named responsible person under each of them. In local authorities and a whole lot of State agencies here, we cannot get that. We could remove an awful lot of the delays and provide information and answers.

**Chairman:** Four people who have left indicated that they wanted to speak. I will go back to the panel and then we will go back to the four members. I am conscious that we will not be finished on time.

**Mr. Paddy Connolly:** In response to Deputies Ó Caoláin and Kelleher, in a lot of cases conflict arises because of poor communication and a reluctance to give information. In advocacy, before we get to that point, there is a need for conflict resolution and mediation processes. This is something at which the HSE and services are really poor. It is often a piece of information that is just not being given. Families get suspicious because they are not getting the information and are waiting weeks. It builds up and up and the conflict becomes entrenched. As the Ombudsman has stated, years down the road the complaint is still running and people have forgotten what it was actually about. The conflict has become the energy in the room. This whole area of conflict mediation and dispute resolution processes could be developed.



In response to Senator van Turnhout, this is where Inclusion Ireland is talking about a broad spectrum of advocacy. An advocate's role is often to build the capacity of a person to understand his or her choices and help him or her take control. It is not just about representing somebody or resolving a conflict. It is also about supporting people who may have been institutionalised or dependent on services for a long time, or whose families may be very articulate and dominant, and helping them to understand that they have some choices and control. Broad-spectrum advocacy addresses that issue. Sometimes the advocate's role is to build a person's capacity. It is a patient and slow job, but that is where different types of advocacy come into play.

The role of advocacy is one of a number of requirements in the context of intellectual disability in largely residential settings. It is one of a series of checks and balances. We have HIQA inspections, but HIQA does not guarantee a good quality of life. That is where advocacy rows in. We have complaints procedures. There should be a series of checks and balances that will reduce the likelihood of abuse. Advocacy is one of a number of checks and balances, but it is not going to work alone.

Reference was made to HIQA and advocacy. A number of HIQA reports have referred to a poster on the wall advertising advocacy. That is wholly inadequate in terms of accessibility or as a way for people to understand the process. Some of these people have been dependent on institutions for a long time. That idea does not represent access to an advocate. Moreover, HIQA does not look into a broad spectrum of advocacy. When we refer to a broad spectrum of advocacy, we are talking about representative advocacy and representing a person's interests as well as self-advocacy, whereby we support persons with a disability in expressing their will and preference. That is a capacity-building role. We are also talking about citizen advocacy and the type of work that Sage does. When we talk about the need for a national advocacy strategy, we are referring to a broad spectrum of advocacy.

**Chairman:** Does anyone wish to comment on any of the questions?

**Mr. Peter Tyndall:** One issue that was raised related to the capacity of elected representatives to access the health service as representatives for people. This issue has been brought to my attention by other Deputies. It links to the issue about statutory representation and a statutory role for advocacy. A clear statutory position should be introduced. This is something my office has called for several times. Whether they are elected representatives acting as advocates or advocates coming through the advocacy organisations, those involved need to have a statutory capacity to act on behalf of the people they are representing. I strongly support that.

I am keen to pick up on the issue of finding a way through the maze. It is linked to Senator Burke's question. We discovered that more than 800 people were responsible for compliance within the HSE. How anyone is expected to find the right person is a mystery to me. We are working to try to get a reduction in the numbers so that a smaller number of people can be properly trained with the skills to deal with this work. We have also taken on the lead role in *healthcomplaints.ie*. We intend to move that from being a website that informs people about where they can go to an online service through which people can complain about any aspect of the health service in such a way that the complaint is sent to the person who is supposed to deal with it. It will take some time to do that, but I believe this will mark a step forward. It is not all that is necessary, but it will certainly mark an improvement.

I am keen to pick up the points about end-of-life care. My office has published a report called *A Good Death*. I will make copies available to the committee. It sets out many of the issues raised at this committee that the HSE has made a commitment to address. The reality is



that we are some considerable way from that. It is something we will continue to pursue.

**Chairman:** This committee has done substantive work on end-of-life care as well. It is important.

**Ms Eileen Fitzgerald:** I am responding in particular to the issues raised by Senator van Turnhout. She referred to statutory powers and the personal advocacy service. There is no doubt advocates are being prevented from accessing services. Statutory powers would make a significant difference. However, it goes beyond that. Statutory powers can get people in and give people access. However, without the necessary training and understanding and without working with the service providers, we will not make progress. Many are working remarkably well with the advocacy services. I am keen to acknowledge that. This is about a person-centred approach. When an advocate comes to a facility, the staff need to be aware that she is coming to work with them to support the person in question. That involves a cultural change and a behavioural shift. This change really will not materialise unless it comes from the bottom up and the top down. The relevant training must be available. We need statutory powers, but we also need the added value of people understanding what advocacy is.

I am going to hand over to my colleague Ms Loughlin in a moment. She will discuss how the national advocacy service for people with disabilities, NAS, accesses and gets out to the services as well as how it gets to those most in need.

Reference was made to HIQA, the level of advocacy available to those in community houses and what happens when people go in. Again, Ms Loughlin might elaborate on that. We have been working with HIQA and we will continue to ensure that when representatives of HIQA go in, they know what to look for in terms of what a good advocacy service is. As Mr. Connolly has said, it is not a question of having a leaflet in a file or a note that an advocate has been to a given place. HIQA needs to be able to specify the outcome, what has changed or what has been achieved. Even for HIQA inspectors, this requires engagement with advocacy and with advocates to understand what they can expect. That will greatly enhance their work as well as supporting the advocacy service.

The national advocacy service findings constantly try to pick up, review and reflect what is happening for NAS. We have a national advisory group made up of key players in the HSE, Sage, Inclusion Ireland and a number of other players. We can raise issues and feedback on issues under that group. We have a social policy remit within the Citizens' Information Board whereby we examine submissions and make reports. It is still a work in progress. Again, the more collaboration there is between the services, ourselves and the HSE, the easier it will be for us. Perhaps Ms Loughlin will explain a little about how we reach into the community.

**Ms Louise Loughlin:** I would be glad to elaborate on some of those points. Senator van Turnhout commented on how this is really about consent, choice and control. In a nutshell, that is what the NAS model of advocacy seeks to uphold. As Mr. Connolly has said, advocacy should also be about self-empowerment and capacity building for the individual. One of our functions is to ensure individuals have the information they need to make an informed decision.

Specific questions included how we know we are getting to the people we are supposed to target. That is very much a challenge; there is no doubt about it. NAS has a remit for all disability types and all settings. We have a particular remit with regard to the most vulnerable and isolated. Primarily, this tends to result in a focus on intellectual disability in congregated settings and group homes, but not exclusively. We map out where those people may be based

on our knowledge base. Then we undertake a process of engagement with service providers and families to raise awareness about the existence of the advocacy service. Throughout the country the NAS does ongoing promotional work to raise the level of awareness. Furthermore, we reach out to community groups such as community mental health teams, primary care teams and general practitioners to try to raise awareness around advocacy. There may be people living in the community who are hard to reach because they are not connected to services, yet they may be in great need of an advocate. This remains a challenge, one we continually review with a view to building on.

Mr. Connolly referred to leaflets on file and HIQA inspections. Our experience echoes the comment about a poster on a wall or a leaflet on people's files. We have experience of what happens in anticipation of a HIQA inspection or after a HIQA inspection. Often, when this arises, a large number of inquiries or referrals come to our service from the service provider. In such cases we aim to meet the service providers to increase their understanding around advocacy in order that they embroider it into their practice. That is what we are seeking to do. It is very challenging work. We are a small service with a sizable remit, so it is a struggle to manage all of that, but that is our aim.

