

Models of patient advocacy

Evidence brief

Deirdre Mongan
Jean Long
Louise Farragher

April 2016

Disclaimer

This evidence brief was produced by the Health Research Board in response to specific questions from the Department of Health. It is not necessarily a comprehensive review of all literature relating to the topic area. It is reproduced for general information and third parties rely upon it at their own risk.

Table of contents

Table of contents.....	1
List of tables.....	2
List of figures	2
Summary.....	3
Introduction.....	9
Purpose of the review.....	9
Research questions.....	9
Methods.....	10
Question 1	12
Definitions of advocacy	12
Models of advocacy.....	13
Approaches to advocacy	15
Questions 2 and 3.....	16
Patient advocacy in New Zealand	16
Background.....	16
Advocacy and complaints process	16
How are advocacy services commissioned and organised?.....	19
What guidelines do advocates have to follow?	20
Evaluation of the New Zealand Advocacy Service	24
Patient advocacy in England	26
NHS Complaints Advocacy Service.....	27
How NHS complaints advocacy services are commissioned.....	30
Ensuring performance and quality in NHS complaints advocacy services.....	33
Evaluation of the NHS Complaints Advocacy Service.....	39
Independent advocacy under the Care Act 2014.....	39
Evaluation of independent advocacy provided under the Care Act 2014	43
Patient advocacy in Western Australia	43
Western Australia complaints system.....	43
The Health Consumers' Council	45
Evaluation of the Western Australia advocacy service	47
Conclusion	48
References.....	50
Appendix 1.....	53

List of tables

Table 1: Description of the most common models of advocacy	13
Table 2: New Zealand health and disability advocacy guidelines	20
Table 3: New Zealand Health & Disability Advocacy Code of Practice.....	23
Table 4: New Zealand health and disability advocacy competencies	24
Table 5: Performance of the New Zealand Advocacy Service for year ended 30 June 2015..	26
Table 6: Description of Healthwatch England	32
Table 7: Key performance indicators for NHS England complaints advocacy services	34
Table 8: Code of Practice for Advocates (National Development Team for Inclusion)	35
Table 9: Standards to support the commissioning, delivery and monitoring of the NHS Complaints Advocacy Service (Healthwatch England)	37
Table 10: Practice guidelines for NHS complaints advocacy services (Local Government Association)	38
Table 11: Anticipated national cost of providing independent advocacy.....	43

List of figures

Figure 1: Empowerment continuum	15
---------------------------------------	----

Summary

Introduction

This report presents the findings of a brief evidence review conducted by the Evidence Centre in the Health Research Board (HRB) on international models of patient advocacy.

Purpose of the review

In its *Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, 2015*, HIQA recommended that a patient advocacy service be established for health services in Ireland. It is proposed that the advocacy service will be external to the Department of Health (DoH) and the Health Service Executive (HSE). The purpose of this review is to identify and examine international models of patient advocacy services for health services to inform the work of the DoH.

Research questions

1. What is advocacy and what models are used for advocacy services?
2. How are state-directed¹ advocacy services established and what are their functions? Countries of interest include England, New Zealand and Australia.
3. In countries with state-directed advocacy services, are these services evaluated?

Methods

We undertook a PubMed search using the Medical Subject Headings (MeSH) term 'patient advocacy'. The search yielded 22,626 hits. Given the tight time frame for completing the review, it was not feasible to screen this number of papers. We then undertook a more targeted PubMed search using the MeSH term 'patient advocacy' and the three English-speaking countries with state-directed advocacy under study, i.e. New Zealand, England and Australia. However, this PubMed search only yielded one relevant paper, which we included in this review. These results determined that the review questions would be best answered by using an iterative or non-systematic process. To answer Question 1 on the different models of advocacy, we undertook a Google search using the following terms; 'models of patient advocacy', 'framework patient advocacy', 'advocacy in healthcare'. We examined the results from the first 10 pages of each search. In order to answer Questions 2 and 3, we repeated the Google search, but we also included the country name under study. Finally, we did a targeted search of websites in each country that may be relevant to this brief.

Findings

Question 1

Definition of advocacy

There are many definitions of the term 'advocacy', and these are broadly similar. The literature on definitions of advocacy is mainly related to the area of disability. One of the

¹ In this review 'state-directed' is defined as carrying out a statutory role specified by the state and funded by the state to do so

more common definitions first appeared in the Australian National Advocacy Research Project; it described advocacy as:

‘Functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous.’

Models of advocacy

There are many advocacy models – one report identified 17 different models. The six models that recurred most often in the literature are:

- **Self-advocacy** – individuals are supported so that they may represent and speak up for themselves;
- **Group advocacy** – people with shared experiences, positions or values coming together in groups to talk and listen to each other and speak up collectively about issues;
- **Peer advocacy** – involves ‘one-on-one’ support by a service user who shares a common experience, past or present, to help another to express and fulfil their wishes;
- **Citizen advocacy** – ordinary citizens are encouraged to become involved with a person in their community who might need support;
- **Independent/Representative advocacy** – an independent service where trained advocates are employed to deal with specific problems and to work with an individual until that problem is resolved;
- **Legal advocacy** – this seeks to defend the rights and interests of people through the legal system.

There is also a model known as **empowerment advocacy**, which is the model of advocacy used by the Health and Disability Advocacy Service in New Zealand. Empowerment advocacy is used to assist, or act on behalf of, a consumer. This requires the advocate to direct the process to assist the consumer to resolve their complaint, rather than directing the content of the complaint. The advocate’s role that works best in empowerment is as a:

- resources person – linking consumers to resources in ways that improve their confidence and solution-finding abilities; or
- coach/mentor – teaching processes and skills, imparting knowledge and information that enable the consumer to retain control of their own concerns and issues.

There are different approaches to advocacy. The focus of advocacy may be on an individual (case advocacy) or a group issue (cause advocacy).

- Case advocacy involves advocating with or for an individual.
- Cause advocacy is issue-based and it aims to influence institutions, governments and society by informing and shaping policies and legislation.

Advocacy may also be instructed or non-instructed.

- Instructed advocacy is working with or on behalf of an individual person or group on the lawful instructions of the person or group.
- Non-instructed advocacy is where the advocate acts independently of the individual, in some cases through necessity, as the individual may be incapacitated or may not have the skills to advocate for themselves. Capacity to instruct or understand can be diminished for a number of reasons, for example, mental health problems, dementia, or learning disabilities.

Questions 2 and 3

Patient advocacy in New Zealand

The Health and Disability Advocacy Service was established in 1996 under the Health and Disability Commissioner Act 1994, following the publication in 1988 of *The report of the Committee of Inquiry into allegations concerning the treatment of Cervical Cancer at National Women's Hospital and into other related matters* (The Cartwright Inquiry). The 1994 Act set up the Office of the Health & Disability Commissioner who acts as the ombudsman, provided for a code of patients' rights, and requires the appointment of an independent statutory officer – the Director of Advocacy. The establishment of the Code of Rights by government regulation gives it legal status and renders it enforceable. Only the Minister of Health can make changes to the code.

Unlike most developed countries, New Zealand has a national no-fault system of compensation for accidental injury, including medical injury. This scheme covers the cost of rehabilitative medical care and earnings-related compensation. Limited lump-sum compensation may be available, and tort claims for damages for negligence are barred. Under this scheme, it is necessary only to prove that the injury was caused by medical treatment and there is no need to establish blame or individual responsibility.

Both the complaints service and the advocacy service are provided by the Commissioner's office. The procedure works as follows. The complainant contacts the advocacy service and an advocate, who is on the side of the complainant, is assigned to assist. The advocate listens to the complainant's story, clarifies rights, and outlines options. If the option selected is a face-to-face resolution meeting, the advocate helps the complainant prepare for this meeting and may attend the meeting. The advocate has a simple resolution agreement form at the meeting in the event that there is agreement to ongoing actions beyond the meeting, and follows up any actions that are not carried out by the date specified. The matter is closed when all or some of the goals have been met, or when the complainant withdraws the complaint, or when an unresolved matter is sent to the Commissioner. Although advocates are on the side of the consumer, the Commissioner is required to be impartial and does not take sides. If a complaint is referred to the Commissioner, both the complainant and the service provider will be asked to provide supporting evidence and may need to be interviewed. The Commissioner may also get advice from an independent expert and may refer the complaint to formal mediation if he thinks the issue can be resolved this way. He will produce a report containing his recommendations, which may range from an apology from the provider to specific recommendations relating to ways in which the provider could improve his or her practice.

Under the 1994 Act, a director of advocacy role was established to purchase advocacy services from community providers and provide the link with, and accountability to, the Commissioner's office. In 1996, three types of groups were awarded the initial contracts: existing advocacy groups working within the health and disability sectors; those working within a mediation model or as complaints services; and newly established services. Initially, there were 10 three-year contracts, but by 1999 the number of contracts had decreased to three, with providers having merged into larger organisations. In 2006, the Director of Advocacy and National Advocacy Trust agreed to one national contract with a National Advocacy Service. Currently, there are 46 advocates in 23 community-based offices. They are supported by administrative staff, four regional team managers, a national education

and training manager, and the national service manager. The expenditure on the advocacy service for the year ended 30 June 2015 was NZ\$4,935,902.

We could not find any independent evaluation of the effectiveness of the advocacy service. The 1994 Act requires the Commissioner to review the Act and the Code of Rights, and report his findings to the Minister. The last review was undertaken in 2009. The Commissioner's annual reports contain information on performance measures. For the year ended 30 June 2015 the advocacy service received 3,635 complaints; 87% were closed within three months; 99% were closed within six months, and 100% were closed within nine months; 92% were partially or fully resolved; and 94% of consumers were satisfied with the service they received. Overall, in 2015, the service achieved its targets for the year.

Patient advocacy in England

In England there are two advocacy services that have a statutory basis – the NHS Complaints Advocacy Service and the independent advocacy service that is provided under the Care Act 2014.

NHS Complaints Advocacy Service

People who wish to complain about their treatment or care received under the NHS in England may receive support from the NHS Complaints Advocacy Service, which was established in 2003. This service only provides advocacy to people who wish to make a complaint about a service they received from the NHS; it does not provide support to people to make decisions about the care they receive. It is free at the point of use, is independent and confidential, and is a legal requirement under the National Health Service Act 2006. In 2009, the *Local Authority Social Services and National Health Service Complaints (England) Regulations* were published, aligning social services and NHS complaints, and subjecting them to the same complaints process; the NHS Complaints Advocacy Service is required to be fully compliant with these regulations. The system of advocacy provision changed in April 2013. The Health and Social Care Act 2012 placed an obligation on all 353 local authorities to commission a local NHS Complaints Advocacy Service.

All healthcare providers within the NHS have a legal obligation to provide an accessible and responsive complaints procedure for service users. The first step in the complaints process is local resolution and this involves raising the matter in writing, or speaking to the NHS commissioned or funded health service provider, e.g. the nurse or doctor concerned. The service provider's employer or organisation should have a complaints manager to deal with the case. Most complaints are resolved at this local stage. The Ombudsman, who is independent of the NHS and government, investigates complaints about the NHS which have not been resolved at local level. Before contacting the Ombudsman, the complainant is generally expected to try to make a complaint to the organisation involved. After doing this, and if a satisfactory answer is not received from the organisation, or if there is no response, complainants are advised to contact the Ombudsman.

The type of support offered by the advocacy service will depend on the needs of the person requiring advocacy support, but can range from supplying information, signposting and providing access to self-advocacy tools to intensive one-to-one support, including complex representation at critical junctures of the complaints process. A complaints advocate will work with a complainant and offer a range of supports at different points in the complaints process.

Until March 2013, the Department of Health commissioned advocacy services directly from the NHS Complaints Advocacy Service, which was provided by three suppliers, and cost approximately £11.75 million each year. As a result of implementing the new commissioning model, £2.5 million was added to the existing funding in 2013, in order to compensate for the loss of economies of scale that were previously delivered by the central procurement method. Local authorities have three options for commissioning. They may use an independent model where advocacy services are commissioned as a stand-alone service from an existing voluntary or community sector organisation. Local Healthwatch may be commissioned to provide the service or to contract with a sub-contractor. Finally, an integrated model may be used where advocacy services are commissioned from existing wider advocacy providers to fit with wider provision of advocacy services e.g. NHS complaints and independent mental health advocacy.

Independent advocacy under the Care Act 2014

From 1 April 2015, the Care Act 2014 places a new duty on local authorities to involve people in decisions made about them and their care and support. An independent advocate must be appointed to a person who has substantial difficulty in being involved, and if there is no appropriate individual who can support them. A person may be deemed to have a substantial difficulty if they find it difficult to understand relevant information, retain information, weigh up information, and communicate their views and wishes. An appropriate individual cannot be someone who is already providing the person with care or treatment in a professional capacity or on a paid basis, for example, a GP, a nurse, a key worker or a care and support worker. The role of the appropriate individual is to support the person's active involvement with the local authority processes. All local authorities must ensure that there is sufficient provision of independent advocacy to meet their obligations under the Care Act and it is unlawful not to provide someone who qualifies with an advocate. The main functions of the advocate are to support the person to make their own decisions and be as involved as possible within decision-making processes, and to represent a person, which may involve speaking on their behalf. Advocates must never take responsibility to sign off or agree plans. The advocacy service is free at the point of use. An impact assessment has estimated that the cost of providing this service will increase from £14.5 million in 2015–2016 to £67.1 million in 2018–2019. It appears that no new funding will be made available to local authorities to provide this advocacy service.

