



Tithe an
Oireachtais
Houses of the
Oireachtas

Tithe an Oireachtais

An Comhchoiste um Shláinte agus Leanaí

Tuarascáil maidir le Ról na Habhcóideachta i dtaca le Seirbhísí Sláinte agus Cúraim Shóisialaigh in Éirinn

Eanáir 2016

Houses of the Oireachtas

Joint Committee on Health and Children

Report on the Role of Advocacy in Health and Social Care Services in Ireland

January 2016

31HHCN024

CHAIRMAN'S FOREWORD



Advocates can play an important role in helping to support and empower vulnerable people who use our health and social services. An independent advocacy service can help patients to have their say on their own care, to access services that they need, or to make a complaint about an aspect of care.

Last year, on November 26th, the Health Committee met with a range of stakeholders to discuss advocacy in the Irish health service. This report explains the role of advocacy in the Irish health and social services, and examines different advocacy models used in other countries.

The discussions identified a number of issues that need consideration at national level. These include the need for formal acknowledgement of advocates, and the lack of co-ordination, and oversight in existing advocacy services. This report makes a number of recommendations, for consideration by the Minister for Health and the Health Service Executive, to support and enhance the effectiveness of advocacy services in the Irish health service.

I would like to thank all the witnesses who attended our hearings, for their contributions to this important issue. The links to the oral presentations made at the hearings, along with the transcripts of those hearings are appended hereunder as the basis of the Joint Committee's report.

I would like to thank all the members of the Joint Committee for their contributions and co-operation on this report. I would also like to thank the Oireachtas Library and Research Service, the Clerk to the Committee and the staff of the Committee Secretariat for their assistance in the production of this report.



Jerry Buttimer, T.D.
Chairman
Joint Committee on Health and Children

Joint Committee on Health & Children

31ST DÁIL MEMBERS OF THE JOINT COMMITTEE ON HEALTH AND CHILDREN			
			
Catherine Byrne TD (Fine Gael)	Ciara Conway TD VICE CHAIR (Labour)	Joe Costello TD (Labour)	Clare Daly TD (Independent)
			
Regina Doherty TD (Fine Gael)	Peter Fitzpatrick TD (Fine Gael)	Seamus Healy TD (Independent - WUAG)	Billy Kelleher TD (Fianna Fáil)
			
Eamonn Maloney TD (Independent)		Sandra McLellan TD Sinn Féin	
			
Mary Mitchell O'Connor TD (Fine Gael)	Dan Neville TD (Fine Gael)	Caoimhghín Ó Caoláin TD (Sinn Féin)	Robert Troy TD (Fianna Fáil)

Joint Committee on Health & Children

			
Senator Colm Burke (Fine Gael)	Senator Thomas Byrne (Fianna Fáil)	Senator John Crown (Independent)	Senator John Gilroy (Labour)

	
Senator Imelda Henry (Fine Gael)	Senator Jillian Van Turnhout (Independent)

TABLE OF CONTENTS

CHAIRMAN'S FOREWORD	2
31ST DÁIL MEMBERS OF THE JOINT COMMITTEE ON HEALTH AND CHILDREN	3
EXECUTIVE SUMMARY.....	7
COMMENTS AND RECOMMENDATIONS.....	9
INTRODUCTION	10
MODELS OF ADVOCACY	13
ADVOCACY FOR USERS OF HEALTH AND SOCIAL CARE SERVICES IN IRELAND.....	15
CHALLENGES IDENTIFIED BY STAKEHOLDER IN THE CURRENT PROVISION OF ADVOCACY SERVICES	20
PLANS TO ESTABLISH A NEW NATIONAL PATIENT ADVOCACY SERVICE	22
STAKEHOLDER RECOMMENDATIONS	24
APPENDIX 2: DETAILS OF PATIENT SAFETY PLANS AS ANNOUNCED BY THE MINISTER	26
APPENDIX 3: PATIENT ADVOCACY SYSTEMS INTERNATIONALLY	27
LINKS TO TRANSCRIPT AND OPENING STATEMENTS OF THE COMMITTEE MEETING	32
BIBLIOGRAPHY.....	33

EXECUTIVE SUMMARY

ADVOCACY

Making your wishes known to any institution may be daunting, but particularly so when a person is ill, has a disability, or is vulnerable. People may also lack the skills or knowledge needed to successfully raise an issue with a hospital or service provider.

On 12th November 2015 the Minister for Health, Dr. Leo Varadkar, T.D., announced that there would be a new national advocacy service. The new advocacy service is intended to be independent of the HSE and the Department of Health, as recommended by the HIQA Report into safety and standards in Midlands Regional Hospital, Portlaoise (2015).

This report from the Joint Committee on Health and Children aims to help define advocacy in an Irish health service context; considers the role that an advocate plays; and examines different models of advocacy.

At the Health Committee meeting to discuss advocacy, the Ombudsman, Mr. Peter Tyndall, defined advocacy as follows:

“Advocacy is about supporting people to say what they want, to represent their interests, secure their rights and obtain services they need. It promotes social inclusion, equality and social justice. Having an independent advocate who is trained to a high standard and who is supported in their work means that patients who are vulnerable have a voice. It also means that complaints which they make in the interest of patients are framed in a clear and concise way.”