**Mr. Mervyn Taylor:** I wish to respond to the remarks of two Deputies who are no longer here but who deserve an answer. Deputy Ó Caoláin raised the issue of approaching development and co-ordination. My answer is that we need a step approach. I do not advocate that a particular organisation with a particular budget be given responsibility for all advocacy. We are at a stage at which we need a step approach. An inter-sector committee is being developed by the HSE to safeguard vulnerable adults. This is bringing together issues to do with people with intellectual disability and the work of elder abuse officers. There is a great opportunity here and I imagine independent advocacy and support groups will have some impact on the group. There is an opportunity to get people around the table and working to develop a common agenda.

We also have the decision support service which is not yet in law. We do not know how that will be formed but we have said it should be an independent agency in its own right rather than being under the Courts Service. As part of its remit, it will have the authority to develop codes of practice or to ask others to develop codes of practice. That is another piece of the jigsaw which could examine common standards on issues of advocacy. We ourselves have made a contribution in this regard recently.

The national patient advocacy service is being proposed but we are very close to a general election and do not know whether that will materialise. I remember that this was announced last year in a different context. As regards grappling with patient safety and advocacy, those issues do not necessarily always sail in the same boat. It was an opportunity but we need to hear what is intended.

The other aspect of not rushing it but getting there nevertheless is that there is a need to prepare service providers. That is because there are some service providers for whom the phrase "human rights" is something to do with Ban Ki-moon and the UN but very little to do with them and their day-to-day work. They just cannot make the link between human rights and the fact that somebody cannot leave their nursing home, so there is a need to prepare the ground. There is also a need to prepare the public ground. Advocacy is not about people simply appointing themselves as advocates, appearing on the Joe Duffy radio show and giving out about something. Legislation is required, as are practitioner skills.

Some of the issues that have been referred to are quite complex. I will touch briefly on

Deputy Kelleher's point about public service monopolies and the difficulty of having only one provider. One of the things we have put in our detailed submission - I am particularly conscious of Portlaoise and other places - is the need for some form of public interest representative role sitting in on relevant sections of senior management meetings. We no longer have this multi-disciplinary approach but we have a multi-perspective one. Somebody is required who can ask hard questions in the public interest, who has access to complaints information on issues from advocates, and who can bring that to the table. We do need to develop a culture of reflection and challenge within that type of monopoly provider.

Senator van Turnhout raised the issue of legislation on access to clients and such legislation will be important. One of the greatest difficulties we have concerns wards of court as well as the difficulty in accessing clients. We can only wish the Assisted Decision-Making (Capacity) Bill well, its speedy emergence and the departure of the whole wards of court system, which has been a terrible blight on our existence.

To come back to the issue of seeking statutory powers, we support that. It should be simple but statutory powers will only bring us so far. The practitioner skills of advocates will also be very important. I am referring to good street-fighting skills as opposed to theoretical and abstract knowledge.

My last point concerns Senator Colm Burke who referred to the enduring power of attorney. SAGE has made a submission to the Department of Justice and Equality to develop this area. I refer to the second-last bullet point in my opening statement, which is the development of a major public campaign to promote the advantages of advanced planning and to give it some financial incentive. If we can incentivise people to plan in advance, we could reduce costs in the system later on. This is because the amount of time that health care practitioners and social care providers often spend in dealing with divided families and complex issues is an enormous cost to the State. If we could encourage early engagement in advanced planning of all forms, including advanced health care directives and the enduring power of attorney, we would be doing the State a great service.

**Deputy Seamus Healy:** I welcome our visitors and thank them for their presentations. I would like to see a statutorily based national advocacy service which is independent, publicly funded and accountable. That is the big picture but I am not sure where the various organisations see a starting point. Is that what they would see as the overall big picture?

My second question arises from that. Mr. Tyndall has described this area as a maze and we would all agree with him. What would the advocacy service that should be available look like in practice? For instance, how can the procedure for making complaints be simplified and is there a time limit for, or stages to, this procedure? Should there be or is there a local support person in each community care area to advocate on behalf of individuals? My main questions are as follows. What will this advocacy service look like on the ground? How will it interchange with individuals, especially those who have a problem and want advocacy services?

**Deputy Dan Neville:** I thank the witnesses for the information in their presentations. I wish to raise one or two issues. One concerns advocacy for mentally ill patients, which is a difficult area. As regards the ethos or practice of many sections of the psychiatric service - I am not painting the whole service with the same brush because there are good communicators - many psychiatrists will refuse even to discuss aftercare with carers, including families. We get this information all the time and it is a historical thing, not something that has developed recently.

In addition, the psychiatric profession sometimes seems to discuss issues almost as if the patient was not present. They may even assume the patient is not in a position to understand or be involved in his or her treatment. We are coming from a time when that was the practice in society concerning the mentally ill. What is the experience of the witnesses in this regard?

I understand that the Irish Advocacy Network does work in the area of mental illness, but it is not represented here. It specifically does peer advocacy. Where somebody has experienced difficulties with treatment from the mental health services, if trained properly in advocacy, such a person would be very suitable and informed. He or she would have a feel for people's experiences in mental health services and who may not have received the respect of being communicating with.

As regards communication with patients who are mentally ill, the more severe the mental illness, the less discussion that takes place with the patients themselves. There is almost an assumption that such a person is not cognitively able to engage about his or her illness, while that is not the case at all. It is probably a historical societal practice going back decades, but it is still there. How do we move away from that?

On the issue of communicating with carers, where a family receives a person home from a psychiatric inpatient unit - I will deal with inpatients because outpatients have an issue as well - and the family is not informed of the aftercare, what to expect or what even the treatment might be, that is very stressful for the patient and the family and does not assist the full recovery. We are moving into recovery rather than containment because recovery is real in the mental illness area. The witnesses might cover those two areas.

**Deputy Sandra McLellan:** I welcome the witnesses and thank them for their presentations. I do not want to go over everything that others have raised but I would like to touch on the point Deputies Ó Caoláin and Kelleher mentioned about public representatives encountering difficulties in making representations on behalf of constituents. It is often perceived that we are interfering rather than being there to help. The point was well made.

On the back of that, Ms Fitzgerald stated, "the front-line staff and local manager are unaware of the inclusion of advocacy in service agreements and do not understand why an advocate has been requested or what their role is ... and therefore can be circumspect about the advocate's involvement". That is an important point. Sometimes it is important that somebody in charge acts on behalf of people or interacts with people. It is something that Senator Colm Burke mentioned, even with regard to the different services, such as housing and grants. One is trying to trawl through the various Departments to find the person who knows about the issue and it can be difficult.

I agree with everything Mr. Tyndall stated in his presentation. A matter about which I could talk to him is the difficulty in making complaints or in knowing how to make them. There is also the issue of making a complaint where one is concerned it may affect the care of a loved one. That is often reflected to us.

Mr. Tyndall referred to Wales in his presentation and mentioned independent professional advocacy. Is there a difference when compared with advocacy here? When he mentions professional, what is the professional background of the advocates? Are they professionally trained? Mr. Tyndall might comment on that. If one needs an advocate, how does one access the service or how does one navigate that? How will it be funded? Will there be a funding stream guaranteed?

Mr. Taylor mentioned in his presentation the comparison with the 46A bus where one waits a long time and then a few come at once. What does the new advocacy service mean for the continuation of the SAGE advocacy service for older people?

How do we measure the quality of an advocate? We now have a diverse culture in the country. There are language barriers and people from other countries. In this regard, how do we match the advocates to the needs of the person?

It was mentioned that there are only 35 advocates nationally. How does one access the 35 advocates? Where are they based? Are there waiting lists? How long does it take to access advocacy?

Another issue that has come up in the context of the private nursing homes and the fear of making complaints is that the confidential recipient does not apply to private nursing homes. I had an issue whereby somebody was administered incorrect medication and that was reported, but the person in the private nursing home was afraid to take that complaint further because they were afraid they would be moved out of the nursing home. How does one overcome that issue?