Evaluation of patient advocacy services in England

There appear to be no published national data on the numbers accessing the service and there are no national data pertaining to the quality of the NHS Complaints Advocacy Service. The NHS publishes annual data on the number of complaints that it receives. It provides no information on the number of complainants who access advocacy through the NHS Complaints Advocacy Service. While some of the local authorities and providers of NHS complaints advocacy publish annual reports which contain data on the advocacy service they provide, this is not done at a NHS national level. No evaluation has been undertaken on the quality of independent advocacy under the Care Act; however, this is not surprising as the service has only been in existence since 1 April 2015. We found no evidence that there are plans to monitor the quality of the advocacy service into the future.

Patient advocacy in Western Australia

None of Australia's states or territories has a state-directed advocacy service. However, in Western Australia the Health Consumers' Council (HCC), an independent, not-for-profit

agency that is almost completely government funded, provides free advocacy for healthcare users.

The Health and Disability Services Complaints Office is an independent statutory authority which provides an impartial resolution service for complaints relating to health and disability services. The Complaints Office reviews and reports on the causes of complaints, undertakes investigations, suggests service improvements and advises service providers about effective complaint resolution. The Complaints Office encourages complaints to initially be raised with the service provider, as offering the provider a chance to address the issues usually results in speedier resolution of a complaint. However, this is not a requirement. If raising the complaint with the service provider proves unsatisfactory, the complainant may call the Complaints Office's Assessment Team. There are two resolution processes: negotiated settlement and conciliation. Negotiated settlement involves an exchange of information between parties via a case manager. 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 is conducted by a trained conciliator

The HCC represents the consumer voice in health policy, planning, research and service delivery. It comments publicly on all issues affecting health and also provides an individual advocacy service, but it does not have the statutory powers to effect change or to require responses from health service providers. The HCC advocate can help consumers to seek the most appropriate options to resolve their complaints about the healthcare they have received. Access to the advocacy services is free. Advocates assist with clarifying the complaint and identifying options, and formulating the complaint; in addition, they attend meetings with consumers. They also assist with complaints that identify a systemic problem.

HCC advocates may offer consumers the opportunity (at no cost) to meet with a lawyer who has expertise in medical negligence. Sometimes, the advocate will suggest this because they believe the consumer may have a chance of making a successful claim. On other occasions it can help consumers to understand the reasons why legal action is not likely to be worthwhile. If a consumer decides to pursue legal action, there is no expectation that they will choose the lawyer they met through the HCC. For the 12-month period 2014/2015 the HCC advocacy team received 621 requests for support; of these, 520 cases received individual advocacy. In that period, the HCC employed 10 people, including 2.8 full-time equivalent (FTE) advocates

Conclusion

The three models of patient advocacy have a number of differences. While the role of the advocate is very similar in each country, there are differences in the legal status of the advocacy services and in how these services are commissioned. While New Zealand appears to have a very good model of patient advocacy, it is unclear what role its no fault medical indemnity scheme plays and how a similar service would operate in Ireland with its tort system.

Introduction

This evidence brief was undertaken by Deirdre Mongan, Jean Long and Louise Farragher of the Evidence Centre in the Health Research Board (HRB) at the request of the Department of Health (DoH). An evidence brief provides a summary overview of key sources of selected research evidence. While it provides insight into a topic for a future formal evidence review or primary research study, it is not a comprehensive overview and may therefore miss excellent papers in obscure or low-level journals. An evidence brief is not suitable for peer review because it is not based on a comprehensive search and analysis. Evidence briefs are undertaken as part of a knowledge brokering service offered to policymakers in the DoH by the Research Services Division in the DoH in collaboration with the Evidence Centre in the HRB. The questions were set by the DoH through an iterative process with the Research Services Division and the Evidence Centre. This review was completed within a three-month time frame.

Purpose of the review

The provision and quality of patient advocacy services provided by the Irish State has recently been criticised in the Ombudsman's *Learning to Get Better*¹ report and HIQA's *Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise*,² which was published in 2015. The HIQA report recommended that a National Patient Advocacy Service be established.

It is proposed that the advocacy service will be external to the Department of Health and the Health Service Executive (HSE).

The DoH requires examination of the most appropriate model to deliver the National Patient Advocacy Service. Models could include the expansion of advocacy services currently provided by existing agencies, or a new advocacy service commissioned by the DoH, or a combination of both. The purpose of this review is to identify and examine international models of patient advocacy services that are currently used.

Research questions

Question 1:

What is advocacy and what models are used for advocacy services?

Question 2

How are state-directed advocacy services established and what are their functions? Countries of interest include England, New Zealand and Australia.

Question 3:

In countries with state-directed advocacy services, are these services evaluated?

Methods

We undertook a PubMed search using the MeSH term 'patient advocacy'. This search yielded 22,626 hits. Given the tight time frame for completing this review, it was not feasible to screen this number of papers. However, an analysis of the most recent 200 hits indicated that the majority of papers were United States based, and related to non-state-directed advocacy, which centred around single issues. We then undertook a more targeted PubMed search using the MeSH term 'patient advocacy' and the three English-speaking countries with state-directed advocacy under study i.e. New Zealand, England and Australia. For New Zealand, there were 220 results; for England, there was 469 results; and for Australia, there was 484 results. Each of these was screened. However, this PubMed search only yielded one relevant paper, which we included in this review. This results of the PubMed search determined that the questions in the review would be best answered by using an iterative or non-systematic process. To answer Question 1 on the different models of advocacy, we undertook a Google search using the following terms: 'models of patient advocacy', 'framework patient advocacy', 'advocacy in healthcare'. We went through the results from the first 10 pages of each search. In order to answer Questions 2 and 3, we repeated the Google search but we also included the country name under study. Finally, we did a targeted search of websites in each country that may be relevant to this brief. The websites searched are as follows:

England

1. www.dh.gov.uk Department of Health UK
2. www.england.nhs.uk NHS England
3. www.local.gov.uk Local Government Association
4. www.nuffieldtrust.org.uk Nuffield Trust
5. www.healthwatch.co.uk Healthwatch England
6. www.kingsfund.org.uk King's Fund UK
7. www.scie.org.uk Social Care Institute for Excellence
8. www.npsa.nhs.uk National Patient Safety Agency UK
9. www.patients-association.com National Patients Association UK
10. www.pickereurope.org Picker Institute Europe UK
11. www.invo.org.uk INVOLVE UK
12. www.napp.org.uk National Association for Patient
13. www.nhssurveys.org NHS Trust Patient Surveys UK
14. www.pifonline.org.uk Patient Information Forum UK
15. www.nice.org.uk National Institute for Clinical Excellence

New Zealand

1. www.hdc.org.nz Health & Disability Commissioner
2. www.cab.org.nz Citizens Advice Bureau New Zealand.
3. www.health.govt.nz New Zealand Ministry of Health
4. www.nzgg.org.nz New Zealand Guidelines Group New Zealand

Australia

1. www.health.gov.au Department of Health Australia
2. www.dss.gov.au Australian Government Department of Social Services
3. www.advocacyfordisability.org.au/ Advocacy for disability
4. www.agedrights.asn.au Aged Rights Advocacy Service Inc
5. www.apo.org.au/source/australian-institute-health-policy-studies Australian Institute of Health Policy Studies

6. www.dana.org.au Disability Advocacy Network Australia
7. www.hconc.org.au Health Consumers' Council

Question 1

What is advocacy and what models are used for advocacy services?

Definitions of advocacy

Our literature search provided many definitions of the term 'advocacy'. These were all broadly similar and a list of the sources we used can be found in Appendix 1. The literature on definitions of advocacy mainly related to the disability area. We also found a literature review by Pearson³ (2009), which was undertaken as part of a project to research the models of advocacy funded under the Australian National Disability Advocacy Program, and which reviewed the literature to define advocacy and the different models of advocacy that exist.

Pearson *et al.* identified three definitions of advocacy in their literature review. As follows:

1. Cocks and Duffy use Wolfensberger's definition of advocacy in their 1993 monograph presenting the results of the Australian National Advocacy Research Project, i.e. advocacy is: **Functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous.**⁴ From our literature search, this appears to one of the more common definitions of advocacy used.
2. Martin (2003)⁵ writes that '**advocacy involves taking action in defence of a person's interests**' and '**may involve the advocate taking direct action, trying to get others to take action, or helping the person to develop skills for personal achievement**'.
3. Parsons (1994)⁶ suggests: **Advocacy is essentially the very ordinary process of standing up for the rights of people who are being treated unfairly.** Parsons goes on to explain that despite its ordinariness, advocacy is rarely easy.

Definitions of advocacy in the jurisdictions under study in this review

In New Zealand, the Health & Disability Commissioner states that advocacy belongs to the family of conflict resolution. Conflict can be resolved using two or three parties, depending on whether a model for mediation, conciliation, negotiation or advocacy is used. Advocacy means to advocate for or defend how you feel about something by advancing a certain viewpoint. In England, the Health and Social Care Act states that the NHS Complaints Advocacy Service provides assistance (by way of representation or otherwise) to persons making or intending to make a complaint.⁷ In relation to advocacy provided under the Care Act 2014, the Department of Health defines advocacy as 'supporting a person to understand information, express their needs and wishes, secure their rights, represent their interests and obtain the care and support they need'.⁸

In Western Australia, no definition of advocacy is provided. In Queensland, Australia the organisation Health Consumers Queensland has developed a health advocacy framework⁹ even though there is a state-directed patient advocacy service. Given the lack of a universally accepted definition of health advocacy and the differing perspectives about the meaning of advocacy, Health Consumers Queensland developed a definition that captures stakeholders' views as to what constitutes health advocacy in Queensland: **Health advocacy is speaking, acting or writing with minimal conflict of interest to support a health consumer or group's wellbeing, and to promote, protect and defend their right to accessible, safe, quality healthcare. Health advocacy can be undertaken by the consumer**

themselves, or by an independent advocate loyally representing the individual or group’s perceived interests.

Models of advocacy

There are many advocacy models and classifications in the literature – at least 17 different models have been described in the literature and a list of the documents we reviewed is provided in Appendix 1. The literature on the models of advocacy mainly relates to the disability field. Table 1 briefly describes the models that recur most often in the literature. There is some overlap between these models.

Table 1: Description of the most common models of advocacy

Model of advocacy	Description
Self-advocacy	<p>In simple terms, it means standing up for oneself. The goal of self-advocacy is for people to decide what they want and to carry out plans to help them get it. Self-advocacy is the process by which people are empowered to develop the skills and confidence to represent their own views and interests. It involves making informed decisions and taking responsibility for those decisions. The core components of self-advocacy have been identified as:</p> <ul style="list-style-type: none"> • being able to express thoughts and feelings with assertiveness if necessary; • being able to make choices and decisions; • having clear knowledge about rights; • being able to make changes.
Group/ Collective advocacy	<p>Group advocacy evolves from self-advocacy and it involves people with shared experiences, positions or values coming together in groups to talk and listen to each other and speak up collectively about issues that are important to them. These groups aim to influence public opinion, policy and service provision. A collective voice can be stronger than that of an individual, as groups are more difficult to ignore. Being part of a group can also help to reduce an individual’s sense of isolation when raising a difficult issue. Groups can vary considerably in size, influence and motive. Similar to self-advocacy, group advocacy is seen as enabling people to have a voice, enhancing personal identity and raising self-esteem. It involves a process through which individuals acquire and develop the skills and confidence to represent their own needs, concerns and interests within a group setting.</p>
Peer advocacy	<p>Peer advocacy occurs when one person advocates for another person who shares a common experience, difficulty or discrimination. Peer advocates are experts by experience, and they use this experience to understand and empathise with their advocacy partner. Peer advocacy works to increase self-awareness, confidence and assertiveness so that the individual can speak out for themselves. Power dynamics are more equal in peer advocacy, because both parties have experienced and struggled through similar issues and experiences. Peer advocacy can be conducted on an individual or collective basis. It is also known as <i>support advocacy</i> and is often used by support groups.</p>
Citizen/ Volunteer advocacy	<p>Citizen advocacy is when ordinary citizens are encouraged to become involved with a person in their community who might need support. The citizen advocate is not paid and is not motivated by personal gain. The relationship between the citizen advocate and their advocacy partner is on a one-to-one, long-term basis. It is based on trust between the partner and the advocate. Citizen advocates are encouraged</p>

Model of advocacy	Description
	to represent the interests of the person as if they were their own. They should be independent of service providers, potential service providers and families, in order to avoid any conflicts of interest. The advocate supports their partner using their natural skills and talents, rather than being trained in the role. Citizen advocates attempt to foster respect for the rights and dignity of those whose interests they are representing. This may involve helping the person express his or her concerns and aspirations, and providing other practical and emotional support to him or her.
Representative /Independent advocacy	Representative advocacy is an independent service where trained advocates are employed to deal with specific problems and to work with an individual until that problem is resolved. It usually involves casework and complex issues that require specific knowledge and expertise. This tends to be a more formal type of advocacy, and trained advocates working to a code of practice are often paid to provide this service. The advocates are experts by training and not necessarily through direct experience. This form of advocacy can apply to formal advocacy enshrined in statute (for example, in New Zealand), where advocates are appointed by an Advocacy Commissioner. An advocate supports an individual to represent their own interests, or the advocate may represent the views of an individual if the person is unable to do this themselves. The advocate provides support, information and representation, with the aim of empowering their partner and enabling them to express their needs and choices.
Legal advocacy	Legal advocacy seeks to defend the rights and interests of people on a one-to-one basis through the legal system. Legal advocacy is undertaken by a lawyer or individual with appropriate legal knowledge. It involves members of the legal profession helping individuals to exercise their rights through the courts and legal system. Legal advocacy has a significant role to play in the area of mental health, where people can be detained in hospital against their wishes.