In discussions with the Committee, stakeholders identified a lack of co-ordination, consistency and oversight in existing advocacy services. They also highlighted a number of steps currently being taken to develop a streamlined complaints system across the health service.

This report makes a number of recommendations, for consideration by the Minister for Health and the Health Service Executive, to support and enhance the effectiveness of advocacy services in the Irish health service.

ROLE OF AN ADVOCATE

- The role of an advocate in a hospital context is to support the patient and empower them to know their rights, make their wishes known, access information or services, or to make a complaint.
- Advocacy therefore is not just about handling patient complaints, providing information or advice - though an advocate may do one or all of these things.

- There are many forms of advocacy but an underlying principle is the representation and empowerment of vulnerable people. Independence is also a key part of a successful patient advocacy system.
- Advocacy is closely associated with the concept of patients' rights, which aim to ensure that patients are supported and informed over the course of their consultation and treatment.
- Internationally there are a number of well-developed patient advocacy systems, some of which operate through a Patient Ombudsman.
- Over recent decades there have been a number of international charters and declarations setting out standards around patients' rights.
- In Ireland, a Patient's Charter was published in 1992 by the Department of Health. The HSE published a new charter in 2010, entitled *"You and your health service."*
- Based on international best practice, an effective patient advocacy service should be:
 - Well-advertised and known to patients
 - Person-centred
 - Accessible to all
 - Independent and without conflicts of interest
 - Sufficiently funded with a reliable revenue stream
 - Staffed with well-trained advocates
 - Supportive of self-advocacy and empowerment

COMMENTS AND RECOMMENDATIONS

1. The Joint Committee on Health and Children acknowledges the important role that advocates can play in supporting decision-making by people with disabilities, vulnerable patients and users of health and social services.
2. The Committee welcomes the decision to extend the remit of the Office of the Ombudsman to clinical cases.
3. Ideally, there should be a single pathway for complaints. The Committee welcomes closer collaboration between the HSE and the Office of the Ombudsman to streamline the complaints process within the health service. The Committee supports the further development of the www.healthcomplaints.ie website to help achieve this.
4. The lack of statutory powers for advocacy are considered to be a barrier which can prevent advocacy services from accessing or acting on behalf of people with disabilities. Consideration should be given to commencing the relevant section of the Citizens' Information Act 2007 in order to resolve this issue.
5. At present, there is no statutory obligation on HSE hospitals or other care settings to acknowledge the input of independent advocates, including advocacy organisations, or voluntary advocates, when they seek to support services. The HSE should consider giving formal recognition to the role of advocates so that, for example, this is reflected in hospital guidelines on patient care, and in training for all professional medical staff.
6. The Committee is concerned at difficulties experienced by a number of parliamentarians, in making representations to the HSE on behalf of health service users. Representation and advocacy is a fundamental part of the role of elected parliamentarians. It is recommended that the HSE work with the Joint Health Committee to ensure that Oireachtas members are supported in making appropriate representations on behalf of service users.
7. Any new patient advocacy service should be independent of the Health Service Executive. Funding should be ring-fenced and independent of the service provider to support its activities and to ensure its independence.
8. Stakeholders identified the importance of setting common standards and a code of practice for advocacy services. It is recommended that the national patient advocacy service help to co-ordinate advocacy services, and develop a Code of Practice for advocacy services in agreement with a range of national stakeholders. This would ensure that all professional and voluntary advocates operate to the same ethical and legal standards.

INTRODUCTION

On 26th November the Joint Committee on Health and Children ('the Committee') met with stakeholders, for the first time, to discuss the role of advocacy in health and social care services.

This Joint Committee report is based on the content of these meetings, written submissions and additional secondary research by the Library and Research Service. There is often confusion around the concepts of advocacy and mediation.¹ At the outset, therefore, it is useful to look at a number of definitions of advocacy.

DEFINITIONS OF ADVOCACY

Advocacy may be defined as any action that helps individuals to:²

- get the information they need;
- understand their rights;
- make their own choices; and
- voice their opinions.

Advocacy is distinct from mediation, the handling of patient complaints, or providing information. This is because the role of an advocate should also be to empower the service user to access or use such information or advice.³ A mediator is required to be neutral, so that they can resolve a conflict, while an advocate should be partial to the person they are representing.⁴ However, in practice, this distinction is not so clear and many stakeholders see mediation as an important function of advocacy.⁵

¹ Drage, J. (2012). New Zealand's National Health and Disability Advocacy Service: A successful model of advocacy. See <http://www.hhrjournal.org/2013/08/19/new-zealands-national-health-and-disability-advocacy-service-a-successful-model-of-advocacy/>

³ Citizens Information. (2010). PathFinder: Evaluation of the Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector. See http://www.citizensinformationboard.ie/mwg-internal/de5fs23hu73ds/progress?id=8RzzNrDbCYRp54ErkN2RaJTnKkMiwro7tyk-2P3j_6g,

⁴ Ibid.

⁵ Citizens Information. (2010). PathFinder: Evaluation of the Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector. See http://www.citizensinformationboard.ie/mwg-internal/de5fs23hu73ds/progress?id=8RzzNrDbCYRp54ErkN2RaJTnKkMiwro7tyk-2P3j_6g,

THE ROLE OF AN ADVOCATE

The role of an advocate is generally seen to include pleading on behalf of others and making sure that the right procedures are followed within health and social care services.⁶ According to the Ombudsman, Mr. Peter Tyndall,⁷ advocates can also help to avoid poor communication which often leads to complaints by ensuring that patients get full and clear explanations early on.