**Senator John Crown:** I apologise for not being here for the earlier presentation. I will also try to be brief.

We clearly need better advocacy services. I am very supportive of it. I am a supporter of transparency and openness in all areas of the public service, from Government down to doctors and hospitals. There should be an automatic right of access to all records which does not have to go through any kind of freedom of information process. Everything should be available to patients. I operate an open records policy for any of my patients who wish to see any aspect of my records. It is the correct thing to do.

I would not want anything I am saying to be misconstrued as being a lack of enthusiasm for an advocacy service. I quote "Titanic" so often that James Cameron may well ask his lawyers to send a letter to me. As *RMS Titanic* was slipping between the waves and the 700 passengers, for whom there were not enough lifeboat places, were drowning and freezing to death, what they did not need as a priority was an advocacy service. What they needed was somebody to have provided enough lifeboats on the ship in the first place. In a perfect health system, if we ever were to achieve that philosophical nirvana of health perfection, there would be no complaints and there would be no need for advocacy or a complaints service, but we always will have complaints and as a result, we should have this service. However, we should not lose sight of the fact the advocacy service must also advocate for reform of the service. It should not be seen as retail exclusively. It should also be wholesale. It needs to look at the service.

The episode of obstetrical problems in the midlands over the past year or two, of which we are all aware and I do not want to personalise this to a particular tragedy, provided some of the impetus for a renewed focus on the need for advocacy services and reform, but what has to be remembered is that the staffing structure in that unit was bizarre. There is no other country in the OECD or the western world that would have allowed a system to develop that would have been staffed by such a tiny number of consultant obstetricians. There is no other system in the world that would look like the Irish system which has a tiny number. With the possible exception of the NHS which is the second worst, the health service has a tiny number of specialists per head of population compared with any system in the OECD. If one also looks at the incredible disproportionate reliance on good, diligent locum doctors, many of whom were trained



abroad and brought their services here, because of the nature of their employment and because of the rapid rotation of locums because we do not have enough consultant positions to provide the critical mass to cover maternity leave, illness leave or holidays, we often have colossal deficiencies in the system which are also plugged by the honest efforts of inappropriately responsible junior doctors. These are the problems. We will need a good advocacy service because it will be really busy.

By all means, one should keep it up but one should not lose sight of the big picture. There is a group about whom the complaints need to be made - Deputy Varadkar, Deputy Reilly, Ms Mary Coughlan, Ms Mary Harney, Deputy Martin, Mr. Brian Cowen, Deputy Howlin, Dr. Rory O'Hanlon, Mr. Barry Desmond and others right to the beginning of the State - because these are the ones who occupied the position of Minister for Health and who, despite repeated warnings, were aware of the extraordinary nature of the public health system, in particular, the public hospital system.

I was elected to the Seanad four years ago with a little idealism and perhaps the tail end of middle-aged youth, thinking we could do something for reform of the health system. We had a new Government which promised reform and which has now welshed and has told us we are not going to have it. For the record, I am despondent. I do not believe the health system is going to get fixed in my lifetime but the witnesses should by all means try to continue to be a powerful force for advocacy, reform and change in it.

**Deputy Catherine Byrne:** I apologise for leaving the meeting, although I heard some of the contributions. I welcome the delegates, particularly the representatives of the Support and Advocacy Service for Older People, SAGE, whom I met in Croke Park in October. It is nice to see them again.

I read some of the documents submitted to the joint committee last night. The document, Think Ahead, while relatively short and compact, is one of the best I have read in a long time. It encourages people to make a written statement on what should be done with the family home and so forth after they have passed away. I give copies of the document to visitors to my constituency office. Not only is it a good read but it also includes a form which people can fill in stating what should happen before and after they pass away. Many families find themselves in turmoil when family members die or become very ill because a loved one has failed to appreciate the value of committing to paper his or her wishes in the event of his or her death. This should not only be done by older persons. Some time ago I met a young girl who has, unfortunately, since passed away. We spoke about her wishes after her death and I explained the document, Think Ahead, to her. I also provided her with a copy, although I do not know if she managed to read it.

As a public representative, I frequently meet people who are distraught because wills have not been made by family members before their death. Housing causes particular problems in this regard. Families should sit down together and discuss in advance what should happen with property if someone passes away because problems in this regard can cause families to fall out for generations. Dealing with this issue is part of my role as a public representative. It is often a sad time because people can feel inadequate and lost in the system. For this reason, I support the Think Ahead initiative which should be supported. Copies of the document should be made available in every library, hospital, nursing home, day care centre, primary care centre, college and school. We must all make plans for when we are no longer here.

Inclusion Ireland provided statistics for the numbers of adverse events recorded by Irish

hospitals and health care facilities in 2011. We learned that there were 10,000 incidences of violence, harassment, aggression or abuse of patients in that year, of which more than 4,300 involved physical assaults on patients, including persons with disabilities. We all saw the shocking television programme showing residents of a nursing home being abused, including being beaten. The individuals in question were abused and made to feel unworthy. Are the data from 2011 the most recent available? Has the position improved or worsened since? I refer, in particular, to nursing homes.

I visit relatives and neighbours in a number of nursing homes. The care I see is top-notch, although things may be different behind closed doors. People are also being abused in families, with older people, in particular, sometimes being neglected in the family home. How do we reach into private homes, as opposed to nursing homes and so forth, and advocate for those being abused at home? This issue has been neglected to a certain extent. If it were not for home help services and carers who visit older people daily, some of them would be left in desperate conditions, with serious implications for their physical and mental health. I compliment those who work in these areas. Perhaps the delegates from Inclusion Ireland will respond to my question on the figures for 2011.

**Chairman:** We will start with Mr. Taylor and work backwards.

**Deputy Catherine Byrne:** Incidentally, I am disappointed with Senator John Crown's remark that the Government has reneged on its commitments on health policy. We have not abandoned anything.

**Chairman:** We will discuss that issue on a different day.

**Deputy Catherine Byrne:** The Senator's statement needs to be corrected.

**Senator John Crown:** The Government's record is very clear.

**Chairman:** We will not have advocacy on either side of the debate.

**Senator John Crown:** I am setting the record straight, not advocating. I have been accused of being untruthful on a matter of public record.

**Chairman:** We are having a good discussion on the issue of advocacy. Members can voice their personal opinions in a different forum on a different day.

**Deputy Catherine Byrne:** The Senator's statement needed to be corrected.

**Senator John Crown:** I reminded the meeting of the point of view of the Government in 2011.

**Mr. Mervyn Taylor:** I thank Deputies and Senators for their questions. To respond to Deputy Seamus Healy's question on having one large, independent statutory advocacy agency, I am a former public servant, having worked in what is now the Citizens Information Board, an organisation that I admire and which I will continue to strongly support. However, statutory agencies are not the only show in town. We need to strike a balance on this issue. We certainly need co-ordination - that is the message we all want to convey in our different ways - but the question for the committee is how do we get there.

Deputy Seamus Healy asked what advocacy looked like on the ground. That is an important question. It looks like whatever the person wants it to look like. It is not advocacy in terms

of everybody jumping up and down in advocating for a cause. It is very often, as I described earlier, a matter of the street-fighting skills of a person who wants to leave a regional hospital to return to live in a house with a clay floor with his or her mangy dogs and smoke 40 Woodbine cigarettes every day because that is what he or she has been accustomed to for many years. Every professional and some of the remaining members of the family may decide that that is not in his or her best interests, even if he or she wants to be at home. It concerns where the matter is determined by the person rather than on the basis of what the system and everybody else believes is in the person's best interests because sometime the best interests of others coincide with their own interests as opposed to those of the older person.