In addition to the models of advocacy described in Table 1 there is also empowerment advocacy, and although this is not described in great detail in the literature it is the model of advocacy used by the Health and Disability Advocacy service in New Zealand, which is pertinent to this review. Empowerment advocacy is used to assist or act on behalf of a consumer. This requires the advocate to direct the process to assist the consumer to resolve his or her complaint, rather than directing the content of the complaint. The aims of empowerment are to assist consumers to see:

- themselves as people with rights who have the resources to find solutions to their own problems;
- themselves as having skills and strengths;
- advocates as having knowledge and skills that consumers can use;
- advocates as peers and partners in finding solutions and driving change;
- that power structures are complex and partly open to influence.

The advocate's role that works best in empowerment is as a:

- resources person – linking consumers to resources in ways which improve their confidence and solution-finding abilities; or
- coach/mentor – teaching processes and skills, imparting knowledge and information that enable the consumer to retain control of their own concerns and issues.

The advocacy service has also visually defined an empowerment continuum (Figure 1). People from time to time may find themselves at different points on the empowerment

continuum, depending on the issue they are facing, the level of support they have, their wellness, ability and motivation, as well as the information and/or knowledge they have. Generally, those people who are experiencing disempowerment require a wider range of advocacy skills and knowledge, and more time. Advocates are likely to need specialist skills when working at the disempowerment end of the continuum, or they may need expert advice or support, for example, an interpreter, cultural advisor or welfare guardian. Advocates need to be flexible in the approaches they use, in order to ensure that consumers receive the type of advocacy support most likely to increase their ability to self-advocate and become empowered to make their own choices about the solutions to their issues and concerns.

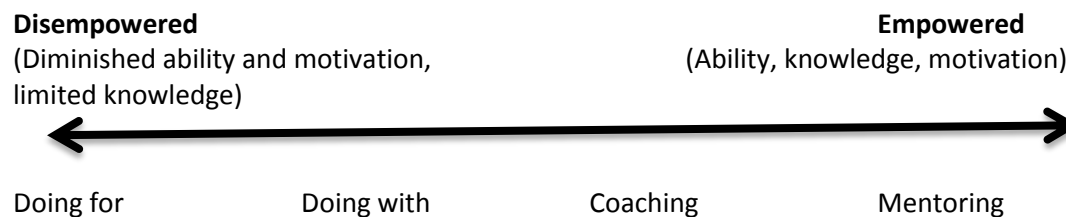


Figure 1: Empowerment continuum

Approaches to advocacy

In addition to different models of advocacy, there are a number of different approaches to advocacy. The focus of advocacy may be on an individual (as in case advocacy) or a group issue (cause advocacy).

- Case advocacy refers to advocating with or for an individual. Advocacy strategies include representing the individual, supporting them to represent their own interests and ensuring that they are empowered to voice their perspectives.
- Cause (or systemic) advocacy is more issue based and group oriented. Systemic advocacy aims to influence agencies, institutions, governments and society by informing and shaping policies and legislation. The focus is usually on structural or political issues, with advocates acting as spokesperson. This form of advocacy does not focus on an individual, but instead represents the rights and interests of a group with similar concerns and issues. This could include lobbying at political level.

Advocacy may also be instructed or non-instructed,

- Instructed advocacy is working with or on behalf of an individual person or group on the lawful instructions of the person or group.
- With non-instructed advocacy, advocates act independently of the individual, in some cases through necessity, as the individual may be incapacitated or does not have the skills to advocate for themselves. This may be because of the person's limitations in grasping concepts, or because they are not able to make others understand their wishes due to significant communication barriers. Capacity to instruct or understand can be diminished for a number of reasons: for example, mental health problems, dementia, or learning disabilities. However, having one of these conditions does not automatically mean a person lacks capacity. An advocate will observe the individual and their situation, look for alternative means of communication with them, gather information from significant others in their life, if appropriate, and ensure that the person's rights are upheld.

Questions 2 and 3

How are state-directed advocacy services established and what are their functions?

In countries with state-directed advocacy services, are these services evaluated?

Countries of interest include New Zealand, England and Australia.

Patient advocacy in New Zealand

Background

New Zealand has a nationwide, publicly funded health and disability advocacy service which was formally established in 1996 under the [Health and Disability Commissioner Act 1994](#).¹⁰ The need for independent patient advocacy within a hospital setting was first mooted in the *Report of the Committee of Inquiry into allegations concerning the treatment of cervical cancer at National Women's Hospital and into other related matters*, which was published in 1988.¹¹ The report recommended the appointment of an independent and powerful advocate for the patient who would ensure a focus on patient needs, better information for patients, the addressing of grievances, and input into ethics committees and teaching. The report also recommended that a health commissioner be appointed to help negotiate and mediate patient complaints and establish and promote a code of patients' rights.

Legislation was eventually passed in 1994 to 'promote and protect the rights of health and disability services consumers' and to 'secure the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights'. The Health and Disability Commissioner Act 1994 set up an Office of the Health & Disability Commissioner, who acts as an independent ombudsman and defines the Commissioner's functions and powers; in addition, it established an advocacy service, and provided for a Code of Rights. The Act also requires the appointment of an independent statutory officer – the Director of Advocacy – who is based within the Health & Disability Commissioner's office, and contracts for advocacy services. In 1996, after a period of public consultation, the Health & Disability Commissioner developed and adopted the code of patients' rights used within the advocacy service. This code is a government regulation, as such, it has legal status and can be enforced. Only the Minister of Health can make changes to the code. It also places an obligation on health and disability service providers to take 'reasonable actions in the circumstances to give effect to the rights, and comply with the duties'.¹²

Advocacy and complaints process

Unlike most developed countries, New Zealand has a national insurance scheme – the Accident Compensation Corporation – to provide a national no fault universal system of compensation for accidental injury, including medical injury. This scheme covers the cost of rehabilitative medical care and earnings-related compensation. Limited lump-sum compensation may be available, and tort claims for damages for negligence are barred. Under this scheme, it is necessary only to prove that the injury was caused by medical treatment and there is no need to establish blame or individual responsibility.¹³ The main enforcement mechanism for aggrieved health consumers is to complain to an independent advocate or to the Health and Disability Commissioner. Any person (the consumer, a family member, or even another provider) may complain about a provider's care, orally or in writing. The role of an advocate is to assist a consumer to resolve concerns directly with the provider. The Commissioner has two options on receipt of a complaint: referral of the matter to an advocate for resolution, or formal investigation.

The complaints and advocacy services are both provided by the Commissioner's office, and are independent of the health system. According to the Health & Disability Commissioner (HDC) website (www.hdc.org.nz), the complaints and advocacy process is as follows:

- The complainant, or person acting on their behalf contacts the advocacy service. The Health & Disability Commissioner then sends referral for advocacy.
- An advocate is assigned to assist, and contacts the complainant directly. As an advocate is on the side of the complainant, they will always contact the complainant even when the complaint is made by another person. The advocate will only work with someone acting on behalf of the complainant if the complainant supports the complaint. If there are issues of competency, the advocate will still make efforts to include the consumer in the process wherever possible. This is very important for people with a mental health crisis as well as for people with an intellectual or neurological impairment. In some cases, this will not be possible; for example, if the person is unconscious or is in an advanced state of dementia.
- The advocate listens to the complainant's story, clarifies rights and outlines options in recognition of the fact that some complainants just need information in order to advocate for themselves. Some complainants may simply want to use the advocate as a sounding board, or to check the letter they have written to the provider themselves.
- The complainant selects the option they feel would work best for them.
- If the complainant wants the support of the advocate to resolve the matter, the advocate will assist them to identify the key issues, and what the goals for resolution are.
- The advocate also assists the complainant to focus on their own strengths and supports for dealing with the complaint, as well as any barriers that are getting in the way.
- The advocate assists the complainant to identify the action steps towards resolution.
- If the option selected is a face-to-face resolution meeting, the advocate will discuss with the complainant how to advise the provider/s, including outlining what the issues are, setting up the meeting, including organising the date, venue and support people attending. Resolution meetings are organised on the basis of transparency and respectful dealings with all parties
- The advocate will have a simple resolution agreement form at the meeting in the event that there is agreement to ongoing actions beyond the meeting. The resolution agreement is a one-page form for the ongoing actions agreed to and the date this will be reported back to the complainant. All parties are provided with a copy, so that they are clear about what has been agreed to. This is an expression of goodwill and is not a legal agreement. The advocate will follow up any actions that are not carried out by the date specified.
- The matter is closed at advocacy, when all or some of the goals have been met, when the complainant withdraws the complaint, or when an unresolved matter is sent to the Commissioner. The options for resolution at advocacy are based on the complainant's goals for resolution and include 'fully resolved', 'partially resolved', and 'not resolved'. With the exception of significant public safety issues, complaints referred to the Health & Disability Commissioner or withdrawn are at the complainant's request.

Role of the Health & Disability Commissioner

The Health & Disability Commissioner's office was established to protect anyone who uses health and disability services, and to help resolve problems between consumers and providers of these services. The Commissioner aims to improve the quality of healthcare and disability services. The Commissioner is also able to refer complaints that he has received to an advocate, in order to resolve the matter. If the Commissioner makes a referral to the advocacy service, all parties are notified and the process is explained, including the time frame for action expected by the Commissioner. The advocate is required to report back formally to the Commissioner on the outcome. Complaints made to an advocate that remain totally or partially unresolved, and are not withdrawn, are referred to the Commissioner. Both parties will be asked to provide supporting evidence and may need to be interviewed. The Commissioner may also get advice from an independent expert and may refer the complaint to formal mediation if he thinks the issue can be resolved this way. He will produce a report containing his recommendations; it is reviewed by both parties before a final version is released. The final report is sent to the complainant, the provider, and usually also to relevant professional registration bodies such as the Medical Council or the Dental Council. The Commissioner may make a number of recommendations, ranging from an apology from the provider to specific recommendations relating to ways in which the provider could improve his or her practice.

Although advocates are on the side of the consumer, the Commissioner is required to be impartial and does not take sides. Advocates may also report to the Commissioner from time to time on any matter concerning the rights and safety of consumers that they consider should be brought to the Commissioner's attention. In this way, advocates perform an important function of being the Commissioner's 'eyes and ears' in the community.

Role of advocates

Broadly, the functions of an advocate are to:

- ensure that health and disability services consumers are aware of their rights, as outlined in the Code of Health and Disability Consumers' Rights;
- promote awareness of the procedures for complaints involving possible breaches of these rights;
- provide consumers with the assistance needed to ensure that informed consent is obtained when healthcare procedures are carried out;
- promote awareness of advocacy and processes for providing information and obtaining informed consent;
- receive complaints regarding healthcare or disability services providers who may have breached the Code of Health and Disability Consumers' Rights;
- represent or assist complainants in the resolution of complaints.

Role of the Director of Advocacy

The Director of Advocacy contracts with advocacy service providers who, in turn, employ advocates to provide the advocacy service. The functions of the Director of Advocacy are as follows:

- administer advocacy services agreements;
- promote, by education and publicity, advocacy services;
- oversee the training of advocates;
- monitor the operation of advocacy services, and report to the Minister from time to time on the results of that monitoring.

How are advocacy services commissioned and organised?

It was initially proposed that the Health & Disability Commissioner would employ advocates, but a change of government coupled with opposition from the medical community to much of the proposed legislation resulted in the establishment of an independent advocacy service. Under this new model, a Director of Advocacy role was established to purchase advocacy services from community providers and provide the link with, and accountability to, the Commissioner's office.¹⁴ After a lengthy contract process, the advocacy service was established in 1996. The prerequisite for these contracts was that services must be totally independent of health and disability purchasers and providers; only 72 of the more than 300 expressions of interest in tendering for the advocacy service fulfilled the independence criteria. Three types of groups were awarded the initial contracts: existing advocacy groups working within the health and disability sectors; those working within a mediation model or as complaints services; and newly established services. Initially, there were 10 three-year contracts, but by 1999 the number of contracts had decreased to three, after providers merged into larger organisations. In 2006, the Director of Advocacy and National Advocacy Trust agreed to a single national contract with a National Advocacy Service.¹⁴

The current National Advocacy Service provides a free, independent, and confidential service throughout New Zealand to all users of health and disability services. Access is provided through a Freephone number coordinated by a national call centre advocate. There are 46 advocates located in 23 community-based offices throughout the country. These advocates are supported by administrative staff; four regional team managers; a national education, training and resource manager; and the national service manager, who has overall responsibility for the day-to-day running of the service. The task of supporting people to be heard is broken down into two major areas of advocacy work.

First, advocates deal with complaints and promote advocacy and the Code of Rights to providers and consumers, and they work with all residential homes to provide education and training. Advocates listen to consumer concerns, provide information, clarify issues, explain available options, and support consumers in the actions they take to resolve the complaint.

Second, advocates train consumers and provider groups on consumer rights and provider obligations

According to the *Health & Disability Commissioner Annual Report for the year ended 30 June 2015*, for the year ended 30 June 2015, over a 12-month period in 2014/2015, the number of new complaints to the Advocacy Service rose from 3,468 to 3,635 in 2013/14, representing an increase of 4.8%. In the five years prior to June 2015, the number of new complaints received by the advocacy service increased by 28.4%. Advocates were able to help consumers resolve 92% of the complaints made, or referred, to the service. Eighty-seven percent of complaints were closed within three months, and over 99% were closed within six months; 84% of the complaints were about health services, and 16% related to disability services. The expenditure on the advocacy service was NZ\$4,935,902.¹⁵

For the year ended 30 June 2015, the Advocacy Service received 13,479 phone and email enquiries, which represented a 12.8% increase on the preceding year; 98% of those enquiries were closed within two days. Enquiries covered a broad range of topics. In addition to requests for information about the role of advocates, as well as information on how to make a complaint and requests for education sessions, advocates received requests for disability resources, information on the role of the Health & Disability Commissioner

(HDC), mental health matters, funding, fees and treatment costs, information privacy, and rest home and residential disability home standards. In 2014/2015, advocates visited all of the 658 certified rest homes nationwide, and 486 rest homes had at least two visits. All of the 994 certified residential services catering to disabled people had at least one visit from an advocate, and 630 had at least two visits.

A key element of this advocacy service is that while publicly funded, it is independent, and this has been enshrined in legislation. The service operates independently of the Health & Disability Commissioner, government agencies, and health and disability services providers. The Director of Advocacy (through whom health and disability advocacy services are purchased) is required by statute to be independent of the Health & Disability Commissioner and to ensure that services are purchased in accordance with requirements set out in the Health and Disability Commissioner Act. The decision to appoint a Director of Advocacy to purchase advocacy services from within the community was also a clear signal that independence was crucial to the successful functioning of this service. While the Director of Advocacy is an independent statutory officer based in the Office of the Health & Disability Commissioner and accountable to the Commissioner for the efficient, effective, and economical management of the service, the Director must act independently. Separating the funding from service provision has ensured this independence, despite the funding coming through the Health & Disability Commissioner's office.¹⁴

What guidelines do advocates have to follow?

Advocates have guidelines (Table 2), a Code of Practice (Table 3), and competencies (Table 4) that describe their role and what consumers can expect from an advocacy service. Advocates' practice is evaluated on a regular basis. Any complaints about an advocate or the advocacy service are reviewed, in order to see where service improvements can be made. The first Health & Disability Commissioner's advocacy service guidelines were approved in 1996. The Minister of Health approved the revised and updated guidelines in 2005, following a comprehensive consultation process including representatives of health consumers, disability services consumers, healthcare providers, disability services providers and professional bodies.

Table 2: New Zealand health and disability advocacy guidelines

Health and disability advocacy guidelines

1. Empowerment principle – Advocacy is committed to the belief that consumers already have skills and experience on which to draw in order to help them resolve their concerns. 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.

2. Low-level resolution – The intention of Health and Disability Commissioner Act and the Code of Health and Disability Services Consumers' Rights (the Code) is to promote resolution of complaints at the lowest appropriate level. Often, the fastest and most satisfactory way of resolving grievances is for the consumer to deal directly with the actual provider of the service. The advocacy service established under the Act is fundamental to this aim of low-level resolution.

3. 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.

4. Interpretation of and comment on rights – Advocacy service organisations and individual advocates shall refer any request for interpretation of the Code to the 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 Health & Disability Commissioner, and to assist consumers or providers to understand those decisions and statements.

5. 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.

6. Empowered – Consumers remain in control and take responsibility for their issues, concerns and rights. 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.

7. 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 or disability consumers. 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. 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 Health & Disability Commissioner's attention. The advocacy service can contact the provider directly when concerns can be appropriately resolved at a low level. 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.

8. 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.

9. 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, in order 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.

10. Role of advocates – An advocate provides information and facilitates the consumer to pursue and resolve their issues with advocacy support. An advocate assists a consumer to develop knowledge and skills so that the consumer is supported to resolve the current issue and is able 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. An advocate 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 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 & Disability Commissioner complaint processes and/or the Director of Proceedings processes.

11. Advocates' role with providers – 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 give free presentations to provider groups, on advocacy services, the Health & Disability Commissioner role, the Code, and the complaints processes available to consumers.

12. 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.

13. Consumers' needs and accessibility – Advocacy services 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 that 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.

14. Advocate support – Advocacy service providers shall ensure that appropriate support systems are in place for individual advocates. This may include induction, training, performance management, peer supervision via support and review, risk management procedures, physical safety and appropriate specialist support.

15. 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.

16. Referrals 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.

17. Information systems – The collection, accurate recording and transfer of information

pertaining to advocacy services, including trends in consumer issues, assists in the efficient and effective management of these 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.

18. Publicity and promotion – The integrity of the advocacy service is maintained by ensuring consistency in all publicity provided about the advocacy service. The Health & Disability Commissioner will provide all generic promotional 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.

Table 3: New Zealand Health & Disability Advocacy Code of Practice

Purpose of health and disability advocates

Advocates aim to help consumers 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

Health and disability advocacy services 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

Health and disability advocates will:

- be trustworthy, act in a non-judgemental way and treat others with respect;
- listen, encourage and validate the consumer's views, taking into account cultural values, beliefs and the unique place of tangata whenua;
- avoid conflicts of interest, and act honestly and in good faith at all times;
- 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; and provide a level of stability, safety and clarity in meetings and other resolution processes.

Quality improvement and professional practice

Advocates will:

- work to continuously improve quality of service to consumers through ongoing training, professional development and quality improvement activities;
 - 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; and
 - demonstrate commitment to the vision, values and standards of the Nationwide Advocacy Service and the principles of the Code of Health and Disability Services Consumers' Rights.
-

Table 4: New Zealand health and disability advocacy competencies

How quality of advocates is measured

The Health & Disability Advocacy service has published the core competencies that advocates should demonstrate.¹⁶ Assessment against the core competencies should occur within the first 12 months after appointment, by which time an advocate is expected to be competent in most competency behaviours and skills. The three core competencies for an advocate are:

- Strengths-based advocacy – based on the empowerment model of advocacy, human rights and strengths-based approaches. It works from a respect for self and others and a focus on people's strengths, to encourage and support people to make positive changes in their lives. It happens when people exercise 'power with' rather than 'power over'.
- Interactive presentations – formal and informal presentations given to a variety of audiences which actively involve the specific audience and meet their specific needs.
- Assertive networking – networking activity is proactive, planned and strategic, and assists with service goals.

For each of the three competency areas, the guidance describes the theoretical basis; outcomes; knowledge, skills and behaviours competencies; and measures. Within the first year in the post (or earlier if the advocate is ready) a full competency assessment occurs. Evidence will be presented of actual practice that demonstrates the competencies. This evidence can include survey results, advocacy outcomes, case studies and feedback from the team. Advocates are expected to be competent in most competency behaviours at this stage.

Evaluation of the New Zealand Advocacy Service

We could not find any independent evaluation of the effectiveness of the New Zealand Advocacy Service. However, the Health & Disability Commissioner's annual report does contain information on performance measures for the year ended 30 June 2015.¹⁵ The Advocacy Service's performance in resolving complaints received about health and disability services is measured by:

- number of complaints received and closed;
- timeliness of complaints resolution;
- level of satisfaction with the Health & Disability Commissioner's complaints management process;
- number of complaints received and resolved by the advocacy service;
- timeliness of complaints resolution by the advocacy service;

- degree of resolution achieved by the advocacy service; and
- level of stakeholder satisfaction with the advocacy service and the professionalism of the advocate.

Table 5 provides an overview of the performance of the advocacy services as presented in the Health & Disability Commissioner's annual report. The most recent report indicates that the Advocacy Service achieved its performance targets and provides a functioning service.

The 1994 Act requires the Health & Disability Commissioner to undertake reviews of both the Act and the Code of Rights, consider whether any amendments are necessary or desirable, and report the findings to the Minister. The most recent review was undertaken in 2009.¹⁷ Before compiling the review, the Health & Disability Commissioner consulted with representative persons and bodies with an interest in health and disability service matters, and also undertook a wider public consultation. He stated that both he and the Director of Advocacy believed that the current contractual model for advocacy services was past its use-by date. Problems with the current model included the Director's inability to recruit or manage the performance of advocates, inefficient use of resources, and challenges in ensuring a consistent quality of service across the country. Most submissions supported change. He recommended that the Act be amended to enable advocates to become employees of the Health & Disability Commissioner, while retaining their independent functions. To date, however, there has been no government support for this recommendation. The Advocacy Service was also intended to serve as a catalyst for quality improvement throughout the health system; however, no outcomes-based data are available to measure the link between the quality of the health system and the complaints mechanism.¹⁴

Table 5: Performance of the New Zealand Advocacy Service for year ended 30 June 2015

Expected targets	Targets achieved
<i>Complaints to advocates are addressed promptly and resolved in a timely manner</i>	
Receive an estimated 3,800 complaints.	3,635 new complaints were received.
Close an estimated 3,800 complaints.	3,679 complaints were closed.
Manage complaints so that: <ul style="list-style-type: none"> • 85% closed within three months • 95% closed within six months • 100% closed within nine months 	<ul style="list-style-type: none"> • 87% were closed within three months. • 99.3% were closed within six months. • 100% were closed within nine months.
<i>Complaints managed reach resolution</i>	
90% of complaints are partially or fully resolved.	92% of complaints were partially or fully resolved.
<i>Consumers and providers are satisfied with the service and the professionalism of the advocate</i>	
Surveys of consumers and providers will report that 80% of the respondents are satisfied with the service and the professionalism of the advocate.	93.5% of consumers and 85.5% of providers said they were satisfied with the service and the professionalism of the advocate.
<i>Vulnerable consumers have access to advocacy and regular visits from advocates</i>	
Advocates to visit 100% of rest homes at least once, with 70% being visited twice. Advocates to visit 100% of residential disability services at least once, with 60% being visited twice.	100% of rest homes received a visit from an advocate and 73% received a second visit. 100% of residential disability services received a visit from an advocate and 63% received a second visit.
<i>Consumer and provider networks have regular contacts from the advocates</i>	
3,500 network contacts with consumers and providers by June 2015.	3,927 network contacts with consumers and providers. 31% of non-residential networks had a disability focus, 20% were with public interest groups and 17% were with older people.
<i>Promote awareness, respect for and observance of the rights of consumers and how they may be enforced</i>	
Advocates provide 2,000 education and training sessions. Definition of a session is when an advocate delivers a training or educational presentation at a venue. Consumers and providers are satisfied with the educational sessions: <ul style="list-style-type: none"> • Seek evaluations on sessions, with 80% of respondents satisfied. • Surveys are provided to all consumers and providers who attend an advocacy education or training session. 	<p>A total of 2,252 education and training sessions were provided.</p> <p>Satisfaction surveys showed that 91% of consumers and 96% of providers were satisfied with the Advocacy Service's education or training sessions.</p> <p>All attendees at presentations and education sessions were provided with survey forms. From 2,252 sessions, 9,082 completed surveys were received.</p>
<i>Ongoing education is provided through Stories about Great Care</i>	
180 case studies/Stories about Great Care published.	180 case studies/Stories about Great Care were collected and published.

Patient advocacy in England

In England there are two advocacy services that have a statutory basis – the NHS Complaints Advocacy Service and the independent advocacy service that is provided under the Care Act 2014.

NHS Complaints Advocacy Service

Background

People who wish to complain about their treatment or care received under the NHS may receive support from the **NHS Complaints Advocacy Service**. This advocacy service only provides advocacy to people who wish to make a complaint about a service they received from the NHS. It does not provide support to people to make decisions about the care they receive. A number of reports have highlighted the need for patient advocacy in the NHS. In 2011, the Health Select Committee published its report on Complaints and Litigation. It expressed its concerns about the visibility of advocacy services to complainants and recommended more work to improve patient awareness and access.^{18, 19} In the Francis report on Mid Staffordshire in 2013,²⁰ the author stated that one of the key themes was that *'support for complainants, whether or not they are specifically vulnerable, with advice and advocacy still requires development; in particular, it should be clear that advocates can offer advice on the substance of the complaint that is required, and information should be provided on available support organisations'*. This was reiterated in the 2013 Clwyd-Hart review launched after the conclusion of the Francis Inquiry.²¹ The Clwyd-Hart review concluded that the attitude of the NHS to complaints must change; complaints should be welcomed, not ignored; patient advocacy must be improved; and the Department of Health must fund patient groups to work to support patients and improve the complaints system.

The NHS Complaints Advocacy Service in England is free at the point of use, and is independent and confidential. The provision of independent advocacy is a legal requirement for the Secretary of State for Health under the National Health Service Act 2006.²² This statutory service, initially named the Independent Complaints Advocacy Service (ICAS), was launched on 1 September 2003, and provided for the first time a national service delivered to agreed quality standards. Within the meaning of the Act, advocacy services related only to the provision of assistance for individuals making or intending to make an NHS complaint. There have been a number of changes in how this service has been delivered since its introduction. In April 2009, the Department of Health published the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009,²³ for the first time aligning social services and NHS complaints and subjecting them to the same complaints process. Under these regulations a complaint can be made to either the commissioner or provider of the NHS service, but not to both, and the NHS Complaints Advocacy Service (previously known as Independent Complaints Advocacy Service) is required to be fully compliant with these regulations.

The complaints process for NHS users in England¹⁹

All healthcare providers within the NHS have a legal obligation to provide an accessible and responsive complaints procedure for service users. NHS complaints may be made about any function of a provider of NHS-funded care, or a commissioner of that care. The NHS complaints process covers:

- all NHS trusts and NHS bodies including NHS foundation trusts;
- family health services provided for the NHS by GPs, dentists, opticians or pharmacists;

- primary care trusts;
- private healthcare establishments if the treatment has been paid for by the NHS;
- all other health services commissioned by NHS funding.

Prior to April 2009 there were two separate processes for handling complaints about health and social care services. These processes had a number of different stages and timescales, and investigations were carried out in different ways for each service. The three stages were:¹⁹

1. Local Resolution
2. Healthcare Commission
3. Parliamentary and Health Service Ombudsman (PHSO).

The Parliamentary and Health Service Ombudsman (PHSO) in her 2005 report *Making things better?*²⁴ identified key weaknesses in the then NHS complaints system and approach:

- Complaints systems were fragmented within the NHS, between the NHS and private healthcare systems, and between health and social care.
- The complaints system was not centred on the patient's needs.
- There was a lack of capacity and competence among staff to deliver a quality service.
- The right leadership, culture and governance were not in place; just remedies were not being secured for justified complaints.

As a result, in April 2009 the Department of Health published the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009.²³ For the first time, social services and NHS complaints were aligned and subject to the same complaints process. If the handling of complaints at a local level is robust, effective, comprehensive and proportionate, it was determined that there was no purpose served by having intermediary stages between local resolution and the Ombudsman. The reformed framework for handling future complaints was reduced from a three-tier process to a two-tier process comprising:

1. Local resolution
2. Parliamentary and Health Service Ombudsman.

The first step in the complaints process is local resolution, and this involves raising the matter in writing or speaking to the NHS commissioned or funded health service provider, e.g. the nurse or doctor concerned. The service provider's employer or organisation should have a complaints manager to deal with the case. Most complaints are resolved at this local stage. There is a time limit of 12 months in which the complaint must be made. The 12-month period starts from the date the incident being complained about came to the attention of the complainant. This time limit can sometimes be extended, provided that it is still possible to investigate the complaint.²³ The following groups are recognised as complainants:²⁵

- people using services;
- people who might use a service;
- friends, family and carers;
- those instructed on behalf of the individual (including advocates);
- those receiving uninstructed support and advocacy;
- worried bystanders.

The Ombudsman investigates complaints about the NHS not resolved at local level. If someone has suffered because of poor service, or as a result of not being treated properly or fairly – and the organisation has not put things right where it could have – the Ombudsman may be able to help. Before contacting the Ombudsman, the complainant is

generally expected to try to make a complaint to the organisation involved. After doing this, and if a satisfactory answer is not received from the organisation, or if there is no response, complainants are advised to contact the Ombudsman who is independent of the NHS and government.

If individuals need assistance in making a complaint, officers from the Patient Advice and Liaison Service (PALS) are available in all hospitals. PALS was established in 2002 to assist individuals in making a complaint. PALS is available in all hospitals and regulations stipulate that information about PALS must be prominently displayed in hospital entrances. PALS officers offer confidential advice, support and information on health-related matters to patients, their families and their carers. While PALS was set up as a facilitator for users of NHS services, part of its role is to provide information about the NHS complaints arrangements and, if users wish to make a complaint, how to get independent help through, for example, the NHS Complaints Advocacy Services. PALS officers provide on-the-spot help and can be powerful arbitrators between service users and staff; moreover, they can enable cooperation and understanding. PALS has no formal role in the complaints process, in the sense that a complaint does not have to be routed through PALS, although there is evidence that use of PALS has the potential to reduce complaints.²⁶

Role of the NHS complaints advocate

According to the Department of Health, the NHS Complaints Advocacy Service aims to ensure that complainants have access to the support they need to articulate their concerns and navigate the complaints system.¹⁹ To access the service, the complainant contacts the NHS Complaints Advocacy Service in their area. The complainant may complete an online enquiry form that will go directly to the advocacy service in the area, and an advocate will contact them within five days to discuss their situation. Alternatively, the complainant may contact them directly via letter, telephone, text, or email.

The type of support offered by the advocacy service will depend on the needs of the person requiring advocacy support, but can range from supplying information, signposting and providing access to self-advocacy tools to intensive one-to-one support, including complex representation at critical junctures of the complaints process. A complaints advocate will work with a complainant and offer a range of supports at different points in the complaints process. The role of the advocate includes:

- 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 PALS, specialist medico-legal advice services, regulatory bodies (such as the General Medical Council or Care Quality Commission) or local Healthwatch services.
- Providing assistance in finding out information 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 i.e. what it is they would like to happen. This is critical in supporting people to define their expectations and plan for advocacy support.
- Providing assistance in exploring options and potential consequences of choices, including 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 rehearsing what it is they would like to express.
- Providing assistance to understand information. This could be because the 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 a certain 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.
- Providing assistance to appeal or escalate concerns. The advocate can offer information on how to contact and make a complaint to the Ombudsman in circumstances where the person wishes to escalate their concerns.
- Providing assistance in understanding the Ombudsman's final decision.

How NHS complaints advocacy services are commissioned

Until 31 March 2013, the Department of Health commissioned advocacy services directly from the Independent Complaints Advocacy Service, which was provided by three suppliers: The Carers Federation, POhWER and SEAP. The Department of Health had responsibility for the management of contracts, and the quality of service provided. These five-year contracts (let centrally by the Department of Health) amounted to approximately £11.75 million each year and expired on 31 March 2013.

The system of advocacy provision changed on 1 April 2013. The Health and Social Care Act 2012⁷ placed an obligation on Local Authorities to commission a local NHS Complaints Advocacy Service. Under this Act, local authorities are required to commission '*the provision of assistance for individuals making or intending to make an NHS complaint*' (which includes complaints to the Ombudsman). It is now the responsibility of local authorities to fund the advocacy service using non-ringfenced funds allocated from the Department of Health. Within a permissive legal framework, local authority commissioners are free to commission independent complaints advocacy services as they see fit. Local authorities can commission an advocacy service for both NHS complaints and social services complaints, using the same contract and service provider. This could be an important development for people with simultaneous complaints against both services. The NHS Complaints Advocacy Service will also be able to support people with a serious complaint about local services to elevate it to the Ombudsman. Local authorities will be required to contract with an organisation to carry out this work and Local Healthwatch can either bid to run the NHS Complaints Advocacy Service, or must refer people to whoever is running the service.

Each local authority has to commission local NHS complaints advocacy, as there are statutory functions that have to be delivered. The local authority also has a duty to ensure that local complaints advocacy operates effectively and delivers value for money. It is up to local authorities to decide the level of funding they provide. They are, however, required to provide effective services. There are a number of possible options for commissioning of a new NHS complaints advocacy service among which local authorities may choose.²⁷

1. To commission this as a ***stand-alone service from an existing voluntary or community sector*** organisation or consortium, a social enterprise or private sector organisation, either as an individual local authority, or as a cross-locality collaborative (independent model). The independent model may be:
 - Individual – one local authority commissions a service for its own locality; or
 - 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.
2. To commission this through ***local Healthwatch***; the legislation permits local Healthwatch (Table 6) to be commissioned by the local authority to provide or to contract with a sub-contractor for the local independent NHS complaints advocacy service for the area, with these additional provisos:
 - Local Healthwatch can directly provide NHS complaints advocacy if commissioned directly by the local authority; and
 - Local Healthwatch cannot be commissioned by a third party to provide NHS complaints advocacy.
3. To commission from existing wider advocacy providers to fit with wider provision of advocacy services in a local authority (***integrated model***); for example, NHS complaints advocacy and social care complaints advocacy services or other local advocacy provision (such as Independent Mental Health Advocacy services) are commissioned together from one provider.

Examples of each type of commissioning are provided in the following document http://www.local.gov.uk/c/document_library/get_file?uuid=f07bf24c-cd0c-458f-8672-419f26a0831a&groupId=10180.

The Department of Health has also produced a briefing document for local authorities who are commissioning NHS complaints advocacy services, and this document provides guidance on what should be included in these contracts. It may be accessed at http://www.local.gov.uk/c/document_library/get_file?uuid=543decdbd-2738-4921-a804-71cb362c0948&groupId=10180

An example of the service specification and contract for NHS Complaints Advocacy Service produced by South of England NHS may be accessed at <http://democratic.bracknell-forest.gov.uk/documents/s58280/121123%20Jones%20-%20NHS%20Complaints%20Advocacy%20Service%20Annex.pdf>

Table 6: Description of Healthwatch England

Healthwatch

The Health and Social Care Act 2012 stated that Local Healthwatch should be established from 1 April 2013. Healthwatch is the new independent consumer champion for both health and social care. It exists in two distinct forms – Local Healthwatch, at local level, and Healthwatch England at national level. Local Healthwatch is an independent organisation, able to employ its own staff and involve volunteers, so that it can become the effective and influential voice of the public. Its aim is to give citizens and communities a stronger voice to influence and challenge how health and social care services are provided within their locality.²⁸

Local Healthwatch:²⁸

- has a seat on the statutory health and well-being boards, ensuring that the views and experiences of patients, carers and other service users are taken into account when local needs assessments and strategies are being prepared;
- enables people to share their views and concerns about their local health and social care services to help build a picture of where services are doing well and where they can be improved;
- alerts Healthwatch England, the Care Quality Commission and/or council scrutiny committees to concerns about specific care providers, health or social care matters;
- provides people with information about their choices and what to do when things go wrong, by either signposting people to the relevant provider, or itself providing (if commissioned by the council) independent advocacy to individuals who wish to complain about NHS services;
- signposts people to information about local health and care services and how to access them;
- gives authoritative, evidence-based feedback to organisations responsible for commissioning or delivering local health and social care services; and
- can help and support Clinical Commissioning Groups and council social care departments to make sure that services really are designed to meet citizens' needs.

Healthwatch England is a national body representing the views of service users and the public. It aims to influence national policy and provide advice to Monitor, the NHS Commissioning Board, the Secretary of State and English local authorities, as well as providing leadership and support to local Healthwatch organisations. Healthwatch England is a statutory committee of the Care Quality Commission, which is the independent regulator of all health and social care services in England. Its role is to ensure that care provided by hospitals, dentists, ambulances, care homes and services in people's own homes and elsewhere meets government standards of quality and safety.

Funding of NHS complaints advocacy services

Up until 31 March 2013 the independent advocacy service was funded at a national level by the Department of Health at a cost of £11.7 million per year. Since 1 April 2013 it has been the responsibility of local authorities (353 in total) to fund the service using non-ringfenced funds allocated from the Department of Health. Following the implementation of the new commissioning model, £2.5 million was added to the existing funding in 2013, in order to compensate for the loss of economies of scale that were previously delivered by the central procurement method.²⁹ It is unclear what the levels of funding for the years 2014 and 2015 were.

Limitations to the NHS Complaints Advocacy Service

People may approach the complaints advocacy service for help in achieving goals that are outside the scope of the complaints handling process and therefore are not appropriate for the advocate to support. Examples may include complaints to regulatory bodies or helping people to navigate the complaint through legal processes, where the goal may be to gain financial compensation. People who wish to pursue these outcomes can be supported by the Complaints Advocacy Service to access other types of service that are better suited to offer the specialist support and advice the person needs. There may be some people who have received health and social care services that have fallen below the expected standard but are unable to make a complaint. In such cases, clear attempts must be made to seek consent from the person. But if this is not possible, the Complaints Advocacy Service should consider submitting a complaint on the individual's behalf. This is particularly important if the person has no family or friends to raise concerns for them. It may require working closely with other forms of advocacy, such as Independent Mental Capacity Advocates or Independent Mental Health Advocates, to ensure that the individual is represented by the most suitable person. Where there are serious concerns, the advocacy service should raise safeguarding alerts and follow these up in line with local procedures.

Qualification of advocates

There is a requirement to have all advocates qualified to national standards (e.g. Level 3 Certificate accredited by City & Guilds). According to the NHS website, all of its advocates hold the National Advocacy Qualification. (www.nhscomplaintsadvocacy.org/our-quality-promise)

Ensuring performance and quality in NHS complaints advocacy services

A number of organisations have produced documents setting out quality measurements. In 2012, the Department of Health produced *key performance indicators* (Table 7) for the NHS Complaints Advocacy Service for 2012–2013.¹⁹ In 2014, the National Development Team for Inclusion published an advocacy *code of practice* (Table 8); this code defines the principles which constitute effective advocacy.³⁰ In 2015, at the request of the Department of Health, Healthwatch England published *standards* (Table 9) for good complaints advocacy.²⁵ In 2015, the Local Government Association published *practice guidelines* (Table 10) for independent health complaints advocacy services.³¹ All of these are described in further detail in Tables 7-10 inclusive.

Table 7: Key performance indicators for NHS England complaints advocacy services

Key performance indicators (KPIs)

In 2012, the Department of Health produced a briefing pack¹⁹ to assist commissioners with responsibility for commissioning NHS Complaints Advocacy services for the first time; it included *key performance indicators* which were included in the Department of Health contract for providing advocacy services that ended on 31 March 2013. It is unclear if each local authority is now required to include KPIs when it is contracting for independent complaints advocacy services.

KPIs for the contract for the NHS Complaints Advocacy Service that ended on 31 March 2013.

KPI 001: Activity and volume

Increase in number of new cases per annum

KPI 002: Diversity and equality

Effective information gathering relating to client diversity/equality:

- a. Percentage of new clients' ethnicity data collected during reporting quarter.
- b. Percentage of new clients' age data collected during reporting quarter.
- c. Percentage of new clients' self-defined disability data collected during the reporting quarter.

KPI 003: Satisfaction

- a. Clients are satisfied with the service provided.
- b. Providers maintain positive relationships with key stakeholders.

KPI 004: Service management (staff)

Team members are actively supported and monitored in their role:

- a. Supervision carried out every two months for every a team member.
- b. Five active case files to be reviewed every two months for every advocate – (30 active case file reviews achieved annually per advocate).

Providers are committed to staff involvement in service development and delivery:

- a. Providers carry out annual anonymous staff survey and achieve target response rate.
- b. Providers achieve target positive response rate to question involvement in business planning and development.

Table 8: Code of Practice for Advocates (National Development Team for Inclusion)

Code of Practice for Advocates

The Code of Practice for Advocates was published in July 2002 and revised in 2014 by the National Development Team for Inclusion. It is a set of guidelines for advocates and their managers, aimed at providing clarity for their practice. It is also a guide for commissioners of advocacy services that outlines the expectations and purpose of the role of advocate and what clients as well as commissioners should expect from the delivery of the service. The Code provides a clear description of what is and is not expected of an advocate in their day-to-day work with clients.³⁰ The Advocacy Quality Performance Mark (QPM) is a quality mark awarded to providers who can demonstrate how they meet the different standards set out in the advocacy code. The QPM gives commissioners of advocacy services reassurance that the providers they are engaging have been assessed to ensure that their organisations are robust and focused on delivering quality services. It is not clear if it is a requirement for complaints advocacy services contracted by local authorities to have the QPM. The key advocacy principles are:

1. Clarity of purpose – The advocacy provider’s aims, objectives and planned activities are within the objects set out in its governing document, and providers should be able to demonstrate how these meet the principles contained in this Code. Advocacy providers should ensure that the people they advocate on behalf of, health and social care services, and funding agencies have information on the scope and limitations of the advocacy provider’s role.
2. Independence – The advocacy provider will be structurally independent from statutory organisations (e.g. NHS and local authorities). The advocacy provider will be as free from conflict of interest as possible, both in design and operation of advocacy services, and will seek actively to reduce conflicting interests, in particular where the organisation delivers additional services such as housing provision.
3. Person-centred approach – The advocacy provider will ensure that the wishes and interests of the people it advocates on behalf of direct its work. Advocates should be non-judgemental and respectful of people’s needs, views, culture and experiences.
4. Empowerment – The advocacy provider will support self-advocacy and empowerment through its work. People who access the service should have a say in the level of involvement and style of advocacy support they want, if they are able to and wish to do this. Where clients lack the ability or capacity to influence the service, the advocacy provider should have a process in place to enable those with an interest in the welfare of the person to influence this. Providers will ensure that people who want to can influence and be involved in the wider activities of the organisation up to and including at Board level.
5. Equal opportunity – The organisation will have a written equal opportunities policy that recognises the need to be proactive in tackling all forms of inequality, discrimination and social exclusion. The advocacy provider will have systems in place for the fair and equitable allocation of advocates’ time.
6. Accessibility – Advocacy will be provided free of charge to eligible people. Where clients need or want to purchase advocacy, or where someone has an appointed deputy/attorney in place who wishes to instruct an advocate on the person’s behalf, suitable processes should be in place to safeguard the person and ensure that they are not open to financial abuse. The advocacy provider will aim to ensure that its premises (where appropriate), policies, procedures and publicity materials promote access for the population it serves.
7. Supporting advocates – The advocacy provider will ensure that advocates are suitably prepared, trained and supported in their role, and provided with

- opportunities to develop their knowledge, skills and experience.
8. Accountability – The advocacy provider will have systems in place for the effective monitoring and evaluation of its work, including identification of outcomes for people supported. All those who access the service will have a named advocate and a means of contacting them.
 9. Confidentiality – The advocacy provider will have a written policy on confidentiality that is in line with the Data Protection Act 1998 and the Mental Capacity Act 2005. It should outline how information about a person accessing the service may be shared, as well as the circumstances under which confidentiality might be breached. Advocates must also be aware of situations that would require making a child or adult safeguarding alert.
 10. Complaints – The advocacy provider will have a written policy describing how individuals, including relevant stakeholders, can make complaints or give feedback about the service or about individual advocates. Where necessary, the organisation will enable people who use its services to access external independent support to make or pursue a complaint.
 11. Safeguarding – Clear policies and procedures will be in place to ensure that safeguarding issues are identified and acted upon. Advocates will be supported to understand the different forms of abuse and neglect, issues relating to confidentiality, and what to do if they suspect a client is at risk.

Table 9: Standards to support the commissioning, delivery and monitoring of the NHS Complaints Advocacy Service (Healthwatch England)

Standards for the NHS Complaints Advocacy Service

The Department of Health asked Healthwatch England to help establish the performance standards for good complaints advocacy in light of concerns raised in the Clwyd Hart review and the Francis report about the visibility and quality of complaints advocacy services. Healthwatch England published these standards in 2015.²⁵ These proposed standards were developed in collaboration with users, providers and commissioners of complaints advocacy services. Healthwatch England stated in this report that it wrote to the Secretary of State in 2015 to ask him to consider the regulatory basis needed to implement the standards. It is unclear whether these standards have become regulations. The eight standards each begin with a service user outcome, followed by a series of 'I statements' which define an ideal complaints advocacy experience from the perspective of a person using the service. Each standard is underpinned by a series of promises that the advocacy provider can commit to. Taken together, they communicate the defining features of a good independent complaints advocacy service; for example, client led, accessible, compassionate and responsive to both the complainant and the system.

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 accessible to everyone who needs a complaints advocate

'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 response

'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 works with other networks to achieve 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.'

Table 10: Practice guidelines for NHS complaints advocacy services (Local Government Association)

Practice guidelines for NHS complaints advocacy services

These guidelines were published on a voluntary basis by the Local Government Association in 2015³¹ and build on the report on standards published by Healthwatch England. The guidelines were developed by the Local Government Association, local authority commissioners and providers of independent health complaints advocacy. They provide a practical tool for local providers and commissioners of independent health complaints advocacy services to use in order to agree local service specifications, which are based on desired outcomes for the people who use the service. The guidance is not mandatory: according to the Local Government Association, it is up to local commissioners and providers to work together and with local people to determine 'what good looks like' and the measures that they will use to assure themselves that independent advocacy services are locally appropriate and performing effectively.

According to the guidance, as a minimum, the core characteristics of an effective service are:

1. Known, accessible and responsive

- 1.1 Clear communication strategy, based on specific characteristics of the community.
- 1.2 Proactive engagement of all sections of the community – in particular seldom-heard groups – and removing barriers to access.
- 1.3 Focused on empowerment and the promotion of self-advocacy, wherever appropriate.
- 1.4 Part of and knowledgeable about the local landscape for complaints, information and signposting.

2. Professional

- 2.1 Clear purpose and description of service.
- 2.2 All staff, including volunteers, are appropriately trained, supported and managed to recognised professional standards.
- 2.3 Staff understand the policy framework and statutory responsibilities for confidentiality, safeguarding and consent, and information management in line with current guidance from the Department of Health.
- 2.4 All staff are accountable, with a clear and accessible complaints procedure.
- 2.5 Clear standards for timeliness and responsiveness.
- 2.6 Clear understanding of best use of resources.

3. Independent

- 3.1 Commissioning and funding arrangements do not compromise provision of independent advocacy to clients.
- 3.2 Clear process for identifying, registering and addressing conflicts of interest.
- 3.3 Demonstrable commitment to the principles of the Advocacy Charter or local equivalent.

4. Makes a difference

- 4.1 Measure and report on outcomes from a client and system perspective and can demonstrate what difference the service has made.
- 4.2 Proactively seeks and acts on client feedback.
- 4.3 Identifies systemic issues and trends and takes action to promote systemic change.
- 4.4 There are robust systems to share information with local and national organisations involved in complaints and service improvement.

For each of the above, the guidance states the service specification, describes how individuals experience this, describes the outcome if successful, a measurement of this.

Evaluation of the NHS Complaints Advocacy Service

We could not find any evaluation on the NHS Complaints Advocacy Service. There appear to be no national data published on the number of people accessing the service and there are no national data pertaining to the quality of the NHS Complaints Advocacy Service. The NHS publishes annual data on the number of complaints it receives, but it provides no information on the number of complainants who access advocacy through the NHS Complaints Advocacy Service. While some of the local authorities publish annual reports which contain data on the advocacy service provided at a local level, this is not done at a NHS national level. A number of providers of NHS complaints advocacy, for example, SEAP and POhWER, also produce annual reports and provide information on the number people they support through the complaints process and their satisfaction with the service.

Independent advocacy under the Care Act 2014

From 1 April 2015, the Care Act 2014³² places a new obligation on local authorities to involve people in decisions made about them and their care and support. Local authorities' advocacy duty will apply from the point of first contact with the local authority and at any subsequent stage of the assessment, planning, care review, safeguarding enquiry or safeguarding adult review. All local authorities must ensure that there is sufficient provision of independent advocacy to meet their obligations under the Care Act 2014. There should be sufficient independent advocates available for all people who qualify, and it is unlawful not to provide an advocate to someone who qualifies for such a service.⁸

Determining eligibility for independent advocacy

If it appears to the authority that a person has care and support needs, then a judgement must be made as to whether that person has **substantial difficulty** in being involved and if there is an **appropriate individual** – carer, family or friend – who can support them. An **independent advocate** must be appointed to support and represent the person for the purpose of assisting their involvement if these two conditions are met. The Department of Health,⁸ the Local Government Association³³ and the Social Care Institute for Excellence³⁴ have all published guidance on commissioning advocacy under the Care Act.

From the first contact with a person, the local authority must consider whether a person would have 'substantial difficulty' in any one of the following areas:

1. Understanding relevant information – Many people can be supported to **understand** relevant information, if it is presented appropriately and if time is taken to explain it. Some people, however, will not be easily able to understand relevant information, for example if they have mid-stage or advanced dementia.
2. Retaining that information – If a person finds it difficult to **retain** information long enough to be able to weigh up options and make decisions, then they are likely to have substantial difficulty in engaging and being involved in the key care and support processes.
3. Using or weighing up the information – A person must be able to **weigh up** information in order to participate fully and express preferences for or choose between options. For example, they need to be able to weigh up the advantages and disadvantages of moving into a care home. If they find it difficult to do this, they will have substantial difficulty in engaging and being involved in the key care and support processes.
4. Communicating their views, wishes and feelings – A person must be able to **communicate their views, wishes and feelings** whether by talking, writing, signing

or any other means, in order to aid the decision-making process and to make priorities clear. If they find it hard to do this, they will have substantial difficulty in engaging and being involved in the process.

In general, a person who has substantial difficulty in being involved in their assessment, plan or review will only become eligible for an independent advocate where there is no one else appropriate to support their involvement. This could be because they do not have any family members or friends who:

- know them very well;
- agree to offer this support;
- are able to offer this support (for example, they themselves could have learning difficulties or dementia, which prevent them from offering support);
- are appropriate (for example, they are suspected of abusing the person);
- are able to help the person put forward their view (for example, they have strong views on what the decision should be, and do not support the person to express their aspirations).

The main thing to consider is whether they would be able to facilitate the person's active involvement in the process. It is not sufficient to know the person well or to love them deeply – the role of the appropriate individual is to support the person's active involvement with the local authority processes. Some people will not be able to fulfil this role easily; for example:

- a family member who lives at a distance and who only has occasional contact with the person;
- a spouse who also finds it difficult to understand the local authority processes;
- a friend who expresses strong opinions of their own prior to finding out those of the individual concerned;
- a housebound elderly parent.

An appropriate individual cannot be someone who is already providing the person or their carer with care or treatment in a professional capacity or on a paid basis; for example, a GP, a nurse, a key worker or care and support worker.

In general, a person who has substantial difficulty in being involved in their assessment, plan and review will only become eligible for an advocate where there is no one appropriate to support their involvement. The exceptions are:

- where the exercising of the assessment or planning function might result in placement in NHS-funded provision in either a hospital for a period exceeding four weeks or in a care home for a period of eight weeks or more, and the local authority believes that it would be in the best interests of the individual to arrange an advocate;
- where there is a disagreement, relating to the individual, between the local authority and the appropriate person whose role it would be to facilitate the individual's involvement, and the local authority and the appropriate person agree that the involvement of an independent advocate would be beneficial to the individual;
- where a deprivation of liberty may be the result of the proposed care and support plan; if the proposed plan involves restricting a person's liberty to the extent that they may be deprived of their liberty, in any setting, an advocate must be involved.

Who can act as an advocate?

According to the Department of Health Care Act guidance,⁸ advocates must have:

- *a suitable level of experience*: this may, for example, be in advocacy or in working with those groups of people who may have substantial difficulty in engaging with assessments and care and support planning.
- *appropriate training*: this may, for example, initially be training in advocacy or dementia, or working with people with learning disabilities. Once appointed, all independent advocates should be expected to work towards the National Qualification in Independent Advocacy (Level 3 City & Guilds) within a year of being appointed, and to achieve this qualification in a reasonable amount of time.
- *competency in the task*: this will require the advocacy organisation to assure itself that the advocates who work for it are all competent and have regular training and assessments.
- *integrity and good character*: this might be assessed through interview and selection processes; seeking and scrutinising references prior to employment, and ongoing Disclosure and Barring Service (DBS) checks.
- *the ability to work independently of the local authority*: this would include the ability to make a judgement about what a person is communicating and what is in a person's best interests, as opposed to in a local authority's best interests, and to act accordingly to represent this.
- *arrangements for regular supervision*: this will require that the person meets regularly and sufficiently frequently with a person who has a good understanding of independent advocacy who is able to guide their practice and develop their competence.

It is recommended that the advocacy **Quality Performance Mark (QPM)** (which was described in the previous section and is a robust, quality assessment and assurance system) should be used for providers of independent advocacy. QPM is a tool used to benchmark independent advocacy services against a framework.

Role of advocate

Advocates appointed under the Care Act have two main functions.

First, they are there to support the person to make their own decisions and to be as involved as possible within decision-making processes. While performing this function, independent advocates will therefore need to:

- be aware of and comply with the rules and regulations under which they operate;
- take into account the requirements of the United Nations Convention on the Rights of Persons with Disabilities, which protects the rights of people to have their views effectively communicated;
- recognise the different approaches required, dependent on the capacity of the individual and adopt a supported decision-making approach wherever possible;
- ensure that if the person has been assessed as lacking the capacity to make the decision, the provisions of the Mental Capacity Act have been correctly applied, and that anyone charged with making a decision takes it in the best interests of the person.

Second, advocates can represent a person, which may involve speaking on their behalf. This is particularly important for people who are not able to self-advocate and put forward their own wishes, aspirations and choices. The independent advocate must 'advocate' on the

person's behalf, to put their case, to scrutinise the options, to question the plans if they do not appear to meet all eligible needs, or do not meet them in a way that fits with the person's wishes and feelings. The ultimate goal of this representation is to secure a person's rights, promote the person's well-being and ensure that their wishes are taken fully into account.

The advocate must always make arrangements to visit and meet with the individual, wherever possible in private, to offer support in the following areas:

Understanding processes – Advocates will assist people to understand the processes they are involved in.

Understanding rights – Advocates will support people to understand their rights under the Care Act.

Making decisions – Advocates will support people to make decisions by assisting them to weigh up various care and support options, as well as choose the ones that best meet their needs and wishes.

Communicating views, wishes and feelings – Advocates will support a person to communicate their views, wishes and feelings to the staff who are carrying out an assessment, are developing a care or support plan or reviewing an existing plan, or are carrying out a safeguarding enquiry or review.

Understanding plans – Once a plan has been made, the person may need the support of an advocate to help understand the decision or plan reached, what it means for them, who is responsible for what and likely timescales involved.

Challenging decisions – The Care Act requires advocates to support people to challenge a decision or process made by the local authority where they wish to do so.

Consult with others – Advocates should always consider whether it would help the individual to consult persons who are, or have been, engaged in providing care or treatment for the individual in a professional capacity, or persons who may be in a position to comment on the individual's wishes, beliefs or values; for example, family members, carers or friends of the individual.

Accessing records – An advocate can access, and take copies of any relevant records relating to the individual where the individual has the capacity, or is competent, to consent to the records being made available to the independent advocate and does so consent; or the individual does not have the capacity, or is not competent, to consent to the records being made available to the advocate, but the advocate and Local authority considers that it is in the best interests of the individual.

Safeguarding – When appropriate, an advocate should support and represent the individual in the safeguarding process

Advocates must never take responsibility to sign off or agree plans. Their role is to support the person to take control of creating their own plan or – where the person lacks the capacity to do this – to gather information to inform the creation of the plan. Advocates retain an important 'check-n-challenge' function: in other words, to check that the plan accurately reflects the person's needs, views, aspirations and well-being, and support a person to challenge the plan (or challenge the plan on the person's behalf if they are unable to do so).

People will be entitled to receive advocacy support from different services and under different legislative frameworks, depending on their eligibility. This will inevitably lead to overlap within advocacy roles – for example, a person detained in a mental health hospital who wishes to make a complaint about their NHS care and treatment could be supported by a complaints advocate or an Independent Mental Health Advocate.

The independence of the service is an important consideration for all commissioners. Anything compromising that independence could easily undermine confidence. The Care Act regulations for independent advocacy are clear: providers of advocacy must be independent of the local authority, with their own constitution, code of practice and complaints procedure. Advocates under the Care Act will be managed by, and primarily accountable to, the advocacy organisation that recruits and employs them, thereby maintaining their independence from the local authority.

Funding of advocacy

The advocacy service is free at the point of use. An impact assessment for the Care Act has set out the anticipated national costs associated with providing access to independent advocacy under the Act³⁴ (Table 11). These costings were based on the expected numbers of needs assessments, carers' assessments and reviews and applied specific assumptions to the expected numbers. It appears that no new funding will be made available to local authorities to provide this advocacy service.

Table 11: Anticipated national cost of providing independent advocacy

Year	Total recurring costs
2015/16	£14.5 million
2016/17	£34.6 million
2017/18	£49.5 million
2018/19	£67.1 million

Evaluation of independent advocacy provided under the Care Act 2014

No evaluation had been undertaken on the quality of independent advocacy under the Care Act 2014. However, this is not surprising as the service has only been in existence since 1 April 2015. We found no evidence that there are plans to monitor the quality of the advocacy service in the future.

Patient advocacy in Western Australia

Unlike England and New Zealand, none of Australia's states or territories has a state-directed advocacy service. However, in Western Australia, the Health Consumers' Council (HCC), an independent agency that is almost completely government funded, provides free advocacy for healthcare users.

Western Australia complaints system

The Health and Disability Services Complaints Office (www.hadscow.wa.gov.au/complaints/) is an independent statutory authority (established under an Act of Parliament) which provides an impartial resolution service for complaints relating to health and disability services in Western Australia (WA). This service is free and available to all users and providers of health and disability services. The Complaints Office reviews and reports on the causes of complaints, undertakes investigations, suggests service improvements and advises service providers about effective complaint resolution. It operates within two key service areas:

- assessment, conciliation and investigation of complaints;
- education and training in the prevention and resolution of complaints.

A complaint can be made by the person who received the service; a relative, representative or carer; a representative of a person who has died; or a provider, on behalf of the person who received the service from another provider. Complaints can be made against any individuals or organisations that provide a health service. Complaints may include allegations that a service provider has acted unreasonably by:

- refusing to provide a service;
- the manner in which a service was provided;
- providing a service;
- denying or restricting the user's access to records;
- breaching confidentiality;
- charging an excessive fee;
- not dealing with a complaint effectively.

The Complaints Office encourages complaints to initially be raised with the service provider, as offering the provider a chance to address the issues usually results in speedier resolution of a complaint. However, this is not a requirement. If raising the complaint with the service provider proves unsatisfactory, the complainant may call the Complaints Office's Assessment Team. They can discuss options, explain the complaints process and organise a complaint form to be sent by post. Alternatively, complaint forms can be completed online or downloaded (PDF) and returned by fax, email or post.

Health service complaints must be made within 24 months of the date the service being complained about was provided. Some discretion exists if there is a good reason for the delay. The Complaints Office is generally unable to assist with complaints that have already been determined by a court, registration board or tribunal. In such circumstances referrals to alternative organisations may be suggested. All complaints must be confirmed in writing. Once completed forms are received, the Complaints Office determines how best to deal with the complaint and may contact the service provider. When complaints relate to a registered health professional, the Complaints Office, by law, is required to consult with the Australian Health Practitioner Regulatory Agency. This will determine which agency is the most appropriate to deal with the complaint.

There are two resolution processes: negotiated settlement and conciliation. All information exchanged during these processes is confidential. Negotiated settlement involves an exchange of information between parties via a case manager. This may be conducted over the telephone, by email or in writing, and generally does not involve a face-to-face meeting. The role of the negotiator is to assist in the exchange of information and promote resolution of the complaint. In some circumstances, specific information or consumers' records may be requested, in order to clarify issues. Conciliation generally involves all parties engaging voluntarily in a face-to-face meeting to discuss the complaint; this is conducted by a trained conciliator. The process offers both parties the opportunity to openly discuss the complaint. The conciliator will meet individually with each party to discuss and clarify issues that have been raised and ensure that everyone is prepared for the conciliation meeting. Prior to the face-to-face meeting the conciliator may need to:

- gather more details about the complaint;
- review any medical or procedural documentation;
- determine any relevant, applicable standards;
- assist with determining realistic outcomes;
- discuss the conciliation process with all parties and actively encourage parties to engage in the resolution of the complaint.

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

The complaint will generally be acknowledged in writing within 14 days. Complaints will be promptly investigated, and in most circumstances a response will be provided within 30 days. More complicated complaints may require more time to investigate. The Complaints Office and the Australian Health Practitioners Regulation Agency will not deal with the same complaint concurrently. They may refer cases between bodies if they feel the complaint falls outside their remit. If a decision has already been made by the Australian Health Practitioners Regulation Agency (even if the complaint did not go to full inquiry), the Complaints Office cannot deal with the complaint. The Complaints Office allows consumers to have an advocate and will explain to complainants how to go about procuring or using an advocate. The Health Consumers' Council provides an advocacy service to assist health consumers in making complaints.

The Health Consumers' Council

According to the Health Consumers' Council (HCC) website (www.hconc.org.au), Western Australia is the only Australian state that offers a comprehensive individual advocacy programme. The HCC in Western Australia was established in 1994 and it is an independent not-for-profit community-based organisation; as such, it does not have the statutory powers to effect change or to require responses from health service providers. It is an incorporated body governed by a Board of Management which is required to abide by the Associations Incorporation Act (1987). The HCC represents the consumer voice in health policy, planning, research and service delivery. It comments publicly on all issues affecting health and also provides an individual advocacy service. The advocacy service covers many aspects of the health service, including hospital, primary care, mental health, dental, and complementary and alternative therapies. The service is flexible and assists the consumer at any stage of their journey – from accessing health services to navigating the health complaints processes. It is the only organisation of its kind in Australia to provide free health advocacy for individual health consumers.³⁵

What the HCC advocate does

The HCC can help consumers to seek the most appropriate options to resolve their complaints about the healthcare they have received. Access to the advocacy services is free. A toll-free telephone number and a reply-paid postal facility is provided for consumers. Recognising that complaints about health services are best resolved by the parties concerned, an HCC advocate will provide advice, information, referral, support and advocacy as follows:

- An HCC advocate can assist consumers to clarify and define the issues in their complaint, so as to ensure that the matter is dealt with by the most appropriate health service staff members.
- The HCC can provide consumers with a sample complaint letter, showing them how to draft their own complaint letters to a health service. An advocate can assist a complainant in writing the complaint if they have difficulty doing so. In most cases, the Complaints Office will ask for written authorisation for the advocate to act on the complainant's behalf.
- The HCC also assists with Freedom of Information applications.

- The HCC can assist individuals or groups of consumers to formulate a complaint if they are unable to do so themselves.
- The HCC will assist with complaints that identify a systemic problem in the health system.
- An HCC advocate can attend meetings with consumers, either as an advocate or as an independent third party. The latter role is a useful one of witness and support. The HCC representative observes the interaction between consumer and provider and, by being present, provides moral support to the consumer.
- If the HCC becomes a participant in such meetings, it will be to assist the consumer to achieve the agreed objectives of the meeting.

In cases where HCC advocates believe it is warranted, they offer consumers the opportunity (at no cost) to meet with a lawyer who has expertise in medical negligence. Sometimes, the advocate will suggest that a consumer attends a free legal information night because they believe they may have a chance of making a successful claim. Such free information sessions can help consumers to understand the reasons why legal action is not likely to be worthwhile. These meetings usually take place at the HCC's 'once a month' free legal information evening, which is held in the HCC offices. The HCC advocate and the consumer usually prepare a short case summary before the half-hour meeting with the lawyer. Although it is generally preferable to meet 'face to face', if it is too difficult for a consumer to attend the free legal information night in person, meetings can be conducted over the telephone. The lawyers volunteer their services. If a consumer decides to pursue legal action, there is no expectation that they will choose the lawyer they met through the HCC.

Cases dealt with by the HCC

The HCC collects data through its individual advocacy programme, and these data are published in the HCC's annual report. The HCC's annual report for 2015 shows that the HCC advocacy team received 621 requests for support; 101 were not proceeded with for a variety of reasons, including that the consumer was not able to identify a specific issue, or the consumer withdrew the request because the issue was resolved. Of the 520 cases that the HCC dealt with, 65% were physical health cases and 35% were mental health cases. Typically, the mental health cases were more complex, with at least 50% of the advocates' workload related to these cases.

Of the physical health cases:

- 35.6% of disputes related to diagnosis and treatment.
- 29% related to denial of access to services.
- 23.5% related to consumer rights.
- 11.8% related to costs.

Of the mental health cases:

- 53.3% related to consumer rights. This was significantly higher than the figure for non-mental health consumer rights issues (23.5%). This was due in part to involuntary detention and treatment of mental health consumers.
- 27% disputes related to diagnosis and treatment.
- 18% related to denial of access to services.
- 2% related to costs.

Funding of advocacy service

Although the HCC receives funding from State and Commonwealth agencies, it is an independent advocacy service. For the 2014/15 financial year it received 95% of its funding from the Western Australia Department of Health. However, we could not find any information regarding the amount of funding it receives. The HCC has 10 staff including 2.8 full-time equivalent (FTE) advocates.

Evaluation of the Western Australia advocacy service

We found no evaluation of the Western Australia (WA) advocacy service. However, the Western Australia Department of Health has recently moved to 'outcomes contracting', which means that all non-governmental organisations (NGOs) in receipt of funding from a government agency report not just on outputs, but also on outcomes. In 2014/15, the HCC began negotiating a five-year outcomes-based contract with the Department of Health for its core contract to deliver individual advocacy and consumer and health sector support services. The new five-year outcomes-based contract commenced in January 2016.

The service outcomes relating to individual advocacy that the HCC will report on are as follows:

- Health consumers are supported to effectively manage their own experience while using the WA healthcare system.
- Health consumers are supported to participate, engage and partner with the WA healthcare system as a result of their involvement with the service.
- Health consumers are appropriately referred, when required, to other agencies in order to meet their needs.

The service outcomes relating to Health Sector Support are as follows:

- Health consumers have the opportunity to be supported and linked to health consumer networks and partnerships in the WA health system.
- The Department of Health and area health services are assisted to facilitate and promote active engagement with health consumers in the planning, delivery and review of health services.
- The Department of Health and area health services are informed on emerging trends and issues affecting health consumers.

Conclusion

There are many definitions and models of advocacy in the literature which are broadly similar, and much of the literature originates in the disability field. There is much less written about patient advocacy in health services and it mainly pertains to advocacy provided by non-state-directed NGOs. We identified very few English-speaking countries that have state-directed advocacy services. Due to the tight time frame for completing this review, it was not feasible to study non-English speaking countries. Therefore, it is possible that other examples of state-directed advocacy services exist elsewhere.

Of the three countries we studied, New Zealand has the longest-established service (since 1996). Its complaints and advocacy services are provided by a single statutory service that is independent of the health service. The legislation underpinning the advocacy service sets out a legal requirement for the positions of Health & Disability Commissioner (Ombudsman) and Director of Advocacy, who are independent of each other. It also sets out a legal requirement for a patients' Code of Rights, and requires the Commissioner to review the Act and the Code periodically. In the 20 years since the advocacy service was established it has undergone changes in how its service is commissioned; initially, it had 10 providers, but by 2006 this had reduced to just one and has remained unchanged since then. Its performance is measured and published annually, and it appears to function well and meet its targets. While the New Zealand model of patient advocacy seems to perform well and has a high level of user satisfaction, it must be emphasized that this occurs in the context of a national no-fault system of compensation for accidental injury, including medical injury. Complainants who suffer a medical injury do not need to prove negligence in order to receive compensation, and it is not possible to bring a compensation case through the courts system, as is the system in Ireland and most other Western countries. The Health & Disability Commissioner's Office is the only place where a service user can bring a complaint.

England also has a long-established independent patient advocacy service, although it has only had a statutory basis since 2006. Its complaints system is separate from the advocacy service and is embedded within the NHS. The English advocacy service has undergone many changes since the mid-2000's, but it is unclear if this has been to the detriment or benefit of the advocacy service. Reports in 2011 and 2013 have highlighted weaknesses in the service. The system of commissioning advocacy services is fragmented and complex, having moved from a system where three advocacy providers were centrally contracted by the Department of Health to provide a national service to the current system whereby each of the 353 local authorities has responsibility for providing a local advocacy service. As this only occurred in 2013, it is unclear what impact the change in commissioning has had. In any case, it will be difficult to measure the impact, as routine data on the advocacy are not collected. While individual advocacy providers and local authorities furnish some data on the advocacy they provide, this is not published on a national basis, making it extremely difficult to assess if a functioning advocacy service is provided or if service users are happy with this service. It also makes it difficult to assess the impact of the changes which the provision of advocacy services has had.

The Western Australian model differs from the other two, as it does not have a statutory basis. While its Health Consumers' Council is contracted by the Department of Health to provide advocacy services, it is unclear what type of service level agreement exists between the two bodies. The complaints system is independent of the advocacy service and is provided by a statutory agency. It also offers complainants an opportunity (at no cost) to meet with a lawyer who has expertise in medical negligence. Sometimes, the advocate will

suggest this because they believe they may have a chance of making a successful claim; on other occasions, it can help consumers to understand the reasons why legal action is not likely to be worthwhile. This is one aspect of the Western Australian model that differs from the New Zealand and English patient advocacy service. While there is little work undertaken regarding evaluation of the Western Australian model, it has recently moved to an outcomes-based system of contracting with the Department of Health, which will lead to more emphasis on measuring the outcomes of the service. There was very little information available on the Western Australian model, and while it provides a good example of a non-statutory, independent, government-funded service, it may be worthwhile contacting the relevant personnel to fill the information gaps we have identified.

References

1. Office of the Ombudsman (2015) Learning to Get Better. An investigation by the Ombudsman into how public hospitals handle complaints. Dublin: Office of the Ombudsman. <https://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/Learning-to-Get-Better/Learning-to-Get-Better.pdf>
2. Health Information and Quality Authority (2015) Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise. Dublin: Health Information and Quality Authority. <https://www.higa.ie/publications/report-investigation-safety-quality-and-standards-services-provided-health-service-exec>
3. Pearson J (2009) Research of the Models of Advocacy Funded under the National Disability Advocacy Program. Adelaide: Jenny Pearson and Associates Pty Ltd https://www.dss.gov.au/sites/default/files/documents/05_2012/rmaf_finalreport.pdf
4. Cocks E and Duffy G (1993) The Nature and Purposes of Advocacy for People with Disabilities. Perth: Edith Cowan University, Perth and Commonwealth Department of Health, Housing, Local Government and Community Services, Canberra.
5. Martin B, (2003) Citizen advocacy and paid advocacy: a comparison. *Interaction*, 17(1): p. 15-20.
6. Parsons I (1994) Oliver Twist Has Asked For More. The politics and practice of getting justice for people with disabilities. Villamanta Publishing Service, Geelong.
7. Health and Social Care Act (2012) <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>
8. Department of Health (2014) Care and Support Statutory Guidance Issued under the Care Act 2014. London: Department of Health,. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf
9. Health Consumers Queensland (2011) Health Advocacy Framework. Brisbane: Health Consumers Queensland. https://www.health.qld.gov.au/hcq/publications/hcq_framework_may11.pdf
10. Health and Disability Commissioner Act 1994 <http://www.legislation.govt.nz/act/public/1994/0088/latest/DLM333584.html>
11. Cartwright S (1988) The report of the committee of inquiry into allegations concerning the treatment of cervical cancer at National Women's Hospital and into other related matters. Auckland: Government Printing Office. <https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/legislation/cervical-screening-inquiry-0>
12. Health and Disability Commissioner The HDC Code of Health and Disability Services Consumers' Rights Regulation 1996. <http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-full>
13. Blake P, (2010) Medical mishap: no fault compensation as an alternative to civil litigation - a review of 30 years' experience with the New Zealand Accident Compensation Corporation System. *Medico Legal Journal*, 78: p. 126-37.
14. Drage J, (2012) New Zealand's National Health and Disability Advocacy Service: a successful model of advocacy. *Health Hum Rights*, 14(1): p. E53-63.
15. Health and Disability Commissioner (2015) Annual report for the year ended 30 June 2015. Auckland: Health and Disability Commissioner. <http://www.hdc.org.nz/media/294868/hdc%20annual%20report%202015.pdf>

16. Health and Disability Advocacy (2008) Advocacy Core Competencies for the Nationwide Health and Disability Advocacy Service.
<http://advocacy.hdc.org.nz/media/212430/advocacy%20core%20competencies%20march%202008.pdf>
17. Health and Disability Commissioner (2009) A review of the Health and Disability Commissioner Act 1994 and Code of Health and Disability Services Consumers' Rights. Auckland: Health and Disability Commissioner.
<http://www.hdc.org.nz/media/21446/report%20on%20the%20review%20of%20the%20act%20and%20code%202009-website.pdf>
18. House of Commons Health Committee (2011) Complaints and Litigation. Sixth Report of Session 2010–12. London: The Stationery Office.
<http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/786/786i.pdf>
19. Department of Health (2012) Commissioning independent NHS complaints advocacy services briefing pack.
http://www.local.gov.uk/c/document_library/get_file?uuid=543decdbd-2738-4921-a804-71cb362c0948&groupId=10180
20. Franics R (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. London: The Stationery Office.
<http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf>
21. Clwyd A and Hart T (2013) A Review of the NHS Hospitals Complaints System Putting Patients Back in the Picture. Final report.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255615/NHS_complaints_accessible.pdf
22. National Health Service Act (2006)
<http://www.legislation.gov.uk/ukpga/2006/41/contents>
23. Statutory Instrument 2009 No. 309 (2009) The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009.
http://www.legislation.gov.uk/uksi/2009/309/pdfs/uksi_20090309_en.pdf
24. Health Service Ombudsman for England (2005) Making things better? A report on reform of the NHS complaints procedure in England. London: The Stationary Office.
http://www.ombudsman.org.uk/_data/assets/pdf_file/0015/1077/Making-things-better.pdf
25. Healthwatch England (2015) Independent Complaints Advocacy: Standards to support the commissioning delivery and monitoring of the service. London: Healthwatch England.
http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/healthwatch_advocacy_standards_10022015.pdf
26. Evans D, Booker S, Daykin N, et al. (2008) National Evaluation of Patient Advice and Liaison Services (PALS). Bristol: University of the West of England.
27. Local Government Association (2012) Commissioning Independent NHS Complaints Advocacy. London: Local Government Association.
http://www.local.gov.uk/c/document_library/get_file?uuid=f07bf24c-cd0c-458f-8672-419f26a0831a&groupId=10180
28. Local Government Association (2013) Delivering effective local Healthwatch.
<http://www.local.gov.uk/documents/10180/11463/Delivering+effective+local+Healthwatch+-+key+success+factors/0aa41576-d5f1-40e9-9b7c-fa2d9716618e>
29. Local Government Association (2012) Healthwatch Factsheet - Independent Complaints Advocacy Service. London: Local Government Association.
<https://shropshire.gov.uk/committee->

- services/Data/Health%20and%20Wellbeing%20Board/20120914/Agenda/6.%20Appendix%202.pdf
30. Advocacy QPM (2014) Recognising quality in independent advocacy. A code of practice. <http://www.qualityadvocacy.org.uk/wp-content/uploads/2014/03/Code-of-Practice.pdf>
 31. Local Government Association (2015) Practice guidelines for independent health complaints advocacy services. London: Local Government Association
<http://www.local.gov.uk/documents/10180/6869714/L15-551+Practice+guidelines+for+independent+health+complaints+advocacy+services/5a8a439f-48f0-4609-b4b1-34f39f02e19c>
 32. Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
 33. Local Government Association (2014) Providing Independent Advocacy under the Care Act. London: Local Government Association.
<http://www.local.gov.uk/documents/10180/5756320/Final+Self+study+pack+Providing+Advocacy+Under+the+Care+Act.pdf/c8993d28-37f0-4b91-96be-442409eb4399>
 34. Social Care Institute for Excellence (2014) Care Act 2014: Commissioning independent advocacy. London: Social Care Institute for Excellence.
<http://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/files/commissioning-independent-advocacy.pdf>
 35. Health Consