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Independent advocacy for complaints relating to health and social care: an overview of models in other jurisdictions

Contents

1 Introduction

The purpose of this desk-based research exercise is to support the work of Workstream 7 in its consideration of **recommendation 37 (iv)** of the Report of the Inquiry into Hyponatraemia-Related Deaths (IHRD), i.e. that:

> *"A fully funded Patient Advocacy Service should be established, independent of individual Trusts to assist families in the process. It should be allowed funded access to independent expert advice in complex cases."*

This research paper outlines the infrastructure established in other jurisdictions to provide independent advocacy for **those seeking to complain about their experience of health and social care services**. For ease of reference, each jurisdiction is divided into a number of sections that cover the **role of the advocacy service**; **the structure (including management structure) of the service**; **how the service is regulated**; and **its annual workload**.

It is important to note at the outset that this paper has certain limitations. Whilst it does provide a useful overview of different complaints advocacy models in other countries, the lack of published independent evaluations of these services makes it somewhat difficult to assess how applicable or effective such models would be in a Northern Ireland health and social care service context. Therefore, should the working group express an interest in a certain model; it would be advisable for the group to contact the advocacy service directly in order to gain further insights and/or to conduct further primary research on that model.

A brief overview of the models

Each section of the paper provides detailed information on the model in a particular jurisdiction, but for ease of reference, a brief summary of each of the models is provided below:

England – independent NHS complaints advocacy: the old and new models

There has been a relatively recent transformation in England on the way independent advocacy relating to complaints against the NHS is commissioned and delivered. Prior to April 2013, the commissioning of independent NHS complaints advocacy was the responsibility of the Secretary of State for Health. A nationwide service, known as the '**Independent Complaints Advocacy Service' (ICAS)**, was established in order to ensure that people making complaints about NHS services had access to independent support. This purpose of this service was to enable individuals and their representatives to articulate their concerns and assist them in navigating the NHS complaints system. ICAS was delivered across England by just three charitable organisations, each of which had prior extensive experience of providing independent advocacy and advice, i.e.:

- PohWER[1]: a charity and membership organisation providing, information, advice, support and advocacy to people with disabilities and/or those experiencing vulnerability, distress and social exclusion. PoHWER provided ICAS to the East of England, London and the West Midlands.
- South of England Advocacy Service (SeAp)[2]: a charity that specialises in the provision of independent advocacy for a range of vulnerable client groups. SeAp provided ICAS to the South East and the South West of England.
- Carers Federation[3]: a charity that provides a diverse range of services and training for carers, including young carers. The Carers Federation provided ICAS to London, the East of England and the West Midlands.

ICAS ceased to exist on 31 March 2013 as a result of the then UK Coalition Government's 'Localism Agenda'. This policy led to the transfer of many statutory duties from central to local government in the belief that local authorities were best placed to identify local needs and to determine what services were required to meet those needs. Responsibility for the commissioning of independent NHS complaints advocacy was one of the functions transferred from the Secretary of State to local authorities in England.

Local authorities in England currently use a number of different commissioning models e.g.:

- Some local authorities continue to commission independent NHS complaints advocacy from one of the original providers (particularly PohWER and SeAp).
- Some commission services from local charities or from a 'hub' consisting of a range of charities. These 'hubs' have either been already in operation for a considerable period of time or can be newly created 'hubs' who have been formed specifically to provide NHS complaints advocacy. In some areas, membership of the 'hubs' consist of the original providers as well as a number of local charities.
- Some local authorities will not only commission NHS complaint advocacy from a provider or a 'hub', but will also commission other statutory advocacy services from that provider e.g. Mental Capacity advocacy services or Care Act advocacy services. In other words, in some local authority areas one provider will provide all statutory advocacy services for that locality.

Illustrative examples of each of these models are provided in section 2 of this research paper.

Scotland – the Patient Advice and Support Service (PASS)

In Scotland, the **Patient Advice and Support Service (PASS)**, provided by Citizens Advice provides free, confidential information and support to anyone who uses the NHS in Scotland. PASS has a number of Specialist Advisers who can help clients to

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[1] POhWER www.pohwer.net/Pages/Category/about-us

[2] SeAp www.seap.org.uk/about/

[3] Carers Federation www.carersfederation.co.uk/

understand their rights and responsibilities as patients as well as providing practical help with making a complaint (e.g. attending meetings with the client). PASS was established under the **Patient Rights (Scotland) Act 2011** with the aim of improving patients' experiences of using health care services. The service is supported by a '**Charter of Patient Rights and Responsibilities**' one of which includes a right for a service user (or their representative) to have any concerns or complaints dealt with in an appropriate way. Service users or their representatives can contact PASS in person at their local Citizens Advice office or can contact the service using a national helpline number.

New Zealand - the Health and Disability Commissioner and the Nationwide Health and Disability Advocacy Service

Independent advocacy in New Zealand is provided under the auspices of the **Health and Disability Commissioner (HDC)**. The Commissioner is supported in his role by a Director of Advocacy who contracts with the National Advocacy Trust (a charitable body). The Trust provides an independent advocacy service, known as the **Nationwide Health and Disability Service**, for people seeking to complain about breaches of their rights under the New Zealand '**Code of Health and Disability Services Consumer Rights**'. Such rights include, for example, the right to be treated with respect; the right to effective communication; and the right to complain about health, social care and disability services. The advocacy is known as the Nationwide Health and Disability Service and is a free independent service for consumers of health and disability services in New Zealand.

The New Zealand **Health and Disability Commissioner Act** requires that the Health and Disability Commissioner and the advocacy service operate independently from one another. Therefore, whilst the Director of Advocacy is an employee of the Commissioner, the role of Director of Advocacy should be performed independently of the Commissioner. In 2017/18, there were approximately 36 advocates operating from 23 community-based offices across New Zealand. The role of advocates is to ensure that both health consumers and disability consumers are made aware of their rights under the Code and to act on the consumer's behalf were necessary. The service is regulated via a '**Nationwide Advocacy Code of Practice**' and associated guidelines.

Western Australia – the Health and Disability Complaints Office

The **Health and Disability Complaints Office (HaDSCO)** is an independent statutory authority that provides a free and impartial resolution service for complaints relating to health, disability and mental health services in Western Australia. The role of HaDSCO is to provide both users and service providers with details of complaints procedures; assist providers in developing and improving complaints procedures; and to provide advice to service users seeking to make complaints about health providers. HaDSCO may also, with the approval of the Minister of Health, inquire into broader issues of healthcare arising from the complaints received.

Complaints can be dealt with by HaDSCO either by complaints resolution/mediation or by formal investigation. Where complaints relate to a registered health professional, HaDSCO is required by law to consult with the Australian Health Practitioner Regulatory Agency (AHPRA)[4]. HaDSCO consults with AHPRA to manage complaints relating to the health, performance or conduct of registered health practitioners to determine which is the more appropriate body to manage the complaint. In some instances, different aspects of a complaint are managed by both bodies. For example, AHPRA may investigation allegations relating to the performance or conduct of an individual practitioner, whilst HaDSCO will manage the broader systemic issues that may have contributed to the cause of the complaint.

HaDSCO is guided by a series of partnership agreements (e.g. the ‘Mental Health Partnership Agreement’) and by memoranda of understanding between HaDSCO and professional medical regulatory bodies regarding the timeliness and consistency in the handing of complaints.

Some further examples in other jurisdictions

The final section of the paper looks very briefly at some other models of independent advocacy in other jurisdictions. The information in this section is not as comprehensive as the previous sections because (a) of the lack of information in the English language for some of the jurisdictions, or (b) because the body commissioned to provide advocacy provides that advocacy for a specific client group rather than for the general population (e.g. people facing mental capacity decisions, older people in long term care).

However, these are still interesting models, but obtaining further information may require primary research. The organisations in this section include:

The **Office of the Alberta Health Advocates** (Canada) is sub-divided into a ‘Health Advocate’ section and a ‘Mental Health Patient Advocate’ section. The purpose of the Office is to offer support to Albertans who have concerns about health safety. The service has a number of Health Advocate Representatives who will listen to concerns and support people to find ways to resolve them; will provide information about patient rights under the Albertan Health Charter; and can review and investigate complaints that come under the Alberta Health Act.

The **National Agency for Patients’ Rights and Complaints** in **Denmark** is an independent body intended to be a single point of access to service users wishing to complain about treatment in the Danish health service. It has also been tasked with ensuring that the knowledge gained from adverse incidents in health care is used to prevent similar incidents being repeated.

Norway has a **Health and Social Service Ombudsman** whose role is to assist patients in meeting with service providers to obtain answers about their care and

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[4] Australian Health Practitioner Regulation Agency https://www.ahpra.gov.au/

treatment; to help formulate a compensation claim if necessary; and to provide advice and guidance regarding patient rights.

Many other countries have specific statutory bodies, or bodies that government health departments have set up contracts with, to provide advocacy for specifically for people with **mental health conditions**. The **California Office for Patient Rights** is contracted by the Department of State Hospitals to ensure that the treatment and legal rights of people receiving mental health treatment are upheld. A similar service is provided by the **Psychiatric Patient Advocate Office** in Ontario and the **Mental Health Patient Advocate** in Alberta. In many of these services, advocates are physically based in psychiatric hospitals in order to ensure that the voices of patients and their carers are heard and their rights protected.

Other jurisdictions offer independent advocacy for people in long-term care. The **Delaware Long Term Care Ombudsman** (USA) is a state-wide programme providing advocacy for residents who live in long-term care facilities including assisted living facilities. The **Iowa Office of the State Long-Term Care Ombudsman** is authorised by federal laws to protect the rights of those living in nursing facilities, residential care, assisted living programmes and in elder care homes. The purpose of these services is to investigate and resolve complaints on behalf of residents and their representatives.

2 England – independent NHS complaints advocacy: the old and new commissioning models

There has been a relatively recent transformation in the way that independent complaints advocacy for health and social care-related complaints is commissioned and provided in England. Prior to April 2013, the commissioning of complaints advocacy was the responsibility of the Secretary of State for Health and was provided on a local level by just three independent providers. However, responsibility for commissioning is now devolved to local authorities, each adopting its own particular model of commissioning advocacy services to support people who wish to complain about health and social services.

Whilst some local authorities continue to commission complaints advocacy services from the three original providers, others have opted to obtain independent complaints advocacy through local charitable organisations or groups of organisations that have come together to provide services in advocacy ‘hubs’. Many of these providers have been commissioned not only to provide complaints advocacy but also other forms of statutory advocacy such as mental capacity advocacy or advocacy legislated for under the Care Act (e.g. providing independent advocates for older people who have substantial difficulties in being involved in the assessment and decision making regarding their transfer into a care home)[5].

This section of the research paper outlines the old and new models for health and social care complaints advocacy provision in England, including information on the structure and regulation of the services.

The Independent Complaints Advocacy Service (ICAS) – the old commissioning model

The provision of independent advocacy was formerly a legal requirement for the Secretary of State for Health and Social Care under section 248(1) of the National Health Service Act 2006[6]. Under the Act, "independent advocacy services" are defined as those services that provide assistance to individuals making (or intending to make) a complaint about the treatment or care they received under the National Health Service (NHS).

Prior to April 2013, independent advocacy in England was provided by the Independent Complaints Advocacy Service (ICAS)[7]. This was a statutory service launched in September 2003 and provided, for the first time, a national service delivered to agreed quality standards. During Spring/Summer 2003, the Department of Health conducted a competitive tendering exercise to identify organisations best suited to be able to deliver an independent advocacy service that would "represent value for money". The tender specification offered organisations the opportunity to bid either to provide a national service or to cover at least one of the nine English Government Regions. A total of 23 expressions of interest were received and the Department invited eighteen organisations to submit tenders.

Ultimately, three providers would be selected to deliver the service, each of which covered several of the nine Government Regions. All of the providers had existing experience of providing advocacy to a range of client groups. One of the providers selected (the charity SeAp) had existing experience of providing **statutory advocacy** services such as Independent Mental Health Advocacy (IMHA) and Independent Mental Capacity Advocacy (IMCA) in a range of settings such as secure units, day hospitals, adolescent psychiatric units, prisons, care homes, and community based projects[8].

What was the role of ICAS?

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[5] For further information on Care Act Advocacy see www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/duties/independent-advocacy-care-act.asp

[6] National Health Service Act 2006. www.legislation.gov.uk/ukpga/2006/41/contents

[7] Archived information on ICAS is available at https://webarchive.nationalarchives.gov.uk/+/http://www.dh.gov.uk/en/Managingyourorganisation/Legalandcontractual/Complaintspolicy/NHScomplaintsprocedure/DH_4087428

[8] House of Commons Health Committee. Sixth Report. Complaints and Litigation. June 2011. Written Evidence from SEAP.

ICAS was designed to be a patient-centred service, delivering support ranging from provision of self-help information through to the assignment of dedicated advocates to assist individuals with letter writing, form filling and attendance at meetings. It aimed to ensure that people making complaints had access to the support they needed to articulate their concerns and navigate the NHS complaints system[9].

The relationship between ICAS and the client was meant to focus on contact at each of the following points or activities in the NHS complaints procedure, i.e.[10].

- Identifying what the available options and possible outcomes are and deciding what options to take;
- Making the complaint to the appropriate Trust(s);
- Deciding how to proceed with the complaint following the initial response of the Trust;
- Supporting client during the local resolution phase by attending meetings or entering correspondence;
- Making a complaint to the Care Quality Commission if necessary;
- Making a complaint to the Parliamentary and Health Service Ombudsman if necessary[11]; and
- Supporting clients with a grievance related to any aspect of healthcare that falls under the jurisdiction of the Parliamentary Health Service Ombudsman, such as complaints about poor treatment or services provided through the NHS in England.

Although ICAS was available to support complainants at all stages of the NHS complaints process, advocates could not offer advocacy where complaints were being pursued with professional regulators such as the General Medical Council (GMC). A 2011 House of Commons Health Committee report on ‘Complaints and Litigation’ felt that this was a “significant anomaly” that *“such complaints are bound to be complex and stressful for complainants. Complainants may find themselves supported by ICAS for one part of the complaint (to the NHS) but not supported to take their claim to the relevant professional regulator”.* The Committee recommended that the UK Government removed this restriction[12].

How was ICAS structured?

The three ICAS providers for England, i.e. the Carers Federation, POhWER and SeAp covered the following nine government regions:

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[9] Department of Health. Commissioning Independent NHS Complaints Advocacy Services Briefing Pack.

[10] Department of Health. Briefing Pack. Commissioning Independent NHS Complaints Advocacy Services.

[11] The Parliamentary and Health Service Ombudsman makes final decisions on complaints that have not be resolved by the NHS in England. www.ombudsman.org.uk/

[12] House of Commons Health Committee. Sixth Report. Complaints and Litigation. June 2011. https://publications.parliament.uk/pa/cm201012/cmselect/cmhealth/786/78606.htm#a6

- PohWER[13]: a charity and membership organisation providing, information, advice, support and advocacy to people with disabilities and/or those experiencing vulnerability, distress and social exclusion. PoHWER provided ICAS to the East of England, London and the West Midlands.
- South of England Advocacy Service (SeAp)[14]: a charity that specialises in the provision of independent advocacy for a range of vulnerable client groups. SeAp provided the ICAS to the South East and the South West of England.
- Carers Federation[15]: a charity that provides a diverse range of services and training for carers, including young carers. The Carers Federation provided ICAS to London, the East of England and the West Midlands.

How was ICAS regulated?

The ICAS contracts were managed by the Department of Health.

ICAS was to be governed by a set of "**Core Principles**" that set out its approach to supporting its clients[16]:

Empowerment	ICAS empowers people by: ▪ Providing them with information, enabling them to decide whether or not they wish to pursue a complaint about the NHS; and ▪ Where needed, by providing an advocate to support them in pursuing their complaint.
Accessibility	ICAS respects the diversity of clients and provides support appropriate to the needs of the client by: ▪ Ensuring support is accessible at the point of contact to all, both in terms of the physical environment of where it is delivered and the mode of communication used; and ▪ Providing appropriate services and materials for those clients who do not have English as their first language.
Resolution	ICAS supports clients in trying to achieve a resolution to the complaint, within the NHS complaints procedure by supporting the process of local resolution. Local resolution is where clients and NHS staff work together to resolve complaints at a point as close as possible to the point of service that has caused dissatisfaction.
Independence	ICAS is not tied to, or controlled by the NHS, enabling ICAS to work solely on behalf of its clients.
Partnership	ICAS supports the aspirations of the NHS in improving the patient experience by working with all stakeholders to promote positive change in the NHS.
Confidentiality	ICAS treats all interactions between clients as confidential, in line with ICAS providers confidentiality policies.
Value for Money	Organisations providing ICAS should deliver the service using the principles of value for money, i.e. economy, efficiency and effectiveness.

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[13] POhWER www.pohwer.net/Pages/Category/about-us
[14] SeAp www.seap.org.uk/about/
[15] Carers Federation www.carersfederation.co.uk/
[16] Department of Health. Commissioning Independent NHS Complaints Advocacy Services Briefing Pack.

In addition to the ICAS core principles, two codes of practice, one relating to the work of ICAS project directors and one relating to the work of ICAS advocates were to underpin effective service delivery[17]. The ICAS contracts also contained a number of Key Performance Indicators against which the service was to be monitored[18].

What was the annual workload of ICAS?

It is somewhat difficult to locate the most recent statistics for the ICAS service prior to its cessation in March 2013. However, a written submission on behalf of ICAS to a House of Commons Health Committee inquiry into complaints and litigation indicated that in 2009-10, ICAS handled:

- 78,500 enquiries about the NHS complaints system;
- Over 12,000 requests for self-help packs; and
- 14,721 cases requiring direct advocacy support.[19].

A 2011 report on "Complaints and Litigation" by the House of Commons Health Committee felt that whilst the ICAS service provided a "*very useful service to patients*", the Health Select Committee had a number of concerns. For example, the Committee expressed concern that some complainants who would benefit from support from ICAS were simply not aware of its existence. The Committee felt some of the PALS (Patient Advice and Liaison Services) within local Trusts were not drawing complainants' attention to ICAS or where not referring serious cases to ICAS with sufficient speed[20].

Independent NHS complaints advocacy – the new commissioning model

The Independent Complaints Advocacy Service (ICAS) ceased to operate on 31 March 2013. As part of the then Coalition Government's 'Localism Agenda', section 185 of the Health and Social Care Act 2012 transferred the duty of commissioning independent complaints advocacy from the Secretary of State for Health to **local authorities**[21]. The then Coalition Government's 'Localism Agenda" was guided by the belief that local authorities where more experienced at identifying local needs and determining the services required to meet those needs. It was felt that local authorities were equipped to deal with these additional advocacy responsibilities given that they had existing experience of commissioning advocacy services for social care complaints

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[17] Ibid.

[18] Local Government Association. Commissioning Independent NHS Complaints Advocacy. December 2012. https://nhscomplaintsadvocacy.org/commissioning-nhs-complaints-advocacy/

[19] House of Commons Health Committee. Sixth Report. Complaints and Litigation. June 2011. Further written evidence on behalf of Independent Complaints Advocacy Service (ICAS) providers and clients. https://publications.parliament.uk/pa/cm201012/cmselect/cmhealth/786/786we15.htm

[20] House of Commons Health Committee. Sixth Report. Complaints and Litigation. June 2011.

[21] Health and Social Care Act 2012. www.legislation.gov.uk/ukpga/2012/7/section/185/enacted

and for providing access to statutory Independent Mental Health Capacity advocacy (under the Mental Capacity Act 2005)[22].

Whilst the duty to commission independent advocacy transferred from 1 April 2013 there was a transition period allowing local governments to prepare for the transfer of responsibilities. It was left to individual local authorities to determine how best to provide the new NHS complaints advocacy service. Services could be commissioned from a voluntary or community sector organisation or consortium, a social enterprise or a private sector organisation[23]. The following commissioning models could be used:

- **Independent model (individual):** one local authority commissions the NHS complaints advocacy service for its own locality.
- **Independent model (collaborative):** an agreement between a number of local authorities on a regional, sub-regional or cross-regional basis to commission an NHS complaints advocacy service jointly covering all participating localities.
- **An integrated model:** NHS complaints advocacy and social care complaints advocacy services, or other local advocacy provision (such as Independent Mental Health Advocacy services) commissioned together from one provider.
- **Commissioned through local** Healthwatch**[24]:** legislation permitted local Healthwatch to be commissioned by the local authority to provide, or to contract with a sub-contractor to provide, NHS complaints advocacy for that area.

Local authorities were advised to prepare for transition in advance of the cessation of the ICAS service on 31 March 2013. A paper prepared by the Local Government Commission advised local authorities to make arrangements with their new providers to conduct preparatory work in advance of the transfer of responsibility. This included for example, liaising with ICAS providers to transfer files and data on casework; setting up a helpline; promoting the new service; and training staff. The outgoing ICAS providers were contractually bound to assist the new providers with the transfer of existing clients[25].

What is the role of the new NHS Complaints Advocacy Service?

NHS complaints advocacy should be free, confidential and independent of the NHS. The service should provide assistance for individuals making, or intending to make, a

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[22] Independent Advocacy Services: Frequently Asked Questions. www.local.gov.uk/healthwatch-independent-complaints-advocacy-services-icas

[23] Local Government Association. Commissioning Independent NHS Complaints Advocacy. December 2012. https://nhscomplaintsadvocacy.org/commissioning-nhs-complaints-advocacy/

[24] Healthwatch is an independent consumer champion for people who use health and social care services in England. It is a statutory mechanism and a key component of the Health and Social Care Act 2012 intended to strengthen the collective voice of users of health and social care services and members of the public both nationally and locally[24]. There is local Healthwatch in each local authority area in England. These local Healthwatch have a set of statutory responsibilities e.g. to provide advice and information on how to access local care services; to promote and support local people to engage in decision making on local health services etc.

[25] Local Government Association. Commissioning Independent NHS Complaints Advocacy. December 2012.

complaint about the NHS in England. This covers all NHS services provided in England, including[26]:

- NHS Trusts (including foundation trusts);
- Primary healthcare services provided for the NHS by GPs, dentists, opticians and community pharmacies;
- Clinical commissioning groups;
- Private health care organisations if the treatment has been paid for by the NHS; and
- All other health services commissioned by the NHS.

Healthwatch[27] has developed a set of standards to the purpose of which was to provide a vision of what a good complaints advocacy service should look like. Healthwatch has anticipated that these standards would offer clarity for health and social care commissioners, providers, professionals and users on the role of an NHS complaints advocacy service[28]. Within these standards, Healthwatch has identified a set of activities/actions that all providers of NHS complaints advocacy should be effectively engaged in (as set out in the table below)[29]:

Activities/Actions that independent complaints advocacy services should provide	Support required
Providing assistance when people are thinking about making a complaint or raising a concern.	The individual may wish to talk things through before deciding whether to submit their complaint. For most people this can be met through a helpline service, but for others with complex needs or who face specific barriers this will be achieved through a more intensive one-to-one relationship.
Providing assistance in accessing the right service.	Many people who contact complaints advocacy services are unclear about what an advocate can do. By supporting the person to work out what they need, an advocate can confirm if they can offer support or if the person needs signposting to a more suitable service such as the NHS PALS[30], specialist medico-legal advice service (such as AvMA[31]), regulatory bodies (such as the General Medical Council or Care Quality Council) or local Healthwatch services.
Providing assistance in finding out information	For example, about the complaints process, including who is involved, the different stages and where to send the complaint.
Providing assistance in defining the person's preferred outcomes.	For example, exploring what it is they would like to happen. This is critical in supporting people to define their expectations and plan for advocacy support.

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[26] Local Government Association (2015) Practice guidelines for independent health complaints advocacy service. www.local.gov.uk/practice-guidelines-independent-health-complaints-advocacy-services

[27] Healthwatch are the 'independent champion for people who use health and social care services' and there is a local Healthwatch in every local authority in England. www.healthwatch.co.uk/what-we-do

[28] Healthwatch. Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service. www.healthwatch.co.uk/sites/healthwatch.co.uk/files/healthwatch_advocacy_standards_10022015.pdf

[29] Ibid.

[30] PALS is the NHS Patient Advice and Liaison Service. Many hospital trusts in England have a PALS which offers confidential advice, support and information on patient concerns or problems encountered when using the NHS. For further information see www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/

[31] AvMA (Action Against Medical Accidents) is a UK charity for patient safety and justice. www.avma.org.uk/

Providing assistance in exploring options and potential consequences of choices.	For example, exploring what is involved, what may be expected and likely timescales.
Providing assistance in writing the complaint.	This could be through the provision of templates to develop self-advocacy skills or through direct support in drafting the complaint or concern.
Providing assistance to attend meetings.	Many people can feel overwhelmed and intimidated at the prospect of attending meetings and require emotional support to participate. The person may also require practical support such as taking notes, asking questions or in rehearsing what it is they would like to express.
Providing assistance to understand information.	This could be because information is particularly complex, contains jargon or is technical in nature. Equally, the person may need help in understanding information due to a specific need (such as a learning disability, dementia or severe mental health problem).
Providing representation.	Some people may feel unable at some point to actively progress the complaint or fully engage with the complaints process. The advocate will need to discuss and plan with the person how they would like to be represented in such circumstances and then make representations on their behalf.

How is the NHS Complaints Advocacy Service structured?

Each local authority in England is now responsible for commissioning its own statutory NHS complaints advocacy services. In addition to NHS complaints advocacy, local authorities are also responsible for commissioning other forms of advocacy including:

- Independent Mental Health Advocacy (IMHA);
- Independent Mental Capacity Act Advocacy (IMCA) including Relevant Person's Paid Representatives (RPPRs)[32] and Deprivation of Liberty (DoL) safeguarding advocacy; and
- Care Act Advocacy (CA) e.g. for people residing in residential facilities.

Local authorities have primarily commissioned third sector organisations to provide NHS complaints advocacy and indeed the other forms of statutory advocacy outlined above. For illustrative purposes, several examples of the different commissioning models that are used by local authorities are available overleaf:

Example 1: **The local authority will commission *all statutory advocacy* services from *a single provider or an 'advocacy hub' consisting of several providers.*** In April 2017, York City Council[33] commissioned York Advocacy Hub to provide Independent NHS Complaints advocacy, Care Act Advocacy, Independent Mental Capacity Act Advocacy (IMCA) and Independent Mental Health Act (IMHA) Advocacy.

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[32] Further information on Relevant Person's Paid Representatives can be found at www.pohwer.net/relevant-persons-paid-representative-service-rppr

[33] York City Council guide to advocacy services www.york.gov.uk/downloads/file/13948/advocacy

York Advocacy Hub is a single point of access advocacy service for the City of York and the Hub is provided York Mind, a mental health charity that has been delivery advocacy services since 1997[34].

A similar model is used by Leeds City Council who has commissioned all advocacy services from Advonet. Advonet leads a consortium of subcontractors who have specialist knowledge of providing advocacy services for a range of client groups including older people, learning disability and mental health[35].

A further example of this model is Staffordshire County Council who has commissioned Total Voice Staffordshire[36] to provide all statutory advocacy services. Total Voice Staffordshire is comprised of two organisations working in partnership to provide these services, i.e. VoiceAbility and a local advocacy charity called Asist who work alongside people with physical disabilities, learning disabilities, or mental health conditions.

Example 2: A local authority will commission statutory advocacy services from different providers. For example, Barking and Dagenham Council commission PoHWER to provide NHS complaints advocacy but commission Barking & Dagenham Advocacy Services[37] to provide Independent Mental Capacity Advocacy (IMCA), Independent Mental Health Advocacy (IMNHA) and Care Act Advocacy. This service is provided by Cambridge House[38] an organisation that offers a range of social justice services including a law centre and education and inclusion services.

In Rotherham, NHS complaints advocacy is provided by the local Healthwatch (Healthwatch Rotherham[39]) and all other statutory advocacy services e.g. Mental Capacity Advocacy is provide by Absolute Advocacy[40] (part of a bigger network known as Cloverleaf Advocacy[41], a charity that provides a range of statutory advocacy services for many local authorities throughout the North of England).

Example 3: A group of local authorities within a locality will jointly commission either one or all statutory advocacy services from a single provider (or a 'hub' of providers). Leicestershire Council, Rutland City Council and Leicester City Council have agreed to jointly procure all statutory advocacy services[42].

Example 4: One advocacy provider will provide a single statutory advocacy service for multiple local authorities within a locality. One of the most notable

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[34] York Advocacy Hub. www.yorkadvocacy.org.uk/about-us/

[35] Advonet. https://advonet.org.uk/about-us/

[36] Total Voice Staffordshire www.totalvoicestaffs.org/about-us/about-total-voicestaffordshire/

[37] Barking and Dagenham Advocacy Services. http://ch1889.org/our-work/advocacy/barking-and-dagenham/

[38] Cambridge House. http://ch1889.org/our-work/

[39] Healthwatch Rotherham. http://healthwatchroterham.org.uk/advocacy/

[40] Absolute Advocacy. https://www.cloverleaf-advocacy.co.uk/offices/rotherham

[41] Cloverleaf Advocacy https://www.cloverleaf-advocacy.co.uk/content/about-us

[42] Leicester City Council. Proposed changes to advocacy services. January 2019. https://consultations.leicester.gov.uk/communications/proposed-changes-to-advocacy-services/

examples of this is the London Independent Health Complaints Advocacy Service[43] provided by POhWER. POhWER provide an independent health complaints advocacy service for 20 London boroughs including e.g. Hackney, Haringey, Tower Hamlets and Greenwich. This service provides a single point of contact for NHS complaints, including an NHS complaints referral form, as well as a range of resources on complaints advocacy for service users and their representatives. Some of these local authorities have also commissioned PohWER to provide other statutory advocacy services such as Mental Capacity Advocacy.

Similarly, an organisation known as North East NHS Independent Complaints Advocacy (managed by the Carers Federation[44]) provides NHS complaints advocacy for numerous local authorities in the North East of England (including Newcastle, Sunderland and Middlesbrough councils)[45].

How is the advocacy service regulated?

NHS complaints advocacy services are guided by a set of non-statutory **national practice guidelines** and **standards**. The national guidelines, entitled 'Practice guidelines for independent health complaints advocacy services', were developed by the Local Government Commission in conjunction with providers of independent health complaints advocacy[46]. The guidelines were published in 2015 and contain four "core characteristics" that should be demonstrated by organisations that provide NHS complaints advocacy, i.e.

- That the advocacy service must be known, accessible and responsive;
- That the advocacy service must be professional;
- That the advocacy service must be independent; and
- That the advocacy service must make a difference.

Further information on these four core characteristics including of their associated service specifications, outcomes and indicators is provided in **Annexe 1** of this research paper.

NHS complaints advocacy providers are also guided by a **set of non-statutory standards**. These standards entitled 'Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service' have been developed by Healthwatch[47], at the request of the Secretary of State for Health[48]. The standards, developed in collaboration with users, providers and commissioners of complaints advocacy services. There are **eight standards** contained within the

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[43] London NHS Complaints Advocacy Service. www.pohwer.net/london-ihcas

[44] Carers Federation. www.carersfederation.co.uk/

[45] North East NHS Complaints Advocacy www.carersfederation.co.uk/services/independent-complaints-advocacy/

[46] Local Government Authority (2015) Practice guidelines for independent health complaints advocacy services. www.local.gov.uk/practice-guidelines-independent-health-complaints-advocacy-services

[47] Healthwatch. www.healthwatch.co.uk/what-we-do

[48] Letter to Jeremy Hunt MP, Secretary of State for Health from Healthwatch. 10 February 2015. www.healthwatch.co.uk/what-we-do

document, each of which have a set of detailed indicators (further information is provide in **Annexe 2** of this research paper). The standards, and what service users are seeking from those standards, are as follows:

Standard	What service users want
Standard 1: The advocacy service is CLIENT LED	I want to be in control of the advocacy process at all times. I don't want the advocate to push their own agenda or tell me what to do. I want them to listen to me and only act on my instructions.
Standard 2: The advocacy service is INDEPENDENT	I want my advocate to offer me the full range of advocacy support without being worried, restricted or limited by the health and care provider, commissioner or anybody else.
Standard 3: The advocacy service is WELL KNOWN and EASY TO USE	I want it to be easy to find my local advocacy service and get an advocate. I want the advocacy service to respond to my needs.
Standard 4: The advocacy service maintains a CLARITY OF PURPOSE	I want to understand precisely how the advocacy service can help me. When I want other types of support I want help to find out about other services and support in accessing them.
Standard 5: The advocacy service provides a COMPASSIONATE REPONSE	I want to be treated with kindness and be shown compassion by an advocacy service that understands my needs. I want the service to understand I may be experiencing a whole range of difficult emotions that may affect my complaint and the ability to complain.
Standard 6: The advocacy service leads to SYSTEMIC CHANGE	I want the advocacy service to make sure it takes action to improve the way health and social care services are delivered, so no one else will have to go through the experiences I went through.
Standard 7: The advocacy service WORKS HARD for its advocates	I want a service that looks after its staff. I want to know my advocate is trained, supervised and maintains professional standards.
Standard 8: The advocacy service has CLEAR LEADERSHIP	I want a service that I trust will deliver the very best quality of complaints advocacy support. I want to know that the people running the advocacy service are good leaders and are committed to excellence.

In addition to the guidance and standards, there are a number of other key documents that can provide guidance on the commissioning, operation and regulation of complaints advocacy including:

- The Advocacy Charter – published by the National Development Team for Inclusion (NDTi), the Advocacy Charter[49] contains a number key principles that should guide advocacy services. There is also an associated Advocacy Code of Practice that advocates must follow[50].

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[49] National Development Team for Inclusion. Advocacy Charter. https://qualityadvocacy.org.uk/resources/advocacy-charter/

[50] National Development Team for Inclusion. Advocacy Code of Practice. Revised Edition 2014. https://qualityadvocacy.org.uk/wp-content/uploads/2018/05/Code-of-Practice-1.pdf

- Advocacy Quality Performance Mark (AQM)[51] is a quality market for organisations that offer independent advocacy and is awarded to organisations who can demonstrate that they provide excellent services in line with QMP standards and the Advocacy Charter.
- Care Quality Commission Regulation 16 on ‘receiving and acting on complaints’[52]: This regulation applies to *NHS service providers and not to advocacy services*. However, the regulation is designed to ensure that *advocates can operate within a complaints system* that is transparent and accessible. The intention of this regulation to ensure that people can make a complaint about their NHS care and treatment. In order to meet this regulation service providers must have an effective and accessible system for identifying, receiving and responding to complaints.
- The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009 introduced a revised procedure for the handing of health and social care complaints by local authorities[53]. This new system of complaints handling is designed to ensure that service users, their families and advocates can operate within a complaints system that is transparent and accessible.

What is the annual workload of the NHS Complaints Advocacy Service?

It has not been possible to locate published centrally collected data on complaints received and handled by NHS *complaints advocacy providers* in England. Advocacy service providers may provide this data in their own published annual reports.

3 Scotland – the Patient Advice and Support Service (PASS)

The Patient Advice and Support Service (PASS) is provided by Citizens Advice Scotland. PASS is an independent service that provides free and confidential information, advice and support to anyone who uses the NHS in Scotland. PASS Patient Advisers can:

- Help clients understand their rights and responsibilities as patients;
- Provide information, advice and supports for clients who wish to give feedback or comments, or raise concerns or complaints, about healthcare delivered by NHS Scotland;
- Provide practical help with making a complaint, including preparing letters, making phone calls and support clients in preparing for and attending meetings; and

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[51] National Development Team for Inclusion. Advocacy Quality Performance Mark (QPM). https://qualityadvocacy.org.uk/

[52] Care Quality Commission Regulation 16. www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-16-receiving-acting-complaints

[53] The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009. www.legislation.gov.uk/uksi/2009/309/contents/made

- Work with NHS Scotland to use feedback to improve the patient experience and improve NHS service provision[54].

PASS was established under sections 17 to 19 of the Patient Rights (Scotland) Act 2011[55]. This Act aims to improve patients' experiences of using NHS services and to support people to become more involved in their health and healthcare. The Act required Scottish Ministers to publish a Charter of Patient Rights and Responsibilities[56]. One of these fundamental rights is to *"have a say about your healthcare and to have any concerns or complaints dealt with in the most appropriate way".*

Patients, their families and carers can access PASS in person at their local Citizens Advice office, or can contact the service by email, by a national phoneline, or can chat to an adviser online[57]. If a person choses to contact their local Citizens Advice Bureau regarding a complaint about NHS Scotland they may be seen or talk to a generalist adviser first. If they require more support, they may then be referred to a specialist PASS Patient Adviser.

What is the annual workload of the Patient Advice and Support Service (PASS)?

According to its latest published annual report for 2017/18, PASS supported 3,151 clients during 2017/18 and handled 7,941 enquiries. Below is a summary of the work carried out throughout the year to support clients:

- 1,701 clients received information from Patient Advisers
- 237 clients received information about patient rights and responsibilities
- 493 clients were given information to take action on their own behalf
- 398 clients had one or more formal letters written on their behalf
- Patient Advisers had informal contact with NHS staff on behalf of 146 clients
- 177 clients were sign-posted to other resources
- 52 clients were assisted to meet with NHS staff
- 36 clients received assistance to access and/or review their medical records

The Annual Report provides the following illustrative example of how a Patient Adviser provided support to an individual client in a more complex case, i.e. the Adviser:

- Met with the client to discuss and draft a complaints letter to the NHS complaints team and sent it on the client's behalf;
- Discussed the response from the NHS with the client and drafted a follow up email asking for more information/clarification from the complaints team;

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[54] See www.nhsinform.scot/care-support-and-rights/health-rights/patients-charter/the-charter-of-patient-rights-and-responsibilities

[55] Patient Rights (Scotland) Act 2011. http://www.legislation.gov.uk/asp/2011/5/contents

[56] Charter of Patient Rights and Responsibilities. www.nhsinform.scot/care-support-and-rights/health-rights/patients-charter/the-charter-of-patient-rights-and-responsibilities

[57] See www.cas.org.uk/pass

- Met with the client to discuss the option of meeting with NHS staff, which the client declined;
- Requested two medical reports on behalf of the client;
- As the client was unhappy with the NHS response, discussed the option of taking the complaint to the Scottish Public Service Ombudsman (SPSO);
- Drafted and, following agreement with the client, submitted a complaint to the SPSO;
- Supported the client during the SPSO investigation; and
- Met with the client to discuss the SPSO response and explained that the SPSO would check that the Health Board implemented their recommendations and that the client would receive an apology from the Board.

PASS is overseen by a Monitoring and Evaluation Advisory Group that provides a forum for obtaining advice and input from key stakeholders in order to ensure effective monitoring and evaluation of the service. The membership of this group is comprised of representatives across NHS Scotland and the wider patient advocacy and support network.

A new NHS complaints handling procedure for Scotland

In addition to establishing the Patient and Advice Support Service (PASS), the Patient Rights Act (Scotland) 2011 required Health Boards in Scotland to seek feedback, comments, concerns and complaints from patients and to use this information to improve services and patient experiences. In April 2014, the Scottish Health Council publishes a report entitled ‘Listening and Learning’ which recommended a more standardised approach for complaints management across Health Boards. The Scottish Government concurred with the recommendation of the report that the Complaints Standards Authority (CSA) should work with NHS Boards to develop a revised NHS model complaints handling procedure[58]. A new model Complaints Handling Procedure[59] has been developed through a partnership approach led by a steering group that has included PASS within its membership.

A report on the Review of the First Year of the new Model Complaints procedure noted that PASS services are frequently demanded by patients and that since the introduction of the PASS helpline demand has continued to increase even though PASS was not at that time actively advertising its helpline. The report recommended

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[58] Bonello, B. The New Model NHS Complaints Handling Procedure – Review of First Year. Scottish Government. March 2019. https://www.gov.scot/publications/new-model-nhs-complaints-handling-procedure-review-first-year/pages/3/

[59] Scottish Government % Scottish Public Service Ombudsman. The NHS Complaints Handling Procedure. www.valuingcomplaints.org.uk/sites/valuingcomplaints/files/resources/NHS%20Model%20CHP%20%28updated%20Aug%202018%29.%20PDF_0.pdf

that the demands on the PASS service be monitored closely to ensure resources are sufficient to meet demands[60].

4 Republic of Ireland – a new patient safety advocacy service

The Department of Health in the Republic of Ireland is in the process of developing a patient safety advocacy service. This has been prompted by a number of recent patient safety incident investigations and reports that made recommendations for a change to the current complaints and advocacy systems. One of these reports reflected the findings of an investigation by the Office of the Ombudsman into how public hospitals in the Republic of Ireland handled complaints about their services. The report entitled 'Learning to Get Better'[61], published in May 2015, looked at how well the Health Service Executive (HSE)[62] and public hospitals listened to feedback and complaints and took steps to improve services as a result of those complaints. The Ombudsman's report made 36 recommendations, one of which was that an *"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 development of a new patient safety advocacy service was also influenced by a the Health Information and Quality Authority[63] "Report of the investigation into the safety, quality and standards of service provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise'[64]. This report was published in May 2015 and examined the quality and safety of clinical services, and the governance arrangements in place for the maternity and general health services at Portlaoise Hospital. Previous to the report, an RTE had broadcast a *Prime Time* programme about the tragic deaths of newborn babies at the hospital and the subsequent management of patients and their families by the hospital and HSE. The Health Information and Quality Authority's report strongly recommended that the Department of Health should commence discussions with the HSE to establish an independent patient advocacy service whose role:

> *"would be to ensure that patients' reported experiences are recorded, listened to and learned from. Such learning needs to be shared between hospitals within hospital groups; between hospital groups; nationally throughout the wider health system; and published."*

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[60] Bonello, B. The New Model NHS Complaints Handling Procedure – Review of First Year. Scottish Government. March 2019.

[61] Office of the Ombudsman. Learning to Get Better: An investigation by the Ombudsman into how public hospitals handle complaints. May 2015. www.ombudsman.ie/publications/reports/learning-to-get-better/index.xml

[62] The Health Service Executive (HSE) provides all of the Republic of Ireland's health services in hospitals and communities. www.hse.ie/eng/about/

[63] The Health Information and Quality Authority (HIQA) is the independent Authority established to drive quality and safe care for people using health and social care services. www.hiqa.ie

[64] Health Information and Quality Authority. Report of the investigation into the safety, quality and standards of service provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise. May 2015. www.hiqa.ie/reports-and-publications/key-reports-and-investigations/report-investigation-safety-quality-and

In January 2016, the Oireachtas Joint Committee on Health and Children published a report on the 'Role of Advocacy in Health and Social Care Services in Ireland'[65] that recommended that any new patient advocacy service should be independent of the Health Service Executive (HSE); that ideally there should be a single pathway for complaints; and highlighted the importance of setting common standards and a code of practice for advocacy services.

Preparatory work for the establishment of the new patient safety advocacy service

A series of research and consultation exercises has been conducted in preparation for the establishment of the new patient safety advocacy service in the Republic of Ireland, i.e:

- In April 2016, the Health Research Board published 'Models of patient advocacy: Evidence Brief'[66]. This research was commissioned by the Department of Health to look at different models of advocacy in England, Western Australia and New Zealand.
- In May 2017, the Department of Health commenced a public consultation[67] exercise on the development of a *Patient Safety Complaints and Advocacy Policy*. Meetings were subsequently held with 23 stakeholder groups and 174 submissions to the consultation were received.
- In May 2018, the Health Research Board published 'Codes of Practice for Patient Safety Healthcare Complaints Advocacy: Evidence Brief'[68]. This research was commissioned by the Department of Health and examined healthcare complaints codes of practice in New Zealand, England and Northern Ireland.
- In July 2018, the Department of Health published a 'Report of the Consultation for the Patient Safety Complaints and Advocacy Policy'[69]. The primary aim of this policy is to provide a framework to support the development and improvement of healthcare complaints handing and the commencement and provision of an independent patient safety complaints advocacy service. This report provides information on the consultation process and including the findings and key emerging issues from both the stakeholder and public consultations. This information is to be used to develop a *Patient Safety Complaints and Advocacy Policy.*

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[65] 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. www.drugsandalcohol.ie/25068/

[66] Mongan, D., Long, J. & Farragher, L. Models of patient advocacy: Evidence Brief. Health Research Board. April 2016. https://health.gov.ie/wp-content/uploads/2016/12/Final-Version-Patient-Advocacy-Services.pdf

[67] Department of Health. Press Release. 'Minister Harris announces public consultation on new Patient Safety Complaints and Advocacy Policy. https://health.gov.ie/blog/press-release/minister-harris-announces-public-consultation-on-new-patient-safety-complaints-and-advocacy-policy/

[68] O'Sullivan, M. & Mongan, D. Codes of Practice for Patient Safety Healthcare Complaints Advocacy: Evidence Brief. May 2018. https://health.gov.ie/wp-content/uploads/2018/07/Codes-of-Practice-HRB-final.pdf

[69] Department of Health. Report of the Consultation for the Patient Safety Complaints and Advocacy Policy. July 2018. https://health.gov.ie/wp-content/uploads/2018/09/COMPLAINTS-REPORT-HIGH-RES-PDF-WITH-COVER-17072018-v2.pdf

- In September 2018, a 'Competency Framework for Patient Safety and Complaints Advocacy Service' was published[70]. The framework was commissioned by the National Patient Safety Office of the Department of Health. This framework sets out the competencies required to work effectively as a Patient Safety and Complaints Advocate.

Announcement of the award of the contract for the new service

On the 21 December 2018, the Department of Health announced the award of the contract for the new independent patient safety advocacy service. This service will support those wishing to make a complaint about their experience of the public health service and will provide support to patients who may have been affected by a patient safety incident. The new service will provide people with the opportunity to talk to someone independent of the health service; will provide information about how to make a complaint; and will *"provide the supports that may be needed throughout the complaints process".* The service will initially be focused on the public acute hospital sector[71]. The Minister for Health stated that the *"awarding of this contact is a significant step towards addressing the important concerns raised to ensure that we have a responsive, compassionate and supportive approach to assisting people when they are unhappy with their care"*[72]*.*

The contract for delivering the new service has been awarded to the National Advocacy Service for People with Disabilities (known as NAS) following a competitive tending process. Founded in 2011, NAS currently provides an independent, confidential and free, issues-based representative advocacy service for people with disabilities. NAS is funded and supported by the Citizens Information Board (CIB)[73] which is a statutory body that has powers under the Citizens Information Act 2007 and the Comhairle Act 2000 to provide advocacy services. Further information about the NAS is available to download here[74]. The Department of Health highlights that NAS was awarded the contract for new patient advocacy service on the basis that it already has extensive experience of providing advocacy support to people with disabilities in all health and social care settings including acute, community and primary care.

It was anticipated that the new Patient Advocacy Service would become operational in the "second half of 2019" following "a programme to enable the establishment of the

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[70] Performance Partnership. Competency Framework for Patient Safety and Complaints Advocacy Service. September 2018. Commissioned by the National Patient Safety Office of the Department of Health. https://health.gov.ie/wp-content/uploads/2018/10/PSCA-Competency-Framework-September-2018.pdf

[71] Department of Health. Press Release. 'Minister announces the award of the contract for the Independent Patient Safety Advocacy Service'. 21 December 2018. https://health.gov.ie/blog/press-release/minister-announces-the-award-of-the-contract-for-the-independent-patient-safety-advocacy-service/

[72] Ibid.

[73] The Citizens Information Board in the Republic of Ireland is the national agency responsible for supporting the provision of information, advice and advocacy. www.citizensinformationboard.ie/en/

[74] See www.citizensinformationboard.ie/en/services/advocacy/

service, and recruitment and training of advocates"[75]. However, there is no further publicly available information on this. **The Department of Health may wish to contact their counterparts in the Republic of Ireland for updated information on the development of the new service**.

5 New Zealand – the Nationwide Health and Disability Advocacy Service

The need for an independent advocacy service in New Zealand emerged from a recommendation of the report of the Cartwright Inquiry[76] published in 1988. Judge Cartwright was appointed by the then Minister of Health in New Zealand to conduct an Inquiry into allegations concerning the treatment of cervical cancer at the National Women's Hospital[77]. The inquiry report identified the need for widespread changes to to the way patients were treated and services provided, and emphasised the need for services to have a patient or consumer-centred approach[78]. In order to achieve this the report recommended (a) the appointment of a **Health Commissioner** to promote and uphold consumer rights; and (b) the appointment of **independent advocates** who would support consumers to ensure that their rights were upheld. This section provides an overview of the role of the Health and Disability Commissioner and the independent advocacy service. It also briefly explains how these to structures interact with one another.

The Health and Disability Commissioner

The role of Health and Disability Commissioner[79] was enacted under the Health and Disability Commissioner Act 1994[80]. The Act and role of Commissioner was broadened to not only cover healthcare but also disability services and "disability services consumers". The Commissioner is supported in his role by a Deputy Commissioner for Disability; a Deputy Commissioner for Complaints Resolution; a Mental Health Commissioner; a **Director of Advocacy**; a Director of Proceedings. The Commissioner is also supported by a Consumer Advisory Group (CAG)[81] that provides representative consumer advice to the Commissioner on strategic operational health and disability issues. The group is comprised of representatives of consumer groups including age, disability, mental health sectors, Māori, and Pacific People.

Some of the key functions of the Commissioner under the Act are set out below:

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[75] 75 Department of Health. Press Release. 'Minister announces the award of the contract for the Independent Patient Safety Advocacy Service'. 21 December 2018.

[76] The Cartwright Inquiry www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/legislation/cervical-screening-inquiry-0

[77] The Inquiry was asked to investigation allegations in a newspaper article that there was a failure to adequately treat cervical carcinoma in situ at the National Women's hospital, and if so, the reasons for that failure.

[78] Nationwide Independent Advocacy Service - www.advocacy.org.nz/about-the-advocacy-service/

[79] Health & Disability Commissioner website www.hdc.org.nz/

[80] Health and Disability Commissioner Act 1994. www.legislation.govt.nz/act/public/1994/0088/latest/DLM333584.html

[81] Consumer Advisory Group www.hdc.org.nz/about-us/our-team/consumer-advisory-group/

Table 1: Health & Disability Commissioner's Key Functions[82]

Complaint's Resolution	Complaints resolution is the central function of the Health & Disability Commissioner (HDC) and provides the platform for achieving the HDC's 4 strategic objectives: ▪ To protect the rights of health consumers and disability service consumers under the Act and Code. ▪ To improve quality within the health and disability sectors. ▪ To hold providers to account appropriately. ▪ To promote, by education and publicity, respect for and observance of the rights of health and disability service consumers.
Advocacy	HDC's Director of Advocacy contracts with the National Advocacy Trust to provide an independent Advocacy Service. The Advocacy Service plays a crucial role in supporting consumers to resolve those complaints that are suitable for resolution between parties. The Advocacy service also offers community-based education and training on the Code to consumers and health and disability service providers.
Proceedings	The Director of Proceedings exercises independent statutory functions under the Health and Disability Commissioner Act 1994. The Commissioner may refer a provider found in breach of the Code to the Director of Proceedings who will consider whether proceedings should be taken.
Monitoring	The Health & Disability Commissioner has a statutory role in monitoring and advocating for improvements to mental health and additional services. This role is delegated to the Mental Health Commissioner.
Education	The HDC delivers a variety of education and training initiatives aimed at educating consumers about their rights and improving the knowledge of health providers and disability service providers of their responsibilities in respect of those rights.
Disability	The Deputy Commissioner (Disability) is responsible for promoting awareness of, respect for, and the observance of, the rights of disability service consumers.

The 'Code of Health and Disability Services Consumers' Rights' and the complaints resolution process

The Code of Health and Disability Services Consumers' Rights (the Code)[83] is prescribed by regulations made under the Health and Disability Commissioner Act 1994. The Code provides consumers of both health services and disability services in New Zealand with 10 rights (as set out below):

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[82] Information extracted from the Disability & Health Commissioner's Annual Report for the year ending 30 June 2018.

[83] The Code of Health and Disability Services Consumers' Rights www.hdc.org.nz/your-rights/the-code-and-your-rights/

- The right to be treated with respect
- The right to freedom from discrimination, coercion, harassment and exploitation
- The right to dignity and independence
- The right to services of an appropriate standard
- The right to effective communication
- The right to be fully informed
- The right to make an informed choice and given informed consent
- The right to support
- Rights in respect of teaching or research
- The right to complain

A detailed version of the Code is available to download here.

If a consumer of health services or disability services has a complaint about their care or treatment and/or a complaint about potential breaches of the Code, the Health & Disability Commissioner recommends that in the first instance, the consumer talks to the provider of the service. If this does not resolve the issue or complaint, the consumer has the option of contacting the Nationwide Health and Disability Advocacy Service[84]. The Nationwide Health and Disability Advocacy Service was formally established in 1996 as a free and independent service for consumers of health and disability services. Since 2007, the Director of Advocacy at Health and Disability Commissioner (HDC) has commissioned the National Advocacy Trust (a charitable trust) to provide and operate the Advocacy Service. It is important to note that whilst the Director of Advocacy comes under the umbrella of the Health and Disability Commissioner, the Health and Disability Act 1994, requires that the Director of Advocacy is independent and not responsible to the Health & Disability Commissioner. Further detailed information on the advocacy service is provided in the next section of this paper.

If the matter still has not reached a resolution, the consumer can then complain to the Health and Disability Commissioner. Complaints resolution staff will assess the complaint and the complaint will likely be sent to the service provider in order to seek a response from them. The Commissioner's complaints handling staff will make recommendations to the Commissioner as to how the complaint should progress. The Commissioner has various options:

- To take no action e.g. if it is deemed that the provider has already responded to the complaint appropriately;
- To take an educational approach and ask for an apology or recommend an action; or

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[84] The Health and Disability Advocacy Service. www.advocacy.org.nz/

- Formally refer the complaint to the Advocacy Service for formal mediation between the consumer and the provider (with the outcome of the referrals reported back to the HDC) or
- Commence a formal investigation.

Around 10% of complaints received by the HDC are investigated formally and investigations can take up to 10 months. The investigation is carried out by an investigator within the HDC who collates the evidence (e.g. oral evidence, documentation, interviews) and presents it to the Commissioner or a Deputy Commissioner. Where the quality of care is an issue, HDC will obtain independent advice from an **expert in the matters under investigation**.

After an investigation, the Commissioner or Deputy Commissioner will form an opinion on whether the provider has breached the Code. If a breach of the Code has been determined, the provider will be given an opportunity to make a written submission. If the complaint is not upheld, the complainant will be given an opportunity to make a written submission. The Commissioner or Deputy Commissioner will then consider these responses and produce his final opinion.

There are several outcomes open to the HDC following an investigation including:

- The service provider being required to provide the consumer with a written apology; and/or
- The provider being required to undertake specific training; and/or
- The provider being required to implement and/or review systems to prevent further breaches in the Code.

Where an investigation suggests that there may be concerns about the competence of a registered health practitioner, the HDC may recommend to the registration authority (e.g. the Medical Council in the case of a doctor) that it considers whether a review of the practitioner's competence is warranted. The HDC cannot award compensation.

The Commissioner or Deputy Commissioner may also refer the matter to the Director of Proceedings[85]. The role of Director of Proceedings comes under the umbrella of the HDC umbrella but is independent of the Commissioner.   The Director of Proceedings will consider whether disciplinary and/or other proceedings should be brought i.e. a claim before the Human Rights Review Tribunal[86] or Disciplinary proceedings before the Health Practitioners Disciplinary Tribunal[87]. It is the Director of Proceedings' sole decision to determine which of these actions is appropriate.

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[85] Further information on the Director of Proceedings is available at www.hdc.org.nz/proceedings/

[86] The Human Rights Review Tribunal in New Zealand hears cases relating to privacy and human rights as well as breaches of the Code of Health and Disability Services Consumers' Rights www.justice.govt.nz/tribunals/human-rights/

[87] The Health Practitioners Disciplinary Tribunal in New Zealand hears and determines disciplinary proceedings brought against health practitioners. For further information see www.hpdt.org.nz/

The Nationwide Health and Disability Advocacy Service

The Nationwide Health and Disability Advocacy Service[88] was formally established in 1996 as a free independent service for consumers of health and disability services. Since 2007, the Director of Advocacy at the Health & Disability Commissioner (HDC) has contracted with the National Advocacy Trust (a charitable Trust)[89] to provide and operate the advocacy service. In June 2018, this arrangement was extended for a further five years[90]. The Health and Disability Commissioner Act requires that the Health and Disability Commissioner and the Advocacy Services **operate independently of each other**. Therefore, whilst the Director of Advocacy is an employee of the Health and Disability Commissioner, the role of Director of Advocacy should be performed independently of the Commissioner.

How is the advocacy service organised?

In 2017/18 there were approximately 36 advocates around the country[91], supported by three administrative staff and four regional managers operating from 23 community-based offices across New Zealand. An organisational chart is available to download here[92].

The Director of Advocacy, who is under the umbrella of the Health and Disability Commissioner, but is required by the HDC Act to act independently from the Commissioner, is responsible for entering into and administering advocacy service agreements and monitoring the operation of the advocacy service. The National Advocacy Trust Board provides the day-to-day governance and oversight of the Advocacy Service. The Advocacy Trust is the employee of the advocates.

The contract arrangements and structure of the advocacy service have changed relatively significantly over the years. For example, in 1997 shortly after the Advocacy Service was first established there were 10 service agreements in place. Three of these service providers were already providing advocacy services to the Ministry of Health prior to the appointment of the Health and Disability Commissioner. Many of the remaining service providers were newly established and faced challenges in setting up their services, appointing staff, and becoming familiar with their new responsibilities under HDC Act and Code[93].

The Advocacy Service was then contracted to three service providers in the early 2000s. In around 2006/7 the service was then contracted to just one national provider, i.e. the Advocacy Service Trust (a charitable body). The Advocacy Trust has recently been awarded a contract to provide the service for the next five years. The Director of

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[88] Nationwide Health and Disability Advocacy Service www.advocacy.org.nz/

[89] National Advocacy Trust www.nat.org.nz/

[90] Health & Disability Commissioner. Annual Report for the year ending 30 June 2018.

[91] There were 41 FTE advocates in 2011/2012 according to the Health and Disability Commissioner's Annual Report for the year ending 30 June 2012.

[92] Nationwide Advocacy Service Organisational Chart. www.advocacy.org.nz/media/4638/advocacy-organisational-chart-2018-04-01.pdf

[93] Report of the Health and Disability Commissioner for the year ended 30 June 1997.

Advocacy has the power to commission, from other organisations, specialist advocacy e.g. for rural Maori communities, deaf communities, and residents of an inpatient forensic unit[94].

There was a difference of opinion, in the early years of the establishment of the Advocacy Service regarding whether the advocates should become employees of the Advocacy Service. Responding to recommendations made by a *previous* Health and Disability Commissioner, the *former* Commissioner Ron Paterson stated in his Annual Report in 2000 that,

> *"Recommendations by my predecessor in two other areas, advocacy and proceedings, are more controversial. It has been suggested that advocacy services…currently contracted by the independent Director of Advocacy, become employees of the Commissioner. I have seen no compelling arguments for such a change, and am concerned that would blur the distinction between the impartial Commissioner, who is required to investigate complaints and the advocates, whose role is a partial one to assist consumers. Although advocates have a valuable role to play as the Commissioner's 'eyes and ears' in the community, I doubt that an employment relationship is necessary to achieve this."*[95]

What is the role of the Advocacy Service?

Advocates work within the parameters of their remit set out in Section 30 of the Health and Disability Commissioner Act 1994[96]. In summary, the functions of advocates under Section 30 are:

- To act as an advocate for health consumers and disability services consumers;
- To ensure that health consumers and disability consumers are made aware of their rights under the Code;
- To promote awareness of the procedures available for the resolution of complaints involving a possible breach of the Code; and
- To provide consumers and/or persons entitled to act on the consumer's behalf.

The Advocacy Service emphasises that advocates are not investigators or mediators, nor do advocates make decisions on whether there has been a breach of the Code of Health and Disability Services Consumers' Rights.

How does the Advocacy Service work?

A consumer can access the Advocacy Service in two ways:

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[94] Health and Disability Commissioner Annual Report for the year ended 30 June 2007.

[95] Report of the Health and Disability Commissioner for the year ended 30 June 2000.

[96] Section 30 of the Health and Disability Commissioner Act 1994.
www.legislation.govt.nz/act/public/1994/0088/latest/DLM333948.html

- they can access the service directly via telephone or email to one of the local Advocacy Service offices; or
- their case can be referred to the Advocacy Service by the Health and Disability Commissioner.

The complaint/issue raised by the consumer can be dealt with in a number of ways. If the complaint ***is not*** within the remit of the Advocacy Service, steps should be taken to refer the consumer to the appropriate agency or organisation and/or provide or direct the consumer with information/tools on self-advocacy.

If the complaint ***is* within** the remit of the Advocacy Service. The Advocacy Service can:

- **Refer the complaint directly to the Health and Disability Commissioner** (e.g. if the compliant requires an interpretation of the Code or requires clarification as to whether the Code has been breached). The advocate can help the consumer or their representative prepare a letter of referral to the Commissioner or will prepare the referral letter if the consumer is unable to (e.g. due to the nature of their illness or disability).
- **Help the consumer through self-advocacy and mentoring**: the Advocacy Service provides a range of resources for consumers on writing a letter of complaint. The Service also provides information on "trouble-shooting and problem solving"; having a face-to-face meeting; and 'finding solutions'[97]. The advocate should maintain regular contact with the consumer throughout this process.
- **Provide active advocacy support**: The Advocacy Service may provide more proactive advocacy support if, for example, the consumer will have difficulties with self-advocacy (e.g. if a consumer had communication difficulties because of the nature of their disability); or the issues involved are complex; or the service provider is failing to respond or is responding inadequately to the issues raised by the consumer.

An Advocacy Service flowchart with further information about the advocacy procedure is available to download here[98]. As highlighted in the next section, the Advocacy Service is guided by a Code of Practice, guidelines and competencies that reinforce that the Service should empower consumers by providing them with the right skills to resolve their own concerns. However, it is also committed to providing a "strong voice" for those consumers who have limited ability to self-advocate and those likely to be experiencing institutional discrimination[99].

How is the Advocacy Service regulated?

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[97] For resources see www.advocacy.org.nz/making-a-complaint-to-the-advocacy-service/self-advocacy/

[98] Advocacy Process Flowchart (February 2017) www.advocacy.org.nz/media/3140/advocacy-process-flowchart-2017-02.pdf

[99] Advocacy Guidelines for the Nationwide Advocacy Service. Revised September 2004. https://gazette.govt.nz/notice/id/2005-go1727

The Advocacy Service is guided by both a Code of Practice[100] and a set ofGuidelines[101]. These have been devised and published by the Health and Disability Commissioner but approved by the Minister of Health.

The Code of Practice, summarised in the table below, states that the mission of the Advocacy Service is to *"promote and protect the rights of health and disability service consumers through empowerment advocacy."* The Code is divided into four short sections outlining the purpose of the service; its independence and accessibility; the importance of confidential and ethical practice; and the role of advocates in quality improvement.

Table 2: Nationwide Advocacy Service Code of Practice

Purpose of Health and Disability Advocates	Advocates aim to assist consumers to achieve consumer-centred health and disability services and resolve complaints by: • Providing advocacy services that focus on the resolution of consumers' concerns and complaints. • Promoting respectful relationships and communication. • Empowering and supporting consumers/complainants to take their own action to improve health and disability services. • Educating both providers and consumers on consumer rights.
Independence and accessibility	The Advocacy Service will: • Be easy to contact. • Be well linked to their community and local networks. • Provide advocacy that is free and independent. • Provide independent information about consumer rights and options for dealing with concerns, including how an advocate can assist.
Confidential and ethical practice	Advocates will: • Be trustworthy, act in a non-judgemental way and treat others with respect. • Listen, encourage and validate the consumer's view, taking into account cultural values and beliefs. • Avoid conflicts of interest, and act honestly and in good faith at all time. • Provide consumers with access to their advocacy record, keep information confidential and not disclose information without the proper authority unless safety is compromised. • Be reliable and follow through on actions agreed between the consumer or the consumer's representative. • Provide a level of stability, safety and clarity in meetings and other resolution processes.
Quality improvement and professional practice	• Work to continuously improve quality of service to consumers through ongoing training, professional development, and quality improvement activities.

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[100] Nationwide Advocacy Service Code of Practice www.advocacy.org.nz/about-the-advocacy-service/code-of-practice/

[101] Advocacy Guidelines for the Nationwide Advocacy Service. Revised September 2004.

	• Use appropriate support such as mentoring, peer support and supervision. • Be accountable, seek consumer feedback, take part in regular review of their practice, and participate in monitoring and evaluation of their work. • Demonstrate a commitment to the vision, and standards of the Nationwide Advocacy Service and the principles of the Code of Health and Disability Services Consumers' Rights.

The Code of Practice is complemented by a more detailed set of guidelines that are provided in **Annexe 3** of this paper. These guidelines are divided into three areas, i.e. governance, advocacy practice and management practice.

In addition to following the Code and Guidelines, advocates must gain a comprehensive understanding of the health and disability sector as well as developing substantial knowledge about their local community[102]. A significant part of developing these skills is through professional development, and all advocates should work towards the Advocacy Service's NZQA approved qualification[103].

What is the annual workload of the Advocacy Service?

In 2017/18, the Advocacy Service:

- responded to 11,000 enquiries;
- guided and supported consumers to process over 2,800 complaints;
- provided almost 1,500 education sessions promoting the Code to consumers and providers; and
- networked with local communities including a specific focus on hard-to-reach and vulnerable consumers.

According to the latest Health & Disability Commissioner Annual Report, 84% of the complaints made to the Advocacy Service were closed within three months, 99% within six months and 100% within nine months.

In 2017/18, 88% of all complaints received by the Advocacy Service related to healthcare services and 10% of all complaints related to mental health services. The most common types of providers complained about were District Health Board Services (DHB) (e.g. DHB hospitals) (41%); general practice (15%); prison health services (12%); and residential care facilities (9%)[104].

The box below is a brief overview of the types of complaints the Advocacy Service has recently supported.

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[102] Health & Disability Commissioner Annual Report for the year ending 30 June 2018. www.hdc.org.nz/media/5043/hdc-annual-report-2018.pdf

[103] New Zealand Qualifications Authority (NZQA) Certificate in Advocacy www.nzqa.govt.nz/nzqf/search/viewQualification.do?selectedItemKey=1636

[104] Health & Disability Commissioner Annual Report for the year ending 30 June 2018

Residential disability facility

A consumer said that she did not like a new support worker's style of communication with her, which she found abrupt, loud, and accusatory. The consumer said that she would like an advocate to support her at a meeting with the House Manager, so that she could raise her concerns. Following the meeting, the House Manager reported back that the support work was now aware that the style of communication she had been using was not appropriate. The consumer said that she felt she had been heard and was happy to move on.

General Practice

A consumer went to her GP to have minor surgery to remove a basal cell cancer from her forehead. On the day of the procedure, the GP advised the consumer that the procedure would be carried out by a medical student because the student had better eyesight, and it would cost less. The consumer told the advocate that she had not been informed prior to her appointment that the procedure would be done by a student. She felt that the GP had not listened to her concerns, had not offered any other options, and had pressured her into allow the procedure to be done by the student.

A meeting was arranged; the GP apologised and agreed that his response to the consumer's concerns on the day had not been appropriate. The GP practice decided to develop written information and a form for consent, the draft of which would be sent to the consumer for her input. The consumer said that she would not have been comfortable meeting with the GP if the advocate had not supported her.

In addition to dealing with complaints and issues raised by consumers, the provision of free education and training[105] sessions is a significant part of the Advocacy Service workload. The aim of these sessions is to promote the Code of Rights and the Advocacy Service via programmes such as self-advocacy; dealing effectively with complaints; using complaints to improve service quality; informed consent; and open disclosure. Advocates also visit residential facilities to ensure that those in older care facilities and disability facilities and their families are aware of the services provided by the Advocacy Service. Advocates visited all of the 660 certified residential care facilities and all 930 residential care facilities for disabled people nationwide. More than half of all these facilities were visited twice[106].

5 Western Australia – the Health and Disability Complaints Office

The Health and Disability Complaints Office[107] (HaDSCO) is an independent statutory authority that provides a free and impartial resolution service for complaints relating to health, disability and mental health services in Western Australia and the Indian Ocean Territories. HaDSCO provides two key services:

- The assessment and investigation of complaints, including conciliation and negotiated settlements. This includes using information about complains to identify

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[105] Arranging for an advocate to provide an education or training session www.advocacy.org.nz/advocacy-service-education-and-resources/arranging-for-an-advocate-to-provide-an-education-or-a-rights-promotion-session/

[106] Health & Disability Commissioner Annual Report for the year ending 30 June 2017.

[107] Health and Disability Complaints Office. www.hadsco.wa.gov.au/home/

systemic issues and working collaboratively with all parties to improve service delivery and complaints management; and

- Education and training in the prevention and resolution of complaints.

HaDSCO is led by a director and three Assistant Directors (responsible for Governance and Executive Services; Strategic Services and Community Engagement; and Complaints and Systemic Improvement). The functions of the Director is set out Health and Disability Services (Complaints) Act 1995[108]. The Act states that the Director will[109]:

- Deal with complaints;
- In collaboration with groups of providers, groups of users, or both, review and identify the causes of complaints and suggest ways of removing and minimising those causes including bringing them to the notice of the public;
- Provide service users and service providers with details of the complaints procedures;
- Assist providers in developing and improving complaints procedures and assist in the training of staff in handing complaints;
- With the approval of the Minister of Health, inquire into broader issues of healthcare arising from complaints received;
- Provide advice generally on any matter relating to complaints; and
- Provide advice to service users on the making of complaints to registration boards and other avenues available for dealing with complaints.

How does the investigation process work?

HaDSCO's complaints resolution process is governed by three pieces of legislation[110] and complaints can be lodged against individuals or organisations that provide a health, disability or mental health service. These may include[111]:

Health Services	Disability Services	Mental Health Services

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[108] The Health and Disability Services (Complaints) Act 1995 www.legislation.wa.gov.au/legislation/statutes.nsf/main_mrtitle_415_homepage.html

[109] Information extracted from www.hadsco.wa.gov.au/aboutus/index.cfm

[110] Health and Disability Services (Complaints) Act 1995; Part 6 of the Disability Services Act 1993; and Part 19 of the Mental Health Act 2014.

[111] Information extracted from www.hadsco.wa.gov.au/aboutus/services.cfm

Medical Practitioners Nurses and midwifery Ambulance service Dentists Chiropractors Occupational therapists Social workers in a health setting Psychologists Public hospitals Private hospitals Screening and immunisation services	Accommodation Advocacy services Carer's respite Day activities, recreation and leisure services In-home support Therapy services	Allied Health Professionals Community mental health services Mental health nurses Non-governmental organisations that are publically funded Private hospitals Private psychiatric hostels Psychiatrists Psychologists Public hospitals

There are two ways in which complaints may be dealt with by HaDSCO, i.e., **complaints resolution** or **formal investigation**.

Complaints resolution[112]

The HaDSCO complaints resolution service is free, impartial and confidential. It encourages parties to discuss complaints and works towards mutually agreed outcomes. HaDSCO is generally unable to deal with complaints that are more than two years old or that have already been determined by a court, registration board or tribunal.

In the first instance HaDSCO encourages complaints to be raised with the service provider. If this proves unsatisfactory, complainants (or their representatives) can call HaDSCO's Assessment Team to discuss the complaint. The Assessment Team will outline the options, explain the complaints process and organise a complaint form to be sent by post. Alternatively, complaint forms can be completed online or sent electronically (e.g. by email). All complaints must be confirmed in writing and once the form is received, HaDSCO will determine how best to deal with the complaint and may contact the service provider.

When complaints relate to a registered health professional, HaDSCO is required by law to consult with the Australian Health Practitioner Regulatory Agency (AHPRA)[113].

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[112] Information in this section extracted from www.hadsco.wa.gov.au/

HaDSCO consults with AHPRA to manage complaints relating to the health, performance or conduct of registered health practitioners in order to determine which is the more appropriate body to manage the complaint. In some cases different aspects of a complaint are managed by both bodies. For example, AHPRA may investigation allegations relating to the performance or conduct of an individual practitioner whilst HaDSCO will manage the broader systemic issues that may have contributed to the cause of the complaint[114].

There are two HaDSCO resolution processes – **negotiated settlement** and **conciliation**. **Negotiated settlement** involves an exchange of information between the parties via a case manager. This can be conducted over the telephone, by email, or in writing and does not generally involve a face-to face meeting. The role of the negotiator is to assist in the exchange of information and to promote resolution of the complaint. **Conciliation** generally involves all parties engaging voluntarily in a face-to-face meeting to discuss the complaint. This will be conducted by a trained conciliator. This process should enable both parties to openly discuss the complaint. The conciliator will meet individually with each party to discuss and clarify issues raised and ensure that all parties are prepared for the meeting.

Prior to the face-to-face meeting, the conciliator may:

- Gather more details about the complaint;
- Review any medical or procedural documentation;
- Determine any relevant applicable standards;
- Assist with determining realistic outcomes; and
- Discuss the conciliation process with all parties and actively encourage parties to engage in the resolution of the complaint.

After the conciliation process, a report is prepared and provided to both parties. The report will highlight important aspects of the complaint and any outcomes that were agreed.

HaDSCO has a dedicated section of the website for young people wishing to make a complaint.[115]

Case study: conciliation process[116]

Mr Knight visited the Emergency Department in a public hospital with head pain. He was treated for a migraine, provided with painkillers and sent home. His pain did not go away and he later visited his GP who informed him he had a bleed to the brain and required surgery.

Mr Knight was unhappy that he had been turned away from the hospital and felt a more in-depth

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[113] Australian Health Practitioner Regulation Agency https://www.ahpra.gov.au/

[114] HaDSCO Annual Report. 2015-16.

[115] See www.hadsco.wa.gov.au/complaints/young-people.cfm

[116] Information extracted from www.hadsco.wa.gov.au/providers/case_studies.cfm

assessment would have highlighted the bleeding. He also felt he could have been made more aware of what to do if the pain did not subside, as he would have returned to hospital sooner.

Mr Knight had attempted to raise these concerns with the service provider, but was not satisfied with the outcome. He lodged a complaint with HaDSCO.

HaDSCO worked with both the service provider and Mr Knight to achieve a mutually agreeable outcome using the conciliation process. The process was facilitated by a HaDSCO case manager which allowed both parties to meet and discuss the issues face-to-face. The service provider was able to openly discuss the issues surrounding the situation and provided an apology to Mr Knight.

In addition, HaDSCO worked with the provider to identify areas for service improvement. An information sheet for staff has been produced which explains to patients the circumstances when they should return to the emergency Department if suffering from headaches.

Investigations

Investigations are undertaken by HaDSCO via a formal process in which it determines if any unreasonable conduct has occurred on the part of the service provider. Investigations will look into a broad range of issues including the identification of areas for improvement. The Director of HaDSCO may also undertake investigations:

- When the Minister is of the opinion that it is in the public interest; or
- At the direction of the Minister for Health, Minister for Mental Health or Minister for Disability Services; or
- If a complaint cannot be resolved through conciliation and warrants investigation.

During the investigation process, the investigator has the power to conduct interviews and view documents. The Director has the statutory power to summon individuals or documents, apply for a warrant to enter a premises; and inspect premises.

At the completion of an investigation, each party is provided with an opportunity to respond to the findings of the investigation and to make representation to the Director. If findings of unreasonable conduct have been made, the provider must advise HaDSCO what measures been put in place to comply with the recommendations.

Outcomes of complaints

In 2017-18 the complaint resolution process produced a redress outcome in 77% of the complaints closed by negotiated settlement, conciliation or investigation. The most common redress outcomes involved:

- the service provider offering an explanation to the individual making the complaint;
- an apology given by the service provider;
- the service provider refunding or waiving costs; or

- a service obtained for an individual who had previously been denied the service, or had experienced difficulties accessing the service[117].

How is HaDSCO regulated?

The service is guided by a series of **partnership agreements** and **memoranda of understanding** including:

- the Mental Health Complaints Partnership Agreement: this is an agreement between the HaDSCO and the Department of Health, Council of Official Visitors, Office of the Chief Psychiatrist and Mental Health Commission. The intention of this agreement is to effectively manage mental health complaints including ensuring that they are dealt with in a timely manner.
- The Memorandum of Understanding between the Australian Health Practitioner Regulation Agency and Health Complaints Entities: the purpose of this MOU is to outline the respective roles, responsibilities and working arrangements to achieve timeliness and consistency in (i) notifying each other about the receipt of complaints and notifications; (ii) consultation about the future management of a complaint or notification; and (iii) the sharing of information.

In addition to this HaDSCO reports annually on a set of '**performance indicators**' relating to effectiveness; legislative requirements; and provision of education and training in the prevention and resolution of complaints. Further information on these indicators is available from HaDSCO annual reports, which are available to download here[118].

What is the annual workload of the service?

According to its 2017/18 Annual Report:

- HaDSCO received 2,719 complaints;
- 39 service improvements were made by service providers as a result of HaDSCO's involvement;
- 163 redress actions were facilitated by HaDSCO; and
- HaDSCO had undertook 159 engagement activities with stakeholders.

6 Other advocacy models

The final section of the paper looks very briefly at some other models of independent advocacy in other jurisdictions. The information in this section is not as comprehensive as the previous sections because (a) of the lack of information in the English language for some of the jurisdictions, or (b) where there is a lack of available information

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[117] HaDSCO Annual Report 2017-18.

[118] HaDSCO annual reports www.hadsco.wa.gov.au/publications/annual_reports.cfm

generally; or (c) because the body commissioned to provide advocacy provides that advocacy for a specific client group rather than for the general population (e.g. people facing mental capacity decisions, older people in long term care, patients in hospitals).

Alberta (Canada) – Office of the Alberta Health Advocates

The role of the Office of the Alberta Health Advocates[119] is to promote self-advocacy and support Albertans in dealing with their concerns about health safety by:

- Listening to the concerns and supporting people in finding ways to resolve them;
- Providing education about the Alberta Health Charter (i.e. a charter of patient rights and responsibilities);
- Referring people to the appropriate complaints resolution process;
- Reviewing or investigating complaints under the Alberta Health Act;
- Reporting to the Minister of Health on the Health Advocates activities and health related issues.

The Advocate service is divided into two sections i.e. a 'Health Advocate' section and a 'Mental Health Patient Advocate' section. The role of the Health Advocate is to *'review, assist, navigate and educate and inform':*[120]:

- **Review:** in cases where no other dispute resolution process exists, the Health Advocate may carry out a review or investigation into situations where it is believed that a service provider has failed to act in a manner consistent with the Alberta Health Charter.
- **Assist:** when someone contacts the Health Advocate office, they will be connected with a **Health Advocate Representative**, who will listen to their concerns. The Health Advocate Representative will conduct any necessary research and inquiry in order to learn more about the concern. They will then work with the individual to develop a plan of action and provide support so that they can act on their own behalf (self-advocacy) when a referral is made to another complaint process, programme or service.
- **Navigate:** given that the health service system is complex and difficult to understand, the Health Advocate assists individuals to locate the appropriate health service and resources.
- **Education and Inform:** the Health Advocate provides education about the Alberta Health Charter and how it applies to Alberta's health system.

The Health Advocate *cannot*:

- Represent an individual at court or tribunals;
- Reverse a clinical or administrative decision;

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[119] Office of the Alberta Health Advocates. www.albertahealthadvocates.ca/Pages/default.aspx

[120] Information extracted from the Health Advocates website www.albertahealthadvocates.ca/advocates/Pages/Health-Advocates-Office.aspx

- Take disciplinary action against any health service provider;
- Impose or order any fines or penalties; or
- Investigate complaints involving federal or municipal governments or non-health related companies.

The Mental Health Patient Advocate[121] (MHPA) also comes under the auspices of the Office of the Alberta Health Advocates. The Mental Health Patient Advocate (MHPA) was established in 1990 under the Albertan Mental Health Act[122]. It reports directly to the Minister of Health and Acts independently of the health system. The MHPA is legislated under this Act to help people who are or have been detained in hospital under admission or renewal certificates and people under community treatment orders (CTO), and those acting on their behalf, to understand and exercise their rights.. Whilst it recommends that people seek to find a resolution to their issue with the provider in the in the first instance it will *"…where our jurisdiction allows…take your complaint and assist you as best we can".* A diagram of the mental health complaints resolution process is available to download here[123].

Denmark – National Agency for Patients' Rights and Complaints

The **National Agency for Patients' Rights and Complaints** is an independent body intended to be a single contact point for complaints. It has four principle responsibilities[124]:

- To provide a single point of access for patients who wish to complain about treatment in the Danish health service;
- To deal with complaints about the disregard of patient rights;
- To deal with complaints about the Patient Insurance Association's decisions over compensation;
- To provide "*for the administration of the system for reporting inadvertent incidents within the health service, and helps to make sure that the knowledge gained from these incidents and patient and liability suits is used preventatively*"; and
- To offer guidance on rights to healthcare in other countries in accordance with Danish legislation, EU regulations and other international agreements.

Complaints relating to treatment and complaints relating to any breach of patient rights are handled by The National Agency for Patient Rights and Complaints. However, complaints about the **professional work of any individual healthcare employee** are settled by **The Disciplinary Board of the National Health Service**, which is a separate part of The National Agency for Patients' Rights and Complaints. The

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[121] Mental Health Patient Advocate www.albertahealthadvocates.ca/complaints/Pages/default.aspx

[122] Alberta Mental Health Act www.albertahealthservices.ca/info/mha.aspx

[123] Office of the Alberta Health Advocates. Mental Health Complaints Resolution Process. www.albertahealthadvocates.ca/SiteCollectionImages/mhpacomplaintprocess.PNG

[124] PRE_MAX Consortium. Patients' Rights in the European Union. European Commission. March 2016.

National Agency for Patients' Rights and Complaints in unable to award compensation, this is the remit of The Patient Insurance Association[125].

Unfortunately, it has not been possible to explore the remit of the National Agency for Patients' Rights and Complaints in further detail due to the lack of information available in the English language.

Hungary – Patients' Rights Advocates

Patients in Hungary have a statutory right to have access to a patient advocate who will assist them in (a) accessing their medical records and/or (b) lodging a complaint with the healthcare institution in question. Advocates have the power to enter the premises of a health service provider; to have access to relevant documents; and to address questions to healthcare workers[126]. Unfortunately, there appears to be very little further information on the Hungarian model available in the English language.

Norway – Health and Social Services Ombudsman

The Health and Social Services Ombudsman[127] is a statutory role under the Heath and Rights Act. The Ombudsman website states that it has *"a low threshold for contact and act as a voice for patient and clients who find it difficult to safeguard their own interests"* and that "*often our work is to create contacts between patients and healthcare services for matters to be resolved outside the formal complaints procedures*". The website further states that the Ombudsman is independent and free to express its views on matters that it feels should be changed in order to provide patients and users with better health services[128]. The role of the Ombudsmen (there should be one in each "county" in Norway) is to:

- Answer and clarify general questions regarding health and social services;
- Hear about patient experiences with health and social services;
- Provide advice and guidance regarding patient rights;
- Assist patients in meetings with service providers to obtain answers to their questions;
- Help formulate a compensation claim if necessary;
- Provide advice on what to do if a patient has been injured; and
- Provide advice on other points of contact if the Ombudsman is unable to provide assistance.

Unfortunately there a lack of further information on this model in the English language.

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[125] Lillebaelt Hospital. My right as a patient: information booklet.

[126] Information extracted from www.szoszolo.hu/50english/frindex.htm

[127] Health and Social Services Ombudsman. https://helsenorge.no/pasient-og-brukerombudet/health-and-services-ombudsman

[128] For further information see "Building a Patient Ombudsman scheme: the Norwegian experience.
www.researchgate.net/publication/230712798_Building_a_Patient_Ombudsman_scheme_the_Norwegian_experience

California – Office of Patient Rights

The California Office of Patient Rights[129] is part of an organisation called Disability Rights California which has a contract with the Department of State Hospitals to ensure the treatment and legal rights of people receiving mental health treatment are maintained. **Patients' Rights Advocates** (PRAs) are available in state hospital and are employees of Disability Rights California. PRAs are legally mandated to investigate and resolve complaints received from individuals about violations or abuse of their rights and to act as an advocate for individuals who are unable or afraid to file a complaint. The California Office of Patient Rights is also responsible for co-ordinating the state hospital patient complaint process, including the intake and tracking of all complaints, the identification of patients' rights for advocate investigation or response, and the referral of all other complaints to appropriate programme/department staff for response and/or resolution.

Ontario and Alberta – mental health and mental capacity advocacy

The Ontario Government launched the Psychiatric Patient Advocate Office[130] (PPAO) in 1983 as a provincial programme aimed at safeguarding the rights and entitlements of patients in the provincial psychiatric hospitals. The PPA) operates as an arm's length programme of the Ontario Ministry of Health[131]. The role of the PPAO is to[132]:

- Advance the legal and civil rights of patients by means of both individual case work and systemic advocacy;
- To inform the patient, family, hospital staff and the community about patients' legal and civil rights;
- To assist, facilitate, and help resolve the complaints made by psychiatric patients by providing an avenue for resolution through negotiation according to the patients' instructions;
- To investigate alleged incidents and to assess institutional and systematic responses to these instances; and
- To refer patients, when necessary, to community advocacy resources such as community organisations, lawyers, or physicians who may offer a second opinion.

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[129] California Office of Patient Rights www.disabilityrightsca.org/what-we-do/programs/california-office-of-patients-rights-copr

[130] Psychiatric Patient Advocate Office www.sse.gov.on.ca/mohltc/ppao/en/Pages/AboutthePPAO/OurServices_A.aspx?openMenu=smenu_OurServices

[131] Psychiatric Patient Advocate Office. Honouring the Past, Shaping the Future. 25th Anniversary Report. www.sse.gov.on.ca/mohltc/ppao/en/default.aspx

[132] Information extracted from the PPAO website www.sse.gov.on.ca/mohltc/ppao/en/Pages/AboutthePPAO/MandateandHistory_C.aspx?openMenu=smenu_MandateandHistory

The PPAO website states that it is the only province-wide programme offering independent, instruction-based advocacy services to in-patients in each of the 9 dedicated psychiatric hospitals in Ontario[133].

There is a similar mental health advocacy body in Alberta known as the Mental Health Patient Advocate (MHPA)[134]. The MHPA was established in 1990 under the Mental Health Act and assist people who are or have been detained in hospital under admission or renewal certificates and people under community treatment orders. The MHPA reports to the Minister of Health in Alberta but acts independently of the health system, i.e. it is not part of a provincial health authority, hospital, clinic or treatment team. The Health Advocate has the authority under the Alberta Health Act to investigation (either formally or informally) where it is alleged that someone has acted in a manner that is inconsistent with the principles set out in the Alberta Health Charter (i.e. a charter of patient rights and responsibilities).

Delaware and Iowa (USA) – long-term care advocacy

The Long Term Care Ombudsman[135] is a state-wide programme advocates for residents who live in long term care facilities (including assisted living facilities) as well as those who live in their own homes but receive community based services. The Ombudsman programme investigates and resolves complaints on behalf of these individuals. The programme also provides opportunities for Volunteer Ombudsmen to serve as friendly visitors/advocates in nursing homes. The Ombudsman programme can assist when residents or family members have questions or concerns about the rights of persons in long-term care; quality of care or treatment from a care service provider; appeals regarding discharges or changes in services; and billings and charges[136]. The Long-Term Care Programme is operated by the Delaware Health and Social Services Office of the Secretary.

In Iowa, the Office of the State Long-Term Care Ombudsman (OSLTCO)[137] is authorised by the federal laws to protect the rights of those living in nursing facilities, residential care facilities, assisted living programmes and elder group homes. The OSLTCO is legislated for under federal law operates as an independent entity within the IOWA Department on Aging. Its purpose is to protect the health, safety, welfare and rights of individuals living in long-term care facilities by investigating complaints, seeking resolutions to problems and providing advocacy with the goal of enhancing quality of life and care.

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[133] Information extracted from www.sse.gov.on.ca/mohltc/ppao/en/Pages/SystemicAdvocacy/AccesstoAdvocacyServices.aspx?openMenu=smenu_SystemicAdvocacy

[134] Mental Health Patient Advocate. www.albertahealthadvocates.ca/advocates/Pages/Mental-Health-Patients%27-Advocate-Office.aspx

[135] Long Term Care Ombudsman - https://dhss.delaware.gov/dhss/dsaapd/ltcop.html

[136] Information extracted from https://www.dibbern.com/ombudsman/de-long-term-care-ombudsman.htm

[137] Office of the State Long-Term Care Ombudsman www.iowaaging.gov/state-long-term-care-ombudsman

Annexe 1

This Annexe sets out the four “core characteristics of independent health complaints advocacy’ contained with the Local Government Association’s ‘**Practice Guidelines for Independent Complaints Advocacy Services**’ in England. It recommends four characteristics an independent complaints advocacy service should have, i.e.:

- The service is **known, accessible and responsive**;
- The service is **professional**;
- The service is **independent**; and
- The service **makes a difference**.

The guidelines also set out in detail individual service specifications; how these characteristics should be measured; what the outcome should be if a service has succeeded in achieving the associated aims; and how individuals should experience the different aspects of the service.

The service is KNOWN, ACCESSIBLE AND RESPONSIVE			
Service Specification	**How do individuals experience this?**	**Outcome if successful**	**Measure**
1.1 Clear communication strategy	I know about the support the service offers and how to access it.	People know about the service and find it easy to use if they need it.	• A clear communication strategy is developed, implemented and subject to regular review using a range of media and networks.
1.2 Proactive engagement strategy will all sectors of the community	I feel that services are appropriate and adaptable to my particular needs.	Evidence of increasing uptake reflective of local demographics (including ‘seldom heard’ groups) and positive client feedback.	• There is evidence that people given support reflect local demographic diversity, in particular ‘seldom heard’ groups. • There is evidence of regular, effective and systematic feedback on service effectiveness and satisfaction. • There is evidence of assessing clients’ advocacy support needs e.g. language, mobility, literacy and mental health.
1.3. Focused on empowerment and the promotion of self-advocacy, wherever appropriate	I can access the level of support I need and gain skills, information and confidence to address complaints myself.	Increasing use of self-advocacy tools and positive client feedback.	• There is evidence of increasing use of self-advocacy resources. • Client satisfaction surveys.
1.4 Good understanding of local landscape,	I was supported to access other services that	Evidence of working with other stakeholders to	• Up to date data on complaints by organisation, topic and trends in complaints.

good relationships with the health and social care system and able to respond to changing needs.	could help me.	signpost and refer appropriately.	- There is evidence of sharing information with other organisations, including local Healthwatch, voluntary and community sector, health commissioners and providers.
The service is PROFESSIONAL			
Service Specification	**How do individuals experience this?**	**Outcome if successful**	**Measure**
2.1 There is a clear purpose and description of service	I understand what the service can and cannot do for me.	Reduction in the proportion of inappropriate referrals and increase in appropriate referrals.	- Evidence of clear purpose and description of service available to all staff and clients. - Evidence that above is regularly reviewed and updated as necessary.
2.2 All staff and volunteers are properly trained, managed to recognised professional standards ad with relevant qualifications, including and with a quality system appropriate for the size and nature of the organisation.	I am confident that staff deliver a high quality professional service.	Evidence that all staff are trained and supported appropriately, and high staff satisfaction levels. Good reputation with other local agencies and providers.	- Evidence of appropriate advocacy qualification for all relevant staff. - Evidence of relevant training for all staff. - Evidence of regular and effective support and management of staff through regular one to one appraisals, performance objectives.
2.3 All appropriate policies and procedures are in place and implemented, especially on safeguarding, confidentiality and consent and information management (i.e. data retention and handling).	I have been given easy to understanding information about confidentiality, safeguarding and consent to share information.	All policies are up to date and the service can demonstrate that it is acting lawfully.	- Evidence that policies are in place, up to date and regularly reviewed, in particular on safeguarding, confidentiality, consent and information management.
2.4 Clear governance of complaints procedures of the	I know how to complain and what to expect from the	Evidence that complaints were addressed and led to appropriate	- Clear complaints procedure in place and regularly reviewed. - Individual and trend data on complaints about service and measures taken to

organisation	complaints process.	improvements in the service	resolve complaint.
2.5 Clear and reasonable standards for timeliness and responsiveness	I am satisfied with the time the service responded to my needs.	Evidence of response times related to targets within service specification.	• Evidence of response times and case duration. • Trend data on response times and case duration.
2.6 Commitment to deploy available resource to best effect	I received support and was advised of other services to meet all my needs.	Evidence of increase in access to self-advocacy tools and evidence of appropriate signposting to other services.	• Evidence of increased use of self-advocacy tools. • Evidence of collaboration with community and third sector partners to ensure best use of resources.
The service is INDEPENDENT			
Service Specification	**How do individuals experience this?**	**Outcome if successful**	**Measure**
3.1 Statement of how organisations will demonstrate independence from providers and commissioners.	I am confident that the service is independent of the NHS and will support my own expressed needs.	Evidence of recognised quality system. Evidence of action taken by service to highlight systemic issues with the commissioning authority.	• Evidence that the provider has signed up to and implemented the Advocacy Charter. • Evidence that the provider has attained and retained the Advocacy Quality Performance Mark (QPM) or equivalent quality system that includes the principles of the Advocacy QPM.
3.2 Clear policy and process for identifying, registering and addressing conflicts of interest	I am confident that any conflicts of interest will be addressed.	Evidence that policies are implemented and acted upon.	• Evidence in terms of reference of provider that conflicts of interest are identified, registered and addressed.
3.3 Adoption of the principles of the National Advocacy Charter	I am confident that, first and foremost, the service is here to support me.	Demonstrable evidence of adherence to Advocacy Charter	• Evidence of compliance with principles of the Advocacy Charter or local equivalent.
The service MAKES A DIFFERENCE			

Service Specification	How do individuals experience this?	Outcome if successful	Measure
4.1 Agreed performance and outcome measures and regular reporting of them	The service explained to me how my complaint could help to improve health services.	Increase in user satisfaction levels.	• Evidence of regular, effective and systemic feedback on service effectiveness and satisfaction. • Quarterly performance data on service use, case duration, case referral and resolution. • Documented and published information on feedback received and changes made.
4.2 Clear arrangements for seeking an acting on client feedback.	I am asked for my experience of the service and I know about changes that have been made.	Increase in user satisfaction levels.	• Evidence of regular, effective and systematic feedback on service effectiveness and satisfaction. • Quarterly performance data on service use, including downloading self-advocacy tools, case duration, case referral and resolution. • Documented and published information on feedback received and changes made.
4.3 Clear processes for raising concerns with commissioners, providers and regulators	I am aware that the service will raise issues on my behalf to make improvements in health services.	Evidence that systematic issues have been raised and followed up with providers, commissioners and regulators.	• Evidence that the provider raises and follows up systemic issues with providers, commissioners and regulators.
Robust information collection and reporting arrangements on trends and issues	I know about trends in health service complaints and what the advocacy service have done to raise this with providers, commissioners and regulators.	Data from advocacy service has been used to identify areas for health service improvements.	• Evidence included in annual reports of advocacy providers. • Quarterly performance reports with commissioners of advocacy services.

Annexe 2

Healthwatch 'Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service'

Standard 1: The advocacy service is client-led

Why is the standard important?	What service users want	Indicators
Advocacy is a service led and controlled by the client at all times. The role of an advocate is to support, inform and represent the client, rather than to give advice, make decisions, or act in the person's best interests if not instructed to do so.	*"I want to be in control of the advocacy process at all times. I don't want the advocate to push their own agenda or tell me what to do. I want them to listen to me and only act on my instructions"*	The advocacy provider demonstrates: • they record what the client wants to happen (their outcome) and agree the actions with the client that will support this outcome to be achieved. • that clients feel in control of the advocacy process and relationship, and the advocacy provider implements reasonable suggestions from clients that enable clients to feel more in control. • that their clients are informed of any limits to confidentiality and if confidentiality is to be breached, clients are informed of the reasons why. • that information is provided to, and reviewed with, their clients who are supported to then decide on their next steps. • that clients have achieved their desired outcome, and if not, the reason for this are identified and discussed with the client. • that they make available, free of charge, tools to help people self-advocate (including templates for letters, information on other services clients may wish to use). • that the advocate follows up on actions agreed with the client and offers regular feedback so the client is informed of progress, especially when developments or delays have occurred. • its advocates are trained in escalating concerns, are escalating concerns appropriately, and that the outcomes of all escalations are monitored. • that their stakeholders are ware that all information given to the advocacy provider will be shared with the client.

Standard 2: The advocacy service is independent

Why is the standard important?	What service users want	Indicators
Advocates must be free to offer a full range of support to clients and not be compromised by conflicts of interest that may prevent them from acting on behalf of service	*"I want my advocate to offer me the full range of advocacy support without being worried, restricted or limited by the health and care provider, commissioner or anybody else"*	The advocacy provider demonstrates: • that its staff and clients understand how the provider is independent from commissioner and funders and how these relationships are managed so as not to compromise independence. • that clients have confidence in the service because people running the organisation – and those involved at trustee or director level – do not work for

users.		the commissioning body or any health or care provider a service user may complaint about. • that they are open and transparent about any funding criteria and performance measures that are in place for their contracts and demonstrate that these are not compromising the integrity of their advocacy service. • that they are recording and managing any conflicts of interest (real or perceived) and can demonstrate the steps they have taken to address any conflict. • they are acting on their clients' instructions; they review and address any concerns raised by clients or staff that an advocate was unable to act according to the wishes and needs of the client. On an occasion the advocacy provider or their client feel the advocate has not acted on a client's instruction, they demonstrate that the reason(s) for this are identified and explained to the client. • that their stakeholders are aware and understand that the advocacy role is independent and client-led.

Standard 3: The advocacy service is accessible to everyone who needs a complaints advocate

Why is the standard important?	What service users want	Indicators
Complaining can be a challenging experience for many people and asking for advocacy can be difficult, particularly when people are not aware of the service.	*"I want it to be easy to find my local advocacy service and get an advocate. I want the advocacy service to respond to my needs"*	The advocacy provider demonstrates: • that it is proactively raising awareness about the right to advocacy and helps other organisations understand when and how to refer people to the service. • that it is raising awareness of its services amongst potential clients in locations where people receive health and care services (e.g. hospitals, care homes, prisons). • that it is promoting awareness to people from health and social care organisations, including complaint managers, explaining the role of an advocate and when to refer people to the service. • agreed protocols are implemented with complaints managers so individuals using these services are provided with information about their right to access advocacy when making a complaint. • It has an appropriate range of marketing information including easy read versions and a user friendly website. • a range of methods for potential service users and referrals to contact the service are available (e.g. telephone, email, text, face to face appointments) and that these meet the needs of the local community. • how caseloads are managed and appropriate supervision provided along with training in both promoting diversity and understanding of the barriers people face in accessing advocacy. • That a client's advocate only changes when absolutely necessary and the steps taken to ensure

		continuity. If any advocate changes, the reasons for any changes are recorded and communicated to the client. • that it has a strategic approach to ensure that it is accessible to the local community; is collecting, analysing and acting on feedback from clients about how accessible the service is; and is collecting monitoring data on who is using the service. This includes identifying if any client groups are under-represented amongst their users and how they are addressing these. • That is it recruiting and training advocates with the specialist skills required to enable advocates to work with seldom-heard groups.
Standard 4: the advocacy service maintains a clarity of purpose		
Why is the standard important?	**What service users want**	**Indicators**
Advocacy can be easily misunderstood and confused with other types of support (such as legal advice or counselling). In order to deliver an effective service, it is essential that service users and other stakeholders are clear about what the advocacy service can (and cannot do).	*"I want to understand precisely how the advocacy service can help me. When I want other types of support I want help to find out about other services and support in accessing them"*	The advocacy provider demonstrates: • that it is ensuring advocates remain in the complaints advocacy role, quality assuring case records to ensure the actions taken by the advocate reflect best advocacy practice and addressing any situations where this is not the case. • it is proactively raising awareness about the right to advocacy and helps other organisations understand when and how to refer people to the service. • that it is ensuring clients are being signposted or referred to other services as required and gathers feedback from other services about the appropriateness of the signposting or referral.
Standard 5: The advocacy service provides a compassionate response		
Why is the standard important?	**What service users want**	**Indicators**
Many people who are thinking about or making a complaint are often exhausted and emotionally spent from their experiences. At the point of asking for advocacy support people require emotionally sensitive support that enables them to progress.	*"I want to be treated with kindness and be shown compassion by an advocacy service that understands my needs. I want the service to understand I may be experiencing a whole range of difficult emotions that may affect my complaint and the ability to complain"*	The advocacy provider demonstrates: • that it learns and acts on feedback from all client users who are provided with the opportunity to comment on whether they feel they received advocacy support which was sensitive and compassionate; were treated with dignity and respect; and felt listen to. • That it is recruiting and training advocates with the specialist skills required to enable advocates to work with clients with complex needs. • That it offers to meet clients in their preferred meeting place and regularly ensures the premises they use to meet with people are suitable. This includes private meeting places for clients in a locked environment e.g. a secure mental health hospital or prison.
Standard 6: The advocacy service works with other networks to achieve systemic		

changes

Why is the standard important?	What service users want	Indicators
Complaints advocates witness the way health and social care services are delivered through the eyes of service users. Through representing individuals, they become aware of systemic issues that affect all service users within their area. By identifying themes and trends and feeding these back to services such as Healthwatch, the Care Quality Commission, and commissioners, the complaints advocacy service can play an important role in improving the way health and care services are delivered. This is not the same as being responsible for this change – but advocacy should contribute to local networks that collectively improve services.	*"I want to advocacy service to make sure it takes action to improve the way health and social care services are delivered, so no one else with have to go through the experiences I went through"*	The advocacy provider demonstrates: • that it is identifying, monitoring and reporting on trends and issues in its casework. Along with concerns, these issues and trends are shared with key stakeholders, including local Healthwatch, the Care Quality Council (CQC), and individuals responsible for commissioning, managing, scrutiny and regulation of health and social care services. • that they obtain consent to use data from clients and only issue reports after they have checked for any breaches in confidentiality. • the advocacy provider demonstrates they are acting appropriately on safeguarding alerts and follow these up in line with local procedures.

Standard 7: The advocacy service works hard for its advocates

Why is the standard important?	What service users want?	Indicators
Advocates work with people at very vulnerable points in their lives, often in the midst of painful and emotive experiences. The service must develop a culture that offers support to its advocates so they deliver world class	*"I want a service that looks after its staff. I want to know my advocate is trained, supervised and maintains professional standards"*	The advocacy provider demonstrates: • that it offers a suitable induction to all staff. • its advocates receive planned and recorded supervision sessions at regular intervals and advocates are supported to gain suitable qualifications in a timely manner. • How it acts and learns from feedback and complaints, with information being discussed and shared with advocates.

effective advocacy that makes a difference.		
Standard 8: The advocacy service has clear leadership		
Why is the standard important?	**What service users want**	**Indicators**
The advocacy service needs to be well run by people who offer clear leadership to staff and who are effective at developing the service so it has maximum impact in its local area.	*"I want a service that I trust will deliver the very best quality of complaints advocacy support. I want to know that the people running the advocacy service are good leaders and are committed to excellence"*	The advocacy provider demonstrates: • The advocacy provider demonstrates it is using relevant tools to ensure that outcomes are measured and reviewed with subsequent learning implemented across the organisation. • including in an annual report, its key achievements and the steps it has taken to implement its learning to improve the service it offers. • that it has the necessary range of organisational policy documents that reflect current best practice and that these are implemented and regularly reviewed. • that it is identifying its priorities for using resources, is acting to minimise risk and taking advantage of suitable opportunities to deliver its business plan and longer term strategy. • that as an organisation it is it striving to future improve, obtaining or working towards relevant accreditation such as the specialist advocacy Quality Performance Mark.

Annexe 3

Advocacy Guidelines for the Nationwide Advocacy Service of New Zealand

Governing Guidelines	
Empowerment principle	The concept of rights is inherently linked to the empowerment principle. Advocacy is committed to the belief that consumers already have the skills and experience on which to draw to assist them in resolving their concerns. Advocates are required to be a strong voice for those consumers who have limited ability to self-advocate, or who are likely to be experiencing institutional discrimination. A consumer-centred and flexible focus with access to a continuum of empowering strategies is required to ensure the most appropriate approach for each consumer. Working in an empowering way is based on the belief that it is better to equip and support consumers to solve their own problems than to take over their problems and fix them on their behalf. The empowerment principle supports the consumer to resolve the current issue with assistance, and to learn skills and knowledge to develop confidence to self-advocate if and when similar issues arise in the future.
Low-level resolution	The intention is to promote resolution of complaints at the lowest appropriate level. Often the quickest and most satisfying way of dealing with grievances is for the consumer to deal directly with the actual provider of the service. The nationwide advocacy service is therefore fundamental to this aim of low-level resolution.
Code of Practice	Advocacy service providers and advocates shall comply with the Code as if they were providers for the purposes of the Code, except where such compliance is inconsistent with these guidelines.
Interpretation of, and comment on, rights	Advocacy service organisations and individual advocates shall refer any request for interpretation of the Code to the Health & Disability Commissioner. Advocacy service organisations and individual advocates shall not offer opinions about the interpretation of the Code or other rights except to refer consumers, providers or media to any relevant decisions or statements by the courts, Human Rights Review Tribunal or the Commissioner and to assist consumers or providers to understand those decisions and statements.
Quality	It is important that the quality and effectiveness of the advocacy service is monitored and evaluated regularly and that improvements to the service are made on the basis of feedback from consumers, complainants, providers and advocates.
Advocacy Practice Guidelines	
Empowering consumers	Consumers remain in control and take responsibility for their issues, concerns and rights. Advocates, through empowerment advocacy and encouragement, assist all consumers and other complainants to act on their own behalf. If the consumer is unable to act on his or her own behalf or it is culturally inappropriate for the consumer to speak on his or her own behalf and requests the advocate to do so, the advocate may accept instructions to act or assist on behalf of the consumer.

Protecting the wider body of consumers	Advocates may have concerns about a provider's practice or any other matter that relates to the rights of health consumers or disability consumers or both (whether in relation to a particular consumer, a group of consumers, or consumers generally). These concerns may have arisen through an advocate working with a consumer who is unwilling or unable to complain, or from trends identified by the advocate in the course of his or her work, or from concerns raised by others in the community. The concerns can relate to an individual provider's practice, a group of providers' practice, and/or systems and processes used by the provider(s), or a combination of provider practice and the systems and processes being used. When concerns are not confided to a specific provider's or a specific system or process, it is sometimes referred to as being a "systemic" concern. In order to protect the wider body of consumers and ensure the proper accountability of providers, an advocacy service may contact providers directly about the concerns raised, or draw the matter directly to the Commissioner's attention. The advocacy service can contact the provider directly in the first instance when concerns can be appropriately resolved at a low level. The service manager shall notify the Director of Advocacy of all direct contacts about systemic and non-systemic concerns made by advocates, in the absence of a formal complaint. An advocate shall refer systemic and non-systemic concerns that cannot be dealt with appropriately with low level resolution directly to the Health & Disability Commissioner. A referral shall also be made where the concern has been raised previously by the advocacy service, and the provider has not responded or taken appropriate action.
Priorities	Persons who are least able to self-advocate, and those persons whose welfare is most at risk and who do not have an appropriate support person, are the priority for all inquiry and complaint advocacy services to consumers. Those considered as having their welfare most at risk are likely to be consumers who may experience two or more of the following: • *Very little social contact* • *Little or no family support* • *Difficulty in communicating and being understood* • *Living in a situation where physical, emotional, mental or financial abuse by an informal or formal caregiver is threatened or has occurred* • *Mental illness and/or drug or alcohol addictions that may impede their ability to reason and/or be understood or taken seriously.* It is important for advocates to establish, build and maintain positive working relationships with informal and formal providers/caregivers where the consumer whose welfare is most at risk is required to use the ongoing service of the provider or caregiver.
Consumer interdependence	When working with consumers, advocates assist and encourage them to develop their own support networks. This enables them to remain in control and take responsibility for their own issues, concerns and rights. Ongoing support networks may include family, extended family, friends and neighbours, other consumers, paid professionals or advocacy groups to meet their ongoing advocacy needs and to assist in the resolution of their issues. Health and disability consumer advocacy may be used in conjunction with a consumer's network of support people.

Role of advocates	An advocate provides information, facilities, and makes it as easy as possible for the consumer to pursue and resolve his or her concerns and issues with advocacy support. An advocate provides assistance to consumers to pursue a complaint through any informal or formal procedures, including proceedings before a health professional body. An advocate assists a consumer to gain knowledge, and offers skills training to assist the consumer to develop confidence to represent her/himself. This is so that the consumer is supported to resolve the current issue with the assistance and to resolve future issues, where possible, using the skills and knowledge gained through working alongside an advocate. When assisting a consumer, advocates shall not offer opinions as to whether there has been a breach of the Code. The advocate represents or assists the consumer to resolve issues. While advocates may need to obtain information about a consumer's concerns, they shall not investigate or adjudicate on issues raised, nor act as an impartial mediator. If resolution is not achieved, the advocate shall, if requested by the consumer, assist the consumer in finding an appropriate forum where issues raised may be mediated or complaints may be investigated. This can involve the advocate in supporting a consumer through the Health and Disability Commissioner complaint processes and/or the Director of Proceedings processes.
Advocates' role with providers	Advocacy services and advocates support consumers who believe their rights under the Code have been breached. Advocates convey the consumer's issues, concerns and/or complaints, not their own. Advocates are on the side of the consumer and may present some challenging situations to the provider, but this does not prevent them from being fair, considerate and professional in all their dealings with providers. Advocates do not offer an opinion as to whether there has been a breach of the Code, nor are they impartial mediators, investigators or adjudicators. Advocates give free presentations to provider groups, on advocacy services, the Health & Disability Commissioner role, the Code, and the complaints processes available to consumers. Presentations should, where possible, be in a format appropriate to the needs of the audience.
Confidentiality	Advocacy services and advocates shall not make statements to the media, or in presentations, or in personal communications that identify individual consumers or providers, nor comment whether specific actions by providers, either real or hypothetical, are or would be in breach of the Code. Advocates shall comply with the Advocacy Service Organisation's media policy, which upholds this guideline.
Management Practice Guidelines	
Consumers' needs and accessibility	Subject to the priorities imposed in guideline eight of the guidelines ('priorities'), advocacy service providers and advocates shall take positive steps to ensure that they are able to meet the needs of any particular person or groups of persons for whom they have contracted with the Director of Advocacy to provide services.

	Advocacy service providers shall therefore take positive steps to ensure advocacy services are equally accessible to all groups of consumers. Specialist nationwide advocacy services may be contracted with the Director of Advocacy to provide consumers with specialised advocacy. Advocates shall inform consumers of the availability of such nationwide advocacy services and any existing specialist community support groups.
Advocate support	Advocacy service providers shall ensure that appropriate support systems are in place of individual advocates. This may include induction, training, performance management, peer supervision via support and review, risk management procedures, physical safety and appropriate specialist support.
Relationship of the service provider to consumer	Advocacy service providers, rather than individual advocates, are contracted to provide services to the consumer. Consumers shall be advised that the advocate is providing the service as an employee of the advocacy service provider.
Referral to other agencies	Advocacy service providers shall establish and maintain effective links with relevant agencies, including community groups, and refer consumers to those agencies as and when appropriate.
Information systems	The collection, accurate recording and transfer of information pertaining to the services provided by advocacy organisations, including trends in consumer issues, assists in the efficient and effective management of advocacy services. It provides valuable information as to the present and future needs of consumers and the need for any improvements to the service. Reporting requirements in line with contractual obligations shall be facilitated by the use of information systems approved by the Health & Disability Commissioner.
Publicity and promotion	The integrity (principles and professionalism) of the advocacy service is maintained by ensuring consistency in all publicity provided about the Health & Disability Commissioners' Advocacy Service. The Health & Disability Commissioner will provide all generic promotion and educational material, about the Code and the role of the Commissioner, directed to consumers and providers. Promotional and educational material will, where possible, be in accessible formats for consumers. Any specific promotional and educational information produced by individual advocacy service providers will be sent to the Director of Advocacy, prior to publication, for comment. Formal public speaking engagements and papers for publication by advocacy service providers and individual advocates will be notified in advance to the Director of Advocacy for comment.