**Deputy Seamus Healy:** In such circumstances how would the person concerned gain access to an advocate?

**Mr. Mervyn Taylor:** I will address an issue that has been raised about the resources available to the National Advocacy Service and in doing so I do not propose to trade wounds. The National Advocacy Service believes it is terribly short of staff, but we have probably half the number of staff it has, yet we still reach people. Recently, we were in Clonmel speaking to hospital staff who wanted to advocate and learn advocacy skills. The question is not so much one of signposting but whether a sufficient number of people will be available at local level. It is very often an issue of working out individual stories, wishes and preferences, sometimes against the wishes of the family and the system.

Deputy Dan Neville raised an issue about mental health. I fully appreciate that mental health services are often the Cinderella service. However, we should be careful not to make mental health a discrete issue because disability, older age and mental health services very often come together.

Issues of clinical governance also arise. If some of the issues raised by the Deputy concern the behaviour of psychiatrists and the attitudes they take, the questions that must be asked - not only in this area but also in others - are what clinical governance system applies, who is supervising the work being done and how does one reach the people in question and make a complaint on the basis that the behaviour is neither responsible nor good enough.

Issues arise about peer advocacy in mental health services. While this approach has been extremely successful for a number of people, there are concerns about how far it can be developed. These concerns must be noted.

On Deputy Sandra McLellan's questions, I have touched on the issue of staff numbers. The fear of making complaints in nursing homes is very real and not limited to them. One of the good things about Irish society is that it is small and people know each other, as Deputy Billy Kelleher noted. This is also a downside, however, in that people are genuinely afraid to make complaints. It will take a number of years to build a culture where people do not always see a complaint as a personal affront and will look on it as an opportunity to learn how to build a quality service. This is important. A complaint must not always be seen as a personal attack but as a contribution towards the development of a service.

In regard to the point made by Senator Crown, I agree there are limits to advocacy. As outlined in our submission, we believe there must be a rationale stated, as there is a grave danger that advocacy will be seen as a last straw that is clutched at by a bureaucrat who is running out of other excuses. The fact is that advocacy has a role to play, but there are other avenues. There is provision in legislation for complaints, the ombudsman, better services, the decision support

service and a range of other options.

Deputy Byrne, who kindly stood in for the Chairman at our conference on 16 October, spoke about Think Ahead. I agree, but we must not just see Think Ahead as a resource but think about the public campaign that is needed to get the public to think ahead. With Think Ahead as a resource, with enduring powers of attorney and with the advance health care directives, people should be advocating for themselves now for a period in the future when somebody else will have to advocate for them and will need to know what they want. This type of approach is as important as legislation or any of the other issues we have mentioned.

The final issue concerns how to get into private homes. It is correct that the greatest abuses happen in the home rather than in congregated settings, although these are the ones that are best known. Home help services can help in this regard, provided they are aware of the advocacy services available. They can tip off the services and can link up with other services. Day care centres and any places where people are in touch with services can also be a touch point for linking up with advocacy services. I agree, getting awareness of our services into private homes is one of the most difficult areas, but it is an area we must apply our minds to.

**Chairman:** Thank you. I apologise for having missed SAGE's conference and thank Deputy Byrne for stepping in at that time.

**Ms Eileen Fitzgerald:** I wish to comment on some of the points raised by Deputy Healy. The Citizens Information Board is a statutory service and the National Advocacy Service is an independent, publicly funded and accountable service under that board. However, I agree with Mr. Taylor that the service is not and cannot be the only show in town. There must be a range of other models of advocacy. Over the past ten years, since we started in 2005 with 46 small pilot projects, through to the service being managed under five citizens information services and now to one national service, one of the most important lessons we have learned - this relates to the question of how we measure the quality of advocacy - is that unless we have good management and support structures in place, it is difficult to measure the quality of advocacy. The National Advocacy Service is keenly aware of this with its model as its advocates must deal with complex cases for people in vulnerable situations. In terms of peer advocacy and other advocacy models, the question is how far can a model be developed and how far can it go. A statutory national service with paid employees who are dealing with the most complex cases needs these structures and supports and it is important to remember that.

I will now hand over to my colleague to deal with some of the questions regarding practice.

**Ms Louise Loughlin:** Deputy Neville raised two issues concerning psychiatric services, namely communication and assumptions made about people's capacity to understand decisions being made. Some of these issues cut across all services in regard to people with disabilities, but there are particular issues in the case of mental health. Our advocacy service is engaged with acute care settings for people with mental health issues and seeks to address some of those by seeking to build up the person's capacity and communication with people such as their consultant psychiatrist. A cultural shift is required in terms of the issues the Deputy identified. There is no doubt but that improvement is required in that area. This improvement needs to come from more than just an advocacy service. As Senator Crown said, it is broader than that. The Assisted Decision-Making (Capacity) Bill should make a difference to the experience of people in these services regarding assumptions around their capacity, because it starts from the premise that everybody has the capacity to make decisions. This will apply across the board and will, hopefully, make some difference.

In regard to the question raised by Deputy McLellan regarding accessing our service, there are a number of pathways to doing that. We offer a telephone service that allows people speak directly to a member of our staff. This contact can be made by family members, through self-referrals or service providers. We also engage in significant promotional work which often leads to a number of referrals. Therefore, there is an extensive programme of engagement. There are waiting lists in some parts of the country. As mentioned already, this is a highly challenging area and there is huge demand for our service.

The Deputy also asked how we match the needs of the advocate to the person. This relates to the skill and training of the advocates and their ability to negotiate. As well as dealing with changes in the Irish environment, advocates must be able to manage work across the different areas of disability. This is about the skill and ability of the advocate. In some situations, people might have particular skills or knowledge and we would try to match these to the individual. We try to represent this in our own staffing also and the modern make-up of Ireland is already included in that.

**Mr. Peter Tyndall:** On the issue of what the independent advocacy service would be like, linking that to some of the issues around the service in Wales, I echo the comments about the need to have well trained, professional advocates as part of any service. It is not for me to determine how an advocacy service across Ireland would work, as there are people better placed than I to do that. However, access to such a service is important. In that context, I believe advocates should be located prominently at each of our general hospitals. They should be easily found and their phone numbers should be well advertised on posters so that issues can be taken up on the spot. The concern would be that this happens rather than a concern about who provides the advocacy.

In Wales, advocates come from a variety of backgrounds but it was the quality of training, induction and the national standards that applied that were significant in raising the quality of the service. Those advocates were significant initiators of complaints to my office there. The volume of complaints that came through involving an advocate made up a significant proportion of the work. This shows that people who might not put their case forward, do so when they have help. I also had experience of seeing peer advocacy operating well within the mental health context and I used some of those advocates to train staff in my office in the past because I found their perspective, from the service user point of view, was very good at helping staff to think about how they approached people with mental health problems who wanted to make a complaint.

I want to deal now with the issue of nursing homes and of people being afraid to complain because they will be identified. My office has the power to investigate complaints on the basis of its own initiative, rather than on the basis of identifying a complainant. A member of staff of a health facility cannot make a complaint to my office. The system is designed for patients, carers, their advocates and so on. However, if a member of staff brings matters to my attention, we can choose to investigate those without a complaint. Therefore, there are possibilities in that regard and my staff has been alerted to the fact that if issues of that nature arise, we should consider making an own-initiative investigation.

Ombudsman investigations are about what has happened and are not about blaming an individual for getting something wrong. They are about investigating whether what happened was right and, if not, what needs to be done to ensure it does not happen again and about making things right for the individual. It is possible within an investigation to identify where things went wrong, without having to place a public spotlight on an individual. This can be very dam-



aging because people become very defensive, and it is not necessarily the best way of seeking improvements. It is sometimes better to work with services to achieve an improvement rather than name and shame, which can have the opposite effect to that intended. Ombudsmen also look at recurring patterns. If we see several cases along a similar line or that kind of systemic issue, this is picked up as a potential role for advocacy services, and I would certainly endorse that. If one has a broad picture as a result of running a national service, for instance, one will see patterns and will be able to contribute to improving services generally and not just in the particular setting. I hope that answers some of the issues that were raised.

**Mr. Paddy Connolly:** On Senator Crown's question on advocacy in the context of reform, I am speaking in the area of intellectual disability and disability primarily. I am not experienced in the hospital sector. The NDA has stated that three quarters of the €1.4 billion it currently spends in the disability sector does not underpin the current policy model. In other words, we have segregated and institutionalised people over a long period in residential settings. Once people are taken out of their communities and segregated in that way, they are exposed to risk, abuse and a lack of choice and control over their lives. That reform programme has not been energised in recent years. We are talking about giving people control over their own funding in order that they can buy their services. I respect what SAGE is saying in that this should not be an authority announced overnight and we have to move towards this. I appreciate that and it has to be carefully considered. However, one of my issues with a step-change process in the delivery of advocacy is that we have large organisations that receive hundreds of millions of euro in Government funding. Over a long period they have not reformed. They have their heads in the sand and they have no desire to reform. Unless we put advocacy services and checks and balances into these organisations and compel change, they will not change over a long period. That is the question of reform.

In terms of Deputy Byrne's question on Áras Attracta, whether things have improved and what figures we are using, they were the 2012 figures reported in the *The Irish Times*. I do not have more up-to-date figures, but the Ombudsman has spoken about how complaints in Ireland are under-reported compared with other jurisdictions. We can safely say, therefore, that the numbers we are using are probably understated. In terms of Áras Attracta, if the CEO of the HSE is coming in later, it is important to say that very significant measures have been taken in terms of the centre itself and a number of other centres. Several measures have been put in place in a number of centres since the Áras Attracta scandal. Can we say with any confidence that it is not happening in any other centres? I am afraid we cannot because we do not have the checks and balances, advocacy and systems reform to say those abuses are not continuing today.

On Deputy Healy's question about what advocacy services look like on the ground, for us advocacy goes beyond the current conversation around hospitals and residential disability services. I will give one example. We have the case of a young girl whom we will call Sophie. She is in a school in the east and has been restrained, face down on the ground, more than 400 times in the last 12 months by three teachers. It is a case we are dealing with at the moment. She has challenging behaviour. We have very significant abuses outside the models we are talking about here, in terms of hospitals and so on, and we have no advocacy for parents.

To answer Deputy McLellan's question about how one gets an advocate, by and large, one does not. We have very under-developed advocacy supports in residential services and in the community, so families find it very difficult to access a service. That is where organisations like us and others come in. We cannot deal with the level of demand on our services to do advocacy

work.

I have two last points. One relates to the confidential recipient. She should be accessible to others. We are the organisation that called for the appointment of a confidential recipient, so while we welcome the call, our difficulty is that if it is about a person picking up the phone to her, she will phone someone else on their behalf. It is not a systems change. It is an important intervention, but it is not a systems change. It functions if a person is fortunate enough to get to a manager or if the confidential recipient gets to a manager for them. It is a personal, one-on-one service and we cannot address the broad array of complaints and concerns that are in the system with those types of personal changes. We need an office and an infrastructure.

I worked in the area of migration for more than ten years. In terms of advocacy and the diverse nature of Ireland's society now, the issue is about cultural competence. Advocates have to be trained up in cultural competence. We cannot provide an advocate with every language for every community, so we need to build the cultural competence of advocacy services.

**Chairman:** We have gone way over time, which is an indication of the thorough discussion and interest we have had as a committee on this matter. I thank all the witnesses for being here. For those in the Gallery, the committee hopes to publish a report on the hearing this morning and to inform the Minister and others of what happened here. I thank all the witnesses for their very lengthy and considerable presentations, which are in the packs the members have. They will also be on the committee website and will form part of our report.

*Sitting suspended at 11.56 a.m. and resumed at 12.06 p.m.*

**Chairman:** I welcome, from the Health Service Executive, Mr. Tony O'Brien, director general, and Mr. Patrick Lynch, national director, quality assurance and verification division, and apologise for the slight delay to the start of this session.

By virtue of section 17(2)(l) of the Defamation Act 2009, witnesses are protected by absolute privilege in respect of their evidence to the committee. However, if they are directed by it to cease giving evidence on a particular matter and they continue to so do, they are entitled thereafter only to 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 and asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person or an entity by name or in such a way as to make him, her or it identifiable. 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 Houses or an official either by name or in such a way as to make him or her identifiable.

I invite Mr. O'Brien to make his opening statement.

**Mr. Tony O'Brien:** I thank the Chairman for the invitation to attend the meeting to speak on the issue of advocacy.

Advocacy in all its forms should ensure people, particularly those who are the most vulnerable or incapacitated because of their illness, are able to have their voice heard on issues that are important to them. The requirement for effective advocacy crosses all of our health services, including acute hospitals, the care of older persons, services for people with disabilities and mental health services. Self-advocacy is the ideal form of advocacy, particularly for people who are able to communicate their wishes and preferences. The ultimate goal of any advocacy model should be to empower people and give them the confidence, where possible, to advocate

for themselves.

In many cases, advocates are front-line workers or trained volunteers and professionals. While I would like it to be otherwise, sometimes people feel powerless in navigating the health care system or in understanding the care options open to them. Often, when they access services, they are very vulnerable or very ill. It is in these situations that friends, relatives or those who have had similar experiences can and often do advocate on their behalf. While some people are fortunate to have powerful advocates among their family and friends, it is also important there are advocacy arrangements in place which are independent of any aspect of the service or any of the statutory agencies involved in providing care.

The HSE invests in several organisations and groups which, either directly or indirectly, provide health information, advocacy, support with complaints handling and more practical support. Examples of these agencies are SAGE and Patient Focus. We have also established a national patient forum, made up of advocacy groups and patients. This forum has already inputted into the medical card review and that relating to ambulance services. It is available to all our service divisions to support the planning, design and delivery of services.

In 2014, the HSE, together with Atlantic Philanthropies, agreed to fund a national support and advocacy service for older people known as SAGE. This service is managed by Third Age, a national voluntary organisation from which the committee heard earlier this morning. SAGE is building a team of people capable of tackling the most complex support and advocacy challenges presented by older people, and to date it has dealt with 652 cases. The service has also mobilised 138 volunteers who serve as facilitators for residents' groups in nursing homes and support for vulnerable older people in hospital emergency departments.

Within our disability services are a significant number of community and voluntary organisations, most of which are funded by the HSE, which provide some form of advocacy. The extent of this provision has not yet been systematically documented, and the HSE has established a project to map this. This process will include consultation with people with disabilities who live in residential settings. The HSE is also working with Inclusion Ireland to establish service user and family councils or forums in a number of intellectual disability service settings. In addition, work is under way with the disability sector to establish a national volunteer advocacy programme based on the SAGE model for older persons. Progress will be made on the development of this programme in 2016.

The committee is aware that in December 2014 the HSE appointed its confidential recipient, Leigh Gath, following revelations of abuse at Áras Attracta in Mayo. The confidential recipient provides a place where individuals with concerns about the abuse of vulnerable adults in residential settings can come to have their concerns listened to and investigated. She also acts as an important advocate for the complainant, navigating the system and ensuring the concerns raised are dealt with appropriately.

The HSE also acknowledges the important work of the National Advocacy Service, supported by the Citizens' Information Board, which provides an independent advocacy service for people with disabilities. While the service has a team of full-time advocates, there is still a large cohort of people with significant disabilities who have either no access or very limited access to a case advocate. The HSE would welcome further enhancement of this service and for it to be put on a statutory footing through the commencement of Part 2 of the Citizens Information Act 2007.

The HSE's acute hospitals division recently developed a plan for greater patient partnership across the hospital system. Hospital groups are putting in place patient advisory councils and some groups have appointed patient advice and liaison co-ordinators. These will be extended to all groups. This work will be supported by a national patients' council.

A key indicator in any assessment of the quality of our health service is the way it reacts to the concerns raised by its clients, patients and service users. Complaints are an important way for the management of services to be accountable to the public, as well as providing valuable information about the performance of the organisation and the conduct of people that work within and for it. It was in this context that in May 2015 the Office of the Ombudsman published a report on its investigation into how public hospitals in Ireland handle complaints about their services. In particular, the Ombudsman looked at how well public hospitals listen to feedback and complaints and whether they are learning from these complaints to improve the services they provide. The HSE has now established a national complaints management office, which will provide leadership in how we respond to and learn from feedback right across our system. In an associated initiative, the HSE will, together with HIQA and the Department of Health, introduce patient experience surveys across our acute hospital system from 2016. We will support the Department of Health in the establishment of the patient safety office and the development of its work.

I should also mention the introduction of the Assisted Decision-Making (Capacity) Bill. The provisions of the Bill will apply to all health and social care settings, and the HSE has established a project team to ensure implementation of the provisions of the Bill once enacted. This will include implementation of the codes of practice for those acting as advocates on behalf of patients and service users. The HSE strategy supports the simplification of legislation governing the complaints process and the extension of the remit of the Ombudsman to include complaints related to clinical areas.

I believe strongly that every patient or user of our services is entitled to be heard on the decisions that affect their lives. Effective advocacy must therefore be supported at all levels of the health service, and the HSE is committed to continuing its work in this important area. There is, however, a very real requirement for advocacy services that are truly independent of and, therefore, not at risk of undue influence from those services. The HSE therefore welcomes the recent announcement by the Minister for Health of the establishment of an independent national patient advocacy service in 2016. We will endeavour to answer any questions committee members may have.

**Deputy Billy Kelleher:** I thank Mr. O'Brien for his presentation. This morning we heard from advocacy groups who outlined their views and concerns on what is required to be done to ensure we have proper accountability in how complaints are followed through in our health services. There are certain cohorts with specific vulnerabilities and areas of disability, where people may be in a congregated setting without family supports. We have seen major problems manifest themselves, such as in Áras Attracta.

The HSE has a monopoly in what it offers to the public, who have no choice but to use this service, be it the local hospital or services for elderly people or people with disabilities. There is an obligation on the HSE to ensure complaints are followed up. One could argue that to improve one's service one should embrace complaints, and most companies dealing with the public in the private sector make the complaints procedure very easy because it is probably the best form of research they can garner on their product or service. The same should be the case with the HSE. It should be very easy for people to make a complaint. This is something we really

need to embrace. While we have moved towards the establishment of advocacy services and patient safety services, we need to accept that it should be easy for an individual to complain and for it to be followed up in a meaningful way to get to the bottom of the complaint one way or the other. The measure of success is that we would not need those advocacy services if the system was working and functioning properly.

This morning, an issue was raised about public representatives following up on behalf of a constituent or somebody who approaches them with a complaint. Often people contact us because they are not happy with a service or they have experienced a delay in a service, difficulty accessing a service or an issue with regard to the treatment or support they were given or not given. By and large, the HSE is very forthcoming in dealing with public representatives' queries. However, I am beginning to detect a slow but incremental creep of the use of patient confidentiality and the protection of patients' details, and it is becoming more difficult for public representatives to make representations on behalf of people who approach us. We are asked for specific details of the person on whose behalf we are making the complaint, but very often it is a third party, such as a family member, who comes to us. Is the HSE using client confidentiality, patient confidentiality and data protection concerns as a means to slow down or obstruct the process? I am not saying this is specific to the HSE, but I am beginning to detect this as an issue across the public service in general. I appreciate that there is an obligation with regard to data protection and client confidentiality, but sometimes we are requested to furnish details we simply cannot get. Earlier, Deputy Ó Caoláin gave photographic evidence of an example of this. We should be conscious of ensuring that when people come to us we can pursue the complaint. If a person or family member comes to me and makes a serious complaint I have two ways of looking at it. I can either do nothing or do something. If I do nothing and at some stage down the road something is shown to have happened, then I did not act in the way I should have. We should not put barriers in this specific area. I accept that public representatives make numerous representations to the HSE but, particularly with regard to complaints, we do not put pen to paper lightly because very often there are implications.

With regard to services, there is no doubt there is an element of fear in a person making a complaint, as it is the only service available. Even if the service is not good or the supports being given are not great, they are the only supports that can be accessed. If people make a complaint, they may feel there may be vindictiveness in the organisation at some stage that could jeopardise treatment in the future. It is a genuine concern I have heard people raise on numerous occasions. They come to us to make a complaint but when we look to pursue it, they say they may have to return to the service next month or next year and they do not want to cause any difficulty for themselves or their families.

Let us be honest in that another area where people can have concerns is that they do not want to get people in trouble. They want a concern to be aired but we are quite a close-knit community, we know each other and we are interdependent. Although one person may cause difficulties, people in general do not want to cause problems for staff providing a service. People very often appreciate the staff providing a service may be under pressure because of resourcing issues. It is a delicate balance of holding people to account while, at the same time, of ensuring that when people have a complaint, they can bring it to the attention of authorities without jeopardising an individual's career or bringing about a disciplinary process over and above what they may have expected. They just want the concern dealt with. This is a tricky balance as there is an element of accountability and obligation as well.

With regard to the comments on independence, the national patient advocacy service, re-



cently announced by the Minister for Health, is meant to be independent. Very often, many of these organisations depend on funding directly from the organisation to which they advocate for a patient. Have we not finally accepted that we need complete independence, including resourcing and finances, in such cases? Let us be honest in that somebody makes a decision about how much an organisation gets. If it does not get enough, the organisation cannot do its job correctly. How independent can a body be if it is fundamentally dependent on getting resources from an organisation it must hold to account?

**Deputy Sandra McLellan:** I thank the delegation for the presentation. We have had some really good presentations this morning, outlining many problems and offering a number of solutions. We had a very lengthy discussion that ran on past noon. I will mention a few issues that arose. Deputy Kelleher mentioned how we, as public representatives, try to act on behalf of vulnerable people. Relatives might contact us as a last resort and, on occasion, it can be quite difficult for us to navigate the health system. Another point was made this morning regarding one of the services run by Ms Eileen Fitzgerald that sometimes front-line staff working in hospital services and local managers are unaware of the inclusion of advocacy in service agreements and the role we might play. Sometimes we might make representations and receive no reply because the staff do not recognise what we are trying to do and that we are looking to help. It is an issue.

A point made about the issue of complaints by the Ombudsman, Mr. Peter Tyndall, was that people find it hard to navigate the complaints system or do not know how to make a complaint in hospitals. People are often nervous of making such complaints because of the potential knock-on effect on care for a person. As Deputy Kelleher noted, as everybody knows everybody else, people might be afraid of getting a person working in the care system into trouble.

We must address this issue and make it easier for people. In the course of the study by the Ombudsman, it emerged that 800 different people deal with complaints in the HSE. That is the reason I welcome, on the back of the study, that the HSE has established a national complaints management office and I hope it will be easier for all of us to access it. I also hope it will be fully aware of advocacy and be happy to deal with the public representatives.

How will advocacy be funded and will funding be guaranteed? What will the training and professional background be of advocates? This morning I asked about how we can measure the quality of advocates. Another issue I raised concerned migrants and the diversity in our country. How do we match advocates to that?

**Deputy Seamus Healy:** We all understand that the complaints area for the health service is particularly difficult. Individuals feel it can be a maze and lead to a significant ordeal if they undertake a complaint. In very many cases, either patients or relatives have a fear of raising issues. For example, they may fear a difficulty for themselves or relatives as patients. There is little support, if any, for assisting a person who wishes to make a complaint. It is a complex process and it tends to take a significant amount of time. It can be an ordeal.

Access to advocacy services in such a context is very important. Will the HSE make infrastructure available at hospital or community care level to assist people in this area? People are often unaware of where to start or where to get information about this area. The provision of some sort of infrastructure at local HSE level is vital. Does the HSE intend to provide an office at the local level where people can be advised of their rights or procedures and steps they might wish to take? Perhaps an advocate could be available to help them in that regard?

Mr. O'Brien raised the question of funding of advocates and groups a number of times. I certainly have the very strong view that advocates and groups should be publicly funded but not through the HSE. I have not had a good experience of this process in the past, although it is not a large number of incidents. In one case in which I have been very strongly involved I had a very bad experience with respect to the funding of groups that claim to advocate on behalf of patients. I strongly call for public funding in this area other than from the HSE.

On the issue of complaints with respect to the HSE, there is a need, and space, for mediation by HSE personnel at local level. When an incident or complaint arises initially, there appears to be little or no consultation, information or mediation at an early stage. If it there was and if there was more openness at an early stage, a significant number of complaints and concerns could probably be addressed at that stage and people would be satisfied that the complaint would be taken on board and a similar complaint would not arise in the future.

**Deputy Dan Neville:** I thank Mr. O'Brien and Mr. Lynch for their attendance and contributions. I would like to deal first with the area of data protection. This issue arose earlier and, for the information of the HSE, the then Ombudsman made it quite clear that in respect of any representations made by a public representative, there was an implication that the constituent had given permission by way of contacting the public representative. At earlier stages in the operation of the HSE, letters were sought from everybody we would represent giving permission, but the Ombudsman, in writing and at a meeting of the Committee on Procedure and Privileges, made it quite clear that a representation made to a public representative indicated that there was implied permission for full disclosure of any information. There is a letter to that effect from the previous Ombudsman.

The issue of a culture of complaints has been dealt with, but the word "complaint" may be the wrong one in this context, as it conveys the message that the complainant is a bit of a nuisance and that he or she is trying to find something about which to complain. However, that is way it is and that is the word that is used. "Concern" might be a better word if we could change the approach to this. A culture of complaints implies that a complainant is one of those people who always complains about everything, although, in fact, people are very slow to complain within the health services because of the delicacy of what is involved. It is only in extreme cases that complaints are made. As was mentioned, there is a fear of retribution. How many of us have found that a person, on calling to see us to make a complaint, has suddenly pulled back from doing so when we say that we will deal with it? They say they do not want to proceed and that they will leave it. It is very frustrating for a public representative who knows that there is something wrong, because the first thing one will be asked on making a complaint is the case concerned and the name of the person involved, which is fair enough. We do not want people walking in off the road saying that they want to make a complaint if they have an issue, although I am not saying that is wrong. That is very frustrating for us and I do not know how we can get over it, but we should be conscious that people are very reluctant to complain. That also inhibits the HSE from being informed of difficulties on the ground. In the previous discussion I dealt with the issue of mental health, the mental health services and the culture of secrecy around communicating with the patient. In one case involving an inpatient, the medics almost spoke over the patient suffering from a mental health difficulty, as if they were not cognisant of or did not understand what was happening.

Another issue I raised earlier was that of communication with carers in the context of after-care for people who are discharged from a mental health inpatient facility. I refer to instances in which a psychiatrist says that a matter concerning a patient is confidential and they cannot

discuss it. They will not even ask the patient for permission to discuss it; they just close down. This does not relate to all psychiatrists; if I were to put a figure on it I would say it applies to around 60% of them, because we have some very good psychiatrists, and I know many of them. It is very difficult and frightening for many people who are not engaged in the mental health services or with the illness that is mental illness. It is because of a tradition going back 20 years before my mother became a psychiatric nurse, when mental health facilities were known as lunatic asylums. We are coming from that era and that attitude. We know about the stigma attached to mental illness and we also know what HSE is doing through the See Change campaign. I will not go into that discussion, but there is that issue. There is an issue around communication with carers in terms of aftercare and how they are informed.

The Irish Advocacy Network, which is a peer advocacy group for mental health services, has not appeared before the committee. If the representatives have any comment to make on their experience of that network, I would welcome hearing it.

With respect to the appointment of Leigh Gath, I must declare an interest because I know her very well. Anyone who wants to study a person who had a serious disability but overcame it very well should read her biography. Hers was an inspired appointment. She is dealing with residential facilities. Do the representatives have any plans in the future to build up that service outside of the residential area? That would be a channel through which we could have the nucleus of a broader advocacy area, which, while semi-independent-----

**Chairman:** Go raibh maith agat.

**Deputy Dan Neville:** The Chairman is telling me that I have talked for too long.

**Chairman:** No; the Deputy is fine.

**Deputy Dan Neville:** We heard from several organisations today which are all doing very good work, and their representatives made very good presentations. I do not know how many more such organisations there are from which we have not heard. I would like to ask about the diversity of the organisations. There is obviously a similarity among them due to the fact that they are engaged in the same work, but now there are many such organisations, and while I would not say there is duplication of the work, there could be a move towards that. That applies to other areas as well and not only to advocacy. In the matter in which I have an interest, that of suicide prevention, there are more than 200 organisations around the country, which is also a concern. It needs to be examined in a way that is supportive of them and that allows them to be assisted. Have the representatives any comment to make on the diversity of the organisations in the advocacy area? Four or five organisations contacted us about today's discussion, but how many similar organisations are there? I know of the Irish Advocacy Network but I do not know much about it other than that it advocates for mental health services.

**Senator Colm Burke:** I apologise for not being here for the presentation, but I read the documentation furnished to us. On the issue of reviewing incidents in which something goes wrong in a hospital, I mentioned earlier today a case in which it was decided within the hospital that there should be a review and two people were to do the review, but it was then decided that there should be an external review, and an external reviewer was appointed. Someone in administration up along the line has now overruled the appointment of the external reviewer. This has been done without any logical explanation in real terms. Eight or nine months after the incident occurred, no information has been given to the people concerned. This type of delay is going to lead to litigation. It is happening within the HSE, particularly in maternity

services. Some bigger units are dealing with such volumes that there seems to be a delay on each occasion. Those who are trying to do the review are reluctant to talk to the parents or provide information to them. It does not seem that this is being dealt with sufficiently quickly. I wonder if something can be done to make sure this is dealt with in a timely manner. Can people be assured that these cases will be concluded within a particular time period? It does not matter whether the period in question is two months or three months, as long as there is a deadline.

I would like to mention a second issue, about which I have previously spoken.

**Chairman:** I remind the Senator that there is a vote in the Seanad.

**Senator Colm Burke:** I will conclude on this point. I refer to delays in the holding of inquests. I know it is outside the control of the HSE. In fairness, the vast majority of coroners are extremely efficient and good. In some parts of the country, there are substantial delays in the holding of inquests by coroners. It is not because of a lack of information from the HSE. There is no statutory requirement on coroners to hold inquests within a certain timeframe. I suggest that such a requirement needs to be put in place in the interests of everyone working in the HSE, especially staff members who are at the coalface dealing with the relatives of people who have died. It is something that should be examined. If there is a need to change the relevant legislation, that should be set out. I will leave it at that. I thank Mr. O'Brien for the time and effort he is devoting to dealing with this area. I know he has brought about many changes which are for everyone's benefit. I think we need to do a few more things to bring the service up to what we require.

**Chairman:** Before Mr. O'Brien responds to Senator Burke, who has to go to vote in the Seanad, I ask him to make a brief comment on the role played by the national advocacy unit of the HSE.

**Mr. Tony O'Brien:** I will cover that issue as I go along, if that is all right. I would like to respond jointly to the points made by Deputies Kelleher and Neville. In any commercial enterprise, a complaint would be regarded as a gift from a customer and considerable investment would be made to reap the benefits of it. I agree absolutely that complaints should be perceived in that way. I also agree that this is not how they are universally perceived at present. We are on the same page there. Equally, I agree that we have a system which is capable of too quickly turning a request or a concern into a complaint, thereby putting it into a highly formalised process set down by legislation. This is equally unhelpful. I will use a particular example to illustrate this. It was put to me recently when I was visiting a service. A service user who was visiting an outpatient service had a particular need to sit down, but there was a shortage of seats. Her physical circumstances meant that she needed a seat. When she approached the desk to express her requirement for a seat, rather than someone getting her a chair it was suggested that she might be given a complaint form. Hopefully that is an extreme example, but it speaks to what I am saying about simple requests or concerns being too quickly turned into complaints and channelled down from there. It is important that as we address this issue at large, we do not institutionalise the process of dealing with feedback, concerns or requests. Complaints should become complaints when it is appropriate that they are dealt with as complaints, rather than because that is the easiest way to deal with any representation in the broadest sense of the word from an individual using a service.

Deputy Kelleher is right when he says that the HSE is a monopoly provider in the sense that it is the provider of last resort. I agree that this creates a sense of dependence on the part of those who use the HSE's services, particularly when there are areas in which demand for

services exceeds current supply, as we all know. This results in waiting lists, which, in turn, results in a sense that there are discretionary decisions to be made. Regardless of whether this concern is actually founded or likely to be the case, it is not unreasonable that an individual would be concerned that discretionary decisions might not go his or her way in the future if he or she is perceived to be a complainant. That is one reason it is critically important that there is access to advocates, in the sense of the word as we are using it today.

The current formal complaints process is, in effect, laid down by the Health Act 2004. It is, by definition, extraordinarily complex. It provides for a necessity to go off in all sorts of different directions, depending on what the complaint is about. In the past fortnight, the Minister announced his intention to make the necessary legislative change to simplify that process. That will be followed through on with the simplification of the ability go on to the second tier - the Ombudsman - regardless of what the complaint is about. This will bring an end to the approach which means, in effect, that the standard complaints procedure cannot deal with a matter that is in any way clinical. Such cases had to be dealt with on an *ad hoc* basis, and whatever we did or did not do was not then subsequently appealable to the Ombudsman. If we make a single doorway or pathway for complaints, it will inevitably make the whole process much easier. We strongly welcomed and indeed advocated for the simplification that was announced recently. A single portal for complaints, *healthcomplaints.ie*, will be given additional investment under the supervision of the Ombudsman to make it a more realistic pathway to get in.

That 800 different complaints persons were identified in the Ombudsman's report is to some extent a legacy issue. As we create more fully the hospital groups and the community health organisations, it is intended that there will be a single identified co-ordinator for all complaints in each of those health delivery entities, just as there will be in the ambulance service and one or two other specialist national services. Mr. Lynch will say a little more about this approach, which will bring absolute standardisation across the system but not in a way that makes it harder to navigate. It is designed to make it easier.

To be honest, I had not been aware of the perceived changes that have increased the barriers to public representatives raising complaints. Now that I am aware of this factor, I will seek to do something about it. Questions can come back at times if it is not clear that the representation is being made on behalf of the person who is the service user. As someone who deals with many representations, I know it is not always entirely clear from the information provided who the individual is or what the service is. Sometimes there will be a requirement to come back looking for more information. There should be no objections in principle to making progress with concerns raised by public representatives. If such objections exist, I ask public representatives to let my office know and we will seek to ensure they are unblocked.

With regard to funding, we agree that advocacy services should be funded in a way that is independent of the service provider. In other words, they should be funded independently of the HSE and entities funded by it. At present, we fund many advocacy services for the simple reason that if we were not doing so, it is probable that nobody would be doing it and that would be worse. Under the initiative announced by the Minister two weeks ago, this will be brought under the national patient safety office. That office will be part of the Department of Health, which is not a service provider. Obviously, the Minister is directly accountable to the Oireachtas in a way that we are not. Advocacy services will be publicly funded through the mechanism in question. It is likely that some of the funding we currently provide will be lifted out of our budget. It will go back into the Department's budget so that no one loses out as a result. We will do some work on this in the period of preparation. We fund advocacy of all sorts of clients.



Not all of it is the type of advocacy we are talking about here. Many of the thousands of entities we fund are engaged in different types of advocacy. We would not that to be disrupted.

We are fully committed to the implementation of the recommendations on complaints contained in the Ombudsman's report. Mr. Tyndall was kind enough to invite me to speak at the launch of that report and we committed ourselves very firmly to it. Mr. Lynch, our national director for quality assurance and verification, is leading out on that.

I will seek to get information from Senator Colm Burke on the individual review he mentioned in order that we might address the matter. We are changing the way we resource reviews because with the traditional methods, there will inevitably be delays because a small number of people are being asked to do a great many external reviews. We have established a new process and Mr. Lynch will speak about it.

The coronial process of inquests is, of course, fully independent and quasi-judicial. We fully respect the independence of coroners but agree, as a general principle, that it is desirable that inquests should be held and brought to conclusion as soon as is practically possible following the event that is being inquired into so that the lessons learned and the recommendations can be obtained by the service providers. I am very conscious that the period leading up to or waiting for an inquest is a particularly stressful period for the surviving relatives in those situations. It is, therefore, generally desirable that it should be brought forward.

I do not know the overall level of funding that will be provided for advocacy under the national patient safety office as those decisions have yet to be made. I think we can be assured, however, that it will be a greater sum than the current sum in aggregate.

**Chairman:** There is a vote in the Dáil.

**Deputy Seamus Healy:** We should finish.

**Chairman:** I will allow Mr. O'Brien to conclude

**Mr. Tony O'Brien:** I will ask Mr. Lynch to speak quickly about how we will handle reviews.

**Mr. Patrick Lynch:** I am aware from previous appearances that this is an area of interest to the committee. In most cases, issues around reviews arise for two reasons. The two things required from a review are, first, to establish if there are any underlying safety issues in a particular service which might impact on other people and, second, to give answers to the individuals concerned who may have been impacted upon or, as in some instances, harmed as a result of an incident. We have a process in place with a 120-day target. We are measuring that. We will be producing a report shortly which, for the first time, will begin to give us more data in what is happening across the system. This will be the first time we will ever have that level of detail. We are signalling to people that in the midst of a process, where timeliness is important, there can be issues of delay that we are trying to overcome. However, that is no excuse for a failure to communicate and involve people in the process the whole way through. That is an area of focus. Second, in terms of reviews - this will apply to the disability services initially - we are establishing a national independent review panel that will be modelled on the panel that is in place in Tusla. That panel, which will deal with incidents of a very serious nature, will be recruited through the Public Appointments Service and will be completely independent and report to the risk committee of the HSE. The planning for it is already in place and we hope it will be established in 2016. It is a significant area of focus for the HSE at present.

INDEPENDENT ADVOCACY SERVICES FOR HEALTH SERVICE USERS: DISCUSSION

**Mr. Tony O'Brien:** The risk committee was established under 2013 Act. It is externally chaired and has a majority of members who are not HSE employees.

**Chairman:** I thank Mr. O'Brien and Mr. Lynch for participating in this work.

The joint committee adjourned at 12.55 p.m. until 4 p.m. on Tuesday, 1 December 2015.