Speaking to the Committee on 26th November 2015, Mr. Mervyn Taylor of Sage said:

“Independent advocacy must be distinguished from the work of staff responsible for complaints and from day-to-day work of professionals and health and social care providers who can advocate on behalf of individuals up to a certain point but beyond that, a conflict of interest can arise.”

On representative advocacy, Eileen Fitzgerald, of the Citizens’ Information Board, stated that:

“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”.

ADVOCACY AND PATIENTS’ RIGHTS

Advocacy is closely associated with the concept of patients’ rights, covering aspects such as: human rights and values; information; consent; confidentiality and privacy; care and treatment; patient safety and application.⁸

Over the past number of decades there have been a number of prominent international charters and declarations setting out standards around patients’ rights, such as:⁹

⁶ <http://www.nhs.uk/conditions/social-care-and-support-guide/pages/advocacy-services.aspx>

⁷ Written submission received by the Committee.

⁸ Office of the Ombudsman Ireland: the rights of patients. Accessed on 17th November 2015 at <https://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/Report-to-the-Health-Service-Executive-concerning-complaints-against-the-Public-Health-Service/The-Rights-of-Patients.html>

⁹ Ibid.

- the Declaration of March 1994 on the promotion of patients' rights in Europe which emerged from an initiative of the World Health Organisation;
- the Council of Europe's 1997 Convention on Human Rights and Biomedicine; and
- the European Charter of Patients' Rights, drafted under the auspices of an Italian-based NGO called the Active Citizenship Network.

MODELS OF ADVOCACY

Many stakeholders regard advocacy as a spectrum with a range of different degrees of support. A common principle which underpins all models of advocacy is the *representation* and *empowerment* of vulnerable people.¹⁰ The most commonly cited forms of advocacy are presented below:

- **Self-advocacy:** individuals are supported so that they may represent and speak up for themselves (individually or collectively). This is generally seen as the ultimate goal.
- **Peer advocacy:** the advocate has personal experience of the same issue.
- **Family advocacy:** a community based model where family members advocate on behalf of another member of their family.
- **Legal advocacy:** seeks to uphold the rights and interests of people on a one-to-one basis by addressing legal aspects of instances of discrimination, abuse and neglect.
- **Systemic advocacy:** seeks to achieve long-term, structural changes that remove barriers and address discriminatory practices. This could include lobbying at political level.
- **Citizen advocacy:** volunteers are matched with an individual, so that they might represent that individual's views, for an extended period of time.
- **Instructed advocacy:** advocates act on the lawful instructions of the individual.
- **Non-instructed advocacy:** advocates act independently of the individual as the individual may be incapacitated or lacking the skills to advocate for themselves.
- **Empowerment advocacy:** emphasises the sharing of resources and information, as well as teaching individuals the skills needed to facilitate their own empowerment.

These models are not mutually exclusive. For instance, citizen advocacy would fall under non-instructed advocacy, while legal advocacy (work that is undertaken by lawyers) is a form of instructed advocacy.¹¹

Advocacy can also be further divided into two predominant forms: 'Case' and 'Cause.'¹² Case advocacy is focused on the individual whereas cause (or systemic) advocacy is issue-based.

¹⁰ Comhairle. (2003). Jigsaw of Advocacy: a research report. See http://www.citizensinformationboard.ie/downloads/Jigsaw_Advocacy.pdf

¹¹ Drage, J. (2012). New Zealand's National Health and Disability Advocacy Service: A successful model of advocacy. See <http://www.hhrjournal.org/2013/08/19/new-zealands-national-health-and-disability-advocacy-service-a-successful-model-of-advocacy/>

Debate around independence of any potential advocacy service

The independence of advocates is a major issue in the debate:

“The independence debate has focused on whether advocates have a conflict of interest between those they are advocating on behalf of and those who fund their employment (plus other workplace tensions).”¹³

In his evidence to the Joint Committee, Mr. Tony O’ Brien, HSE, stated that self-advocacy represents the most desirable solution for patients:

“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.”

However, he stated that, in practice:

“...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 healthcare system or in understanding the care options open to them....”

He also pointed out that, if the HSE did not fund a number of advocacy organisations, they would not be able to carry out their work.

In an oral answer to a PQ on 28th May 2015, the Minister for Health, Dr. Leo Varadkar, T.D. said:¹⁴

“I am strongly of the view that any new patient advocacy service should be set up independent of the HSE from the outset.”

The general consensus in the Committee meeting was that an independent advocacy system was very desirable, in line with the stated position of the Minister.

¹² Ibid.

¹³ Drage, J. (2012). New Zealand’s National Health and Disability Advocacy Service: A successful model of advocacy. See <http://www.hhrjournal.org/2013/08/19/new-zealands-national-health-and-disability-advocacy-service-a-successful-model-of-advocacy/>

¹⁴ PQ 28th May 2015, see <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2015052800004?opendocument>

ADVOCACY FOR USERS OF HEALTH AND SOCIAL CARE SERVICES IN IRELAND

This section looks at some of the more prominent State-funded, national advocacy services.

NATIONAL ADVOCACY SERVICE (NAS): THE CITIZENS INFORMATION BOARD

The Citizens Information Board (CIB) is the statutory body responsible for supporting the provision of information, advice and advocacy services to all citizens. One of the functions of the CIB, as defined in the *Comhairle Act 2000* and the *Citizens Information Act 2007*, is to directly provide or support the provision of advocacy services to individuals, and assist those with a disability to secure their entitlements to social services.¹⁵

Between 2005 and 2010 CIB developed and funded a pilot programme of 46 advocacy projects for people with disabilities in the Community and Voluntary sector.¹⁶ The evaluation of this pilot was published in 2010 as *Evaluation of the Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector*.¹⁷ The report recommended the establishment of a single service to provide improved advocacy services to people who need them, regardless of location, disability type or level of vulnerability.¹⁸

The National Advocacy Service (NAS) was established in 2011 on foot of this report.¹⁹

The aim of the National Advocacy Service is to ensure that people with disabilities have a voice and that their rights are safeguarded.²⁰

¹⁵ PQ 14th January 2015. Ref Nos: 49655-14/ 1516-15/1517-15

¹⁶ Citizens Information Board. (2012). National Advocacy Service for People with Disabilities Annual Report 2012. Accessed on 11th November 2015 at http://www.citizensinformationboard.ie/publications/advocacy/NAS_AnnualReport_2012.pdf

¹⁷ Citizens Information. (2010). PathFinder: Evaluation of the Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector. See http://www.citizensinformationboard.ie/mwg-internal/de5fs23hu73ds/progress?id=P8NIAh4XaY55Ntl53A3bXltpn4M_z02bZSyzXKlhhUY,

¹⁸ PQ 14th January 2015. Ref Nos: 49655-14/ 1516-15/1517-15

¹⁹ Flynn, E. (2012). National Advocacy Service in the Spotlight. See <http://humanrights.ie/mental-health-law-and-disability-law/national-advocacy-service-in-the-spotlight/>

²⁰ Ibid.

The NAS has 45 staff and its office is located in Dublin.²¹ The service is managed by five Citizens Information Services in Dublin (Clondalkin), Westmeath, Offaly, Waterford and Leitrim and staffed by five Managers, 35 advocates (FTE) and five administrators.²²

Between 2011 and 2015, the National Advocacy Service has engaged extensively with over 2,000 people with “disabilities who are isolated from their community and services, have communication differences, are inappropriately accommodated, live in residential services, attend day services and have limited or no natural supports” (Eileen Fitzgerald, Opening Statement).

During 2014, the NAS provided an advocacy service to 1,012 people, 340 of which were new cases. Overall 28% of advocacy services related to housing issues, 19% related to health issues, 13% related to social welfare, 11% to justice issues and 7% related to court cases regarding children.²³

FUNDING AND TYPES OF CASES DEALT WITH

The budget allocation to the NAS for 2013, 2014, and 2015 was: €3,058,958, €3,077,266 and €3,135,748 respectively.²⁴

Box 1 provides detail on the Advocacy Unit in the HSE which, is, in effect, a patient complaint handling service rather than an advocacy service.

²¹ Ibid.

²² Citizens Information Board. (2012). National Advocacy Service for People with Disabilities Annual Report 2012. Accessed on 11th November 2015 at http://www.citizensinformationboard.ie/publications/advocacy/NAS_AnnualReport_2012.pdf

²³ PQ Ref Nos: 10385-15/10388-15

²⁴ Figures provided in response to a PQ by the Tánaiste and Minister for Social Protection Ms. Joan Burton, T.D. on 21st October 2015.

BOX 1: NATIONAL ADVOCACY UNIT IN THE HSE

The National Advocacy Unit in the HSE (formerly called Consumer Affairs) manages patients' complaints within the HSE. It is currently in the process of changing its name to more properly reflect its function.

If a patient is unhappy with the way their complaint was handled at point of care they can contact the National Advocacy Unit within the HSE. The National Advocacy Unit will appoint an independent officer to review the complaint.²⁵ The Executive also has a National Safety Incident Management Policy which sets out the steps to be taken in an investigation.

As the unit is part of the HSE, it is not independent. When independence from the HSE is required, the HSE policy provides for national and international experts to be part of reviews.²⁶ If an individual is still unhappy with the outcome of this process he/she can request an independent review of the complaint from the Office of the Ombudsman.

In addition, www.healthcomplaints.ie is an on-line information service which was developed by the Office of the Ombudsman in cooperation the Department of Health and the HSE. The website has been developed for people who use health and social care services in Ireland, as well as for their families, care-givers and advocates. It is planned to develop this website as a single portal for making complaints in future.

²⁵ Written answer to PQ dated 28th April 2015, Ref Nos 16620/15.

²⁶ Ibid.

SAGE ADVOCACY SERVICE

Sage provides support and advocacy services to older people and operates under the governance of Third Age. It receives funding from the HSE and Atlantic Philanthropies and is being developed to provide advocacy services to older people in a number of settings including: in their own home, acute hospitals, long stay residential units, primary care centres and in the community.²⁷

Underlying principles of the service are:²⁸

- Person-centred support.
- Acting professionally and ethically.
- Empowering older people individually and collectively.
- Protecting and promoting the rights of older people.
- Acting always in a 'duty of care' role.
- Ensuring the wishes and preferences of individuals are taken into account.
- Protecting older people from all forms of abuse.
- Maintaining independence from service and resource providers.
- Maintaining confidentiality.
- Acting with competence and compassion.
- Being accountable for the support provided.
- Building relationships of trust and respect.

Sage also aims to develop linkages with existing advocacy support providers at national and local levels, including, in particular:

- HIQA (in relation to developing and implementing National Quality Standards for Support and Advocacy Work with Older Persons).
- HSE (in relation to implementing the *Safeguarding Vulnerable Persons at Risk of Abuse National Policy & Procedures*).
- The National Advocacy Service for People with Disabilities (NAS).
- The Carers Association.
- The Alzheimer Society of Ireland.
- Age Action.
- Local partnership, development and social inclusion groups.

²⁷ Sage. (2015). Policies and Operational Guidelines. Accessed on 11th November 2015 at http://www.thirdageireland.ie/assets/site/files/pr/Sage_Policies_Operational_Guidelines_Draft_6_effective_290115.pdf

²⁸ Ibid.

INCLUSION IRELAND

Inclusion Ireland is a national advocacy organisation which works to promote the rights of people with an intellectual disability and their families. Inclusion Ireland is also an umbrella group for individuals and organisations in the intellectual disability sector. Inclusion Ireland's approach to advocacy is about building capacity and empowerment of parents and family members. It also works to change laws, policy and practice which discriminate against people with disabilities.

According to the HSE's Annual Report for 2014²⁹, Inclusion Ireland received a revenue grant of €430,000 from the HSE in 2014.

IRISH ADVOCACY NETWORK

The Irish Advocacy Network Ltd is an island-wide, independent, mental health organisation led by people with personal experience of mental health difficulties. As such it is a peer advocacy service that aims to help people with mental health difficulties to self-advocate.³⁰ It offers services in 25 counties in the Republic (there is no service in Donegal). It also offers a service in Belfast.

FUNDING OF THE IRISH ADVOCACY NETWORK

According to the HSE's Annual Report for 2014³¹ the Irish Advocacy Network received a revenue grant of €799,000 for 2014.

²⁹ HSE.(2015). Annual Report and Financial Statements 2014. Accessed on 11th November 2015 at http://www.hse.ie/mwg-internal/de5fs23hu73ds/progress?id=i5KINXrlXg_qZkAsnL65Kd2_lqNSKTABnOw0LZs_YRc

³⁰ Irish Advocacy Network. (2015). Peer Advocacy in Mental Health. Accessed on 11th November 2015 at <http://irishadvocacynetwork.com/wp/>

³¹ HSE.(2015). Annual Report and Financial Statements 2014. Accessed on 11th November 2015 at http://www.hse.ie/mwg-internal/de5fs23hu73ds/progress?id=i5KINXrlXg_qZkAsnL65Kd2_lqNSKTABnOw0LZs_YRc

CHALLENGES IDENTIFIED BY STAKEHOLDER IN THE CURRENT PROVISION OF ADVOCACY SERVICES

This section summarises issues raised by stakeholders during the Committee discussion on the issue of advocacy.

ADVOCACY SERVICES GENERALLY

- There are no national guidelines or standards and there is no co-ordination body to oversee existing advocacy services:
“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.” (Mr. Paddy Connolly, Inclusion Ireland, evidence to the Committee, November 26, 2015)
- There is no central funding stream, and funding of advocacy services has been cut in recent years:
- There is a large cohort of people with significant disabilities with limited access to a case advocate.
- The lack of statutory powers means that the NAS is hindered in its ability to provide an advocacy service because the “relevant section of the Citizens Information Act that would afford legislative powers to an independent advocacy service has not been commenced...”
- There is a lack of awareness of or recognition for the role of advocates:
“...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 can therefore be circumspect about the advocate’s involvement...”
(Ms. Eileen Fitzgerald, evidence to the Committee, November 26, 2015).
- Public representatives can experience difficulties making representations on behalf of families or patients accessing the health service as
 - *“...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...”*
(Caoimhghin Ó Caoláin, Committee debates, November 26, 2015)

MAKING COMPLAINTS

- There is a lower rate of health complaints in Ireland, compared to other jurisdictions.
- There are problems in residential settings with reports of restraints, poor conditions and cases of physical abuse most likely under-reported.
- Advocacy services are underdeveloped in residential services.
- Some people are afraid to complain in case it has adverse consequences for the treatment of their family member.
- Making complaints is seen by some as an arduous and complex process.
- HSE and voluntary hospitals do not provide sufficient advice and information on the complaints process.
- There is no recognisable person dealing with complaints in hospitals.

PLANS TO ESTABLISH A NEW NATIONAL PATIENT ADVOCACY SERVICE

CALLS TO ESTABLISH A NEW NATIONAL PATIENT ADVOCACY SERVICE

The [Programme for Government 2011-2016](#) committed to establishing a Patient Safety Authority, incorporating HIQA. Since then, a number of recent reports have called for the establishment of an independent, national advocacy service. These include:

- The Office of the Ombudsman's (2015) [Learning to get Better](#). The report was the culmination of an investigation into how well the HSE and public hospitals listen to feedback and complaints. One recommendation made in the report states that:

"Independent advocacy services should be sufficiently supported and signposted within each hospital so patients and their families know where to get support if they want to raise a concern or issue."

- The Health Information and Quality Authority (HIQA) (2015) [report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise](#)

Recommendation 1 of this report states:

*"The Department of Health should commence discussions with the Health Service Executive (HSE) **to establish an independent patient advocacy service**, with a view to having a service in place by May 2016...In the interim, the Department of Health and the HSE should provide regular updates on their websites to inform the public on the progress of establishing this service."*

PLANS TO CREATE A NATIONAL PATIENT ADVOCACY SERVICE ANNOUNCED

On 12th November 2015, at the Fifth National Patient Safety Conference in the Aviva Stadium, the Minister for Health, Dr. Leo Varadkar, T.D., announced the creation of a new National Patient Advocacy Service. The new advocacy service would be independent of the HSE and the Department of Health. The Minister has stated that the new advocacy service will:³²

³² Minister Varadkar's speech to the Fifth National Patient Safety Conference, 12th November 2015. Accessed on 12th November 2015 at <http://health.gov.ie/wp-content/uploads/2015/11/Patient-Safety-Conference-12.11.2015.pdf>

- Provide an information service for patients
- Refer patients to appropriate agencies
- Record and analyse patient complaints

Work on this has already commenced and the Minister has stated that the service will be “...in line with international best practice.” ³³

³³ Department of Health. (2015). Patient Safety. Accessed on 12th November 2015 at <http://health.gov.ie/wp-content/uploads/2015/11/Patient-Safety-Conference-12.11.2015.pdf>

STAKEHOLDER RECOMMENDATIONS

This section contains a short summary of various recommendations made by stakeholders in written submissions which were considered during their meeting with the Committee.

AWARENESS

- There should be proper signposting of advocacy services with advocates in prominent locations in each general hospital.
- Hospitals should encourage volunteer advocates who can help and support patients. A public sector volunteering policy needs to be developed outlining how those who want to make a contribution can do so.
- Advocates often encounter barriers to access in the health service. Health service providers should recognise and co-operate with different types of advocacy supports made on behalf of service users.

THE NEW ADVOCACY SERVICE

- The new advocacy service should introduce a national signposting service (modelled on the complaints signposting service in Wales)
- The new service should have a sufficiently high profile so that people know where to go to access it
- Advocacy is not a panacea; the quality of health and social services still needs to be improved.
- Funding and resources: the new advocacy service should have a central and sustainable funding stream.
- Statutory powers: the new advocacy service should be given statutory powers to ensure cooperation with the service.

STANDARDS AND TRAINING

- Advocates should receive training. Frontline staff should also be trained so that they are aware of and recognise the role of different types of advocates.
- There is a need to develop codes of practice and common quality standards across the advocacy sector.
- Training should be provided for advocates and also for frontline staff so that they understand the role of advocates.
- Advocates should be trained in 'cultural competence' as they will be working with people from various communities.

CO-ORDINATION AND RECOGNITION

- There is a need for advocacy services to be co-ordinated; including the new patient advocacy service, voluntary bodies and any public body they operate alongside such as:

- i. Office of the Ombudsman
- ii. Office for the Ombudsman for Children
- iii. the Irish Human Rights and Equality Commission and;
- iv. the Citizens Information Board.

PATIENT COMPLAINTS HANDLING

- There is a recognised need for a streamlined complaints system to be used across the health system
- Work is underway between the Office of the Ombudsman and the HSE to progress this
- As part of this work, the healthcomplaints.ie website is being developed as a portal to handle complaints.

APPENDIX 2: DETAILS OF PATIENT SAFETY PLANS AS ANNOUNCED BY THE MINISTER

The general patient safety measures announced on 12th November 2015 aim to:³⁴

- Simplify the complaints process and look to extending the remit of the Ombudsman across the health service in consultation with the Department of Public Expenditure and Reform and other interested parties;
- Conduct a National Patient Experience Survey across all hospitals. This survey will be conducted annually using recognised guidelines to allow international comparisons;
- The National Healthcare Quality Reporting System, first published in 2015, will continue to be published annually;
- Run ongoing Patient Safety Campaigns with defined safety targets such as reducing medication errors;
- Set up a National Patient Safety Office in the Department of Health to report directly to the Minister, oversee the programme of patient safety measures and advise the HSE, HIQA and health professional regulatory bodies on patient safety issues;
- The Patient Safety Office will be guided by an independent Advisory Council, established through public invitation from the Public Appointments Service. This will advise the Office, publish independent patient safety reports prompted by safety information, and act as an early-warning mechanism;
- Set up an independent National Patient Advocacy Service as recommended in the HIQA Portlaoise Report to provide advice and information directly to patients;
- Implement the Code of Conduct for Health & Social Care Providers;
- A National Patient Safety Surveillance System will collate data from across the health service to help the HSE to monitor patient safety, and to guide Government health policy.

³⁴ Department of Health. (2015). Press release: Varadkar announces major package of patient safety reforms. Accessed on 12th November 2015 at <http://health.gov.ie/blog/press-release/varadkar-announces-major-package-of-patient-safety-reforms/>

APPENDIX 3: PATIENT ADVOCACY SYSTEMS INTERNATIONALLY

This section briefly examines patient advocacy systems in New Zealand, Australia, Hungary, Norway and the UK.

Case study 1: New Zealand - Health and Disability Advocacy Service

Background

An independent patient advocacy service, within a hospital setting, was first proposed in New Zealand in 1987 after a judicial inquiry into medical research. In 1994 legislation was passed to set up an Office of the Health and Disability Commissioner and to establish an independent advocacy service.

While this advocacy service is State-funded, it operates independently of the Health and Disability Commissioner, government agencies, and health service providers.

In 1996 a code of patients' rights to be used within the advocacy service was developed by the Office of the Health and Disability Commissioner. This may be legally enforced and only the Minister for Health has the power to change the code.

How the advocacy service works

The Health and Disability Advocacy Service in New Zealand³⁵ provides a free, independent and confidential service throughout New Zealand. There are 25 community-based offices throughout the country. There are over 40 advocates employed across four regions.³⁶ Consumers can access the service through a Freephone number and there is a nationwide database for all inquiries and complaints.

Case study 2: Western Australia - Health Consumers' Council

The purpose of the Health Consumers' Council (HCC) is to raise awareness of and advocate for health consumers rights in Western Australia. The HCC comments publicly on all issues affecting health but also provides an individual service. HCC receives funding from State and Commonwealth agencies. However, it is an independent advocacy service.³⁷

³⁵ See the Health and Disability Advocacy Service website at <http://advocacy.hdc.org.nz/>

³⁶ Organisational flowchart is available at this link
<http://advocacy.hdc.org.nz/media/73934/org%20chart%20as%20september2015.pdf>

³⁷ Health Consumers' Council of Western Australia. (2015). Who we are. Accessed on 16th November 2015 at <http://www.hconc.org.au/about-us/who-we-are/>

Cases dealt with by the HCC

The HCC provides services across a range of health areas such as: hospital, mental health, primary care, dental, as well as complementary and alternative therapies. The HCC's Annual Report for 2015³⁸ shows that, of all the cases it dealt with, 65% were physical health cases and 35% were mental health cases.

³⁸ Health Consumers' Council of Western Australia. (2015). Annual report 2015. Accessed on 16th Novemebr 2015 at http://www.hconc.org.au/wp-content/uploads/2015/10/Annual-Report_2015_Website-copy.compressed.pdf

Case Study 3: Patient Ombudsman – Hungary and Norway

In some countries the role of the Ombudsman has been supplemented with additional systems (formally or informally) to provide individual advocacy services.³⁹

Two countries that have established patient advocates through a national Ombudsman are looked at here: Hungary and Norway.

Hungary

The Szószóló (Spokesperson) Foundation for Patients' Rights was founded in Hungary in 1994. The Foundation was instrumental in constructing the [Health Care Act 1997](#).

The Act creates the official position of Patient Advocate (or Patient Ombudsman/Patients' Rights Representative). An advocacy model was officially launched in 2000, and 54 advocates began working under the control of ÁNTSZ (National Service of Medical Officers).⁴⁰ Due to the relatively small number of advocates, an advocate would cover 5- 6 hospitals and spend only a few hours at any one hospital per week.

In 2012 the National Center for Patients' Rights and Documentation (OBDK) was established.⁴¹ Once a complaint has been made, the OBDK assists the complainant in finding the patient rights advocate assigned to the healthcare provider in question. The OBDK also operates the national bureau of complaints.⁴²

Norway

In Norway a Patient Ombudsman scheme has been in existence for over twenty-five years and, as with Hungary, the Norwegian scheme also has its origin in a Patients' Rights Act.⁴³ The aim of the Norwegian Patient Ombudsman is to work to safeguard needs, interests and legal rights and to improve the quality of the health care services.⁴⁴

³⁹ Ibid.

⁴⁰ Fábián, T. (2004). Patient advocacy system in Hungary. Accessed on 17th November 2015 at http://www.szoszolo.hu/06tanulmanyaink/220509.titusz_e.htm

⁴¹ Established by Government Decree 214/2012 (VII. 30.).

⁴² OBDK. (2015). Investigating Patients' Complaints. Accessed on 18th November 2015 at <http://www.patientsrights.hu/investigating-patients-complaints.html>

⁴³ Molven, O. (2012). Building a Patient Ombudsman Scheme: the Norwegian Experience. *Medicine and Law*, 31: 57-70.

⁴⁴ Ibid.

The Health and Social Services Ombudsman is the statutory body in charge of handling patient complaints.⁴⁵ There are 19 Ombudsmen operating in Norway (one for every county) who, as well as providing advice and information, act as mediators, advocates and arbitrators.⁴⁶ These Ombudsmen must assist all users of health services and social services free of charge.

Table 1 gives an idea of the range of services Ombudsmen provide.⁴⁷ It shows that in 69% of cases the Patient Ombudsmen provided guidance, in 15% of cases they assisted the patient in communication with the provider and in 7% of cases they contacted health care services.

Table 1: Steps taken by Patient Ombudsmen to support patients

	Number	%
Gave advice and guidance	7338	60%
Gave advice and guidance especially about PICS ⁴⁸	1182	9%
Oral communication with the health care services	559	5%
Communication in writing with the health care services	1069	9%
Communication in a meeting with the health care services	97	1%
Sent complaints to BHSC ⁴⁹	354	3%
Asked PICS for economic compensation	482	4%
Received information	812	6%
Others	377	3%
Total	12,270	100%

⁴⁵ See the Health and Social Services Ombudsman website at this link <https://helsenorge.no/pasient-og-brukerombudet/health-and-services-ombudsman>

⁴⁶ Ibid.

⁴⁷ Molven, O. (2012). Building a Patient Ombudsman Scheme: the Norwegian Experience. *Medicine and Law*, 31: 57-70.

⁴⁸ PICS is the Patient Injury Compensation Scheme

⁴⁹ BHSC is the Board of Health Supervision in the Counties

Source: Molven (2012)

Case study 4: UK – NHS Complaints Advocacy Service and Patient Advice and Liaison Services (PALS)

The NHS Complaints Advocacy Service (CAS) is free, confidential and independent and commissioned locally by each local authority. While NHS CAS is primarily commissioned to focus on health complaints, in some areas support is offered to those who have a complaint regarding social care. All advocates are trained and experienced and provide the following services to patients:⁵⁰

- provide an opportunity to speak confidentially to someone independent of the NHS;
- advise on what support is needed to make a complaint;
- give information about the ways concerns may be raised;
- help to write an effective letter;
- prepare the complainant for any meetings relating to the complaint; and
- contact and speak to third parties.

In addition, the Patient Advice and Liaison Services (PALS) were created in 2002 to offer a point of contact for patients, their families and their carers. As well as offering advice and information, PALS staff will resolve small issues directly with the NHS on behalf of a patient.⁵¹

Problems identified with the NHS Complaints Advocacy Service and PALS

Notwithstanding these initiatives, Healthwatch (2013) found that patients still had problems knowing where to go for help, and identified variations in standards of advocacy services. The same report also finds that in some hospitals there is little independence and no separation between advocacy and complaint management services.

⁵⁰ NHS Complaints Advocacy. How can an advocate support me? Accessed on 18th November 2015 at <http://nhscomplaintsadvocacy.org/what-is-nhs-complaints-advocacy/how-can-an-advocate-support-me/>

⁵¹ NHS complaints advocacy. Accessed on 17th November 2015 at <http://nhscomplaintsadvocacy.org/what-is-nhs-complaints-advocacy/find-out-more-about-pals/>

Joint Committee on Health & Children

LINKS TO TRANSCRIPT AND OPENING STATEMENTS OF THE COMMITTEE MEETING
--

[Link to Transcript of Meeting of Thursday 26th November 2015](#)

Links to Opening Statements

Session A

[Opening Statement by Mr. Peter Tyndall, Ombudsman and Information Commissioner](#)

[Opening Statement by Mr. Paddy Connolly, CEO, Inclusion Ireland](#)

[Opening Statement by Ms. Eileen Fitzgerald, Senior Manager, Citizens Information](#)

[Opening Statement by Mr. Mervyn Taylor, Manager, SAGE](#)

Session B

[Opening Statement by Mr. Tony O'Brien, Director General, HSE](#)

BIBLIOGRAPHY

[Australian Government Department of Social Services. \(2015\). Models of disability advocacy.](#)

[Department of Health. \(2015\). Press release: Varadkar announces major package of patient safety reforms. Accessed on 12th November 2015](#)

[Drage, J. \(2012\). New Zealand's National Health and Disability Advocacy Service: A successful model of advocacy.](#)

[Fallberg, L. and Mackenney, S. \(2003\). Patient Ombudsmen in Seven European Countries: an Effective Way to Implement Patients' Rights?](#)

[Fábián, T. \(2004\). Patient advocacy system in Hungary. Accessed on 17th November 2015](#)

[Health and Disability Advocacy Service website](#)

[Healthwatch. \(2013\). Improving independent complaints advocacy in health and social care Background and position briefing. Accessed on 17th November 2015](#)

[Health Consumers' Council of Western Australia. \(2015\). Who we are. Accessed on 16th November 2015](#)

[Health Consumers' Council of Western Australia. \(2015\). Annual Report 2015. Accessed on 16th November 2015](#)

[Irish Advocacy Network. \(2015\). Peer Advocacy in Mental Health. Accessed on 11th November 2015](#)

[Institute for Research and Innovation in Social Services \(IRIS\). \(2013\). Insights: advocacy: models and effectiveness.](#)

[Mackenney, S. and Fallberg, L. \(2004\). Protecting Patients' Rights?: A Comparative Study of the Ombudsman in Healthcare.](#)

[Molven, O. \(2012\). Building a Patient Ombudsman Scheme: the Norwegian Experience. Medicine and Law.](#)

[NHS Complaints Advocacy. How can an advocate support me? Accessed on 18th November 2015](#)

[OBDK. \(2015\). Investigating Patients' Complaints. Accessed on 18th November 2015](#)

[Office of the Ombudsman Ireland: the rights of patients. Accessed on 17th November 2015.](#)

[Sage. \(2015\). Policies and Operational Guidelines. Accessed on 11th November 2015](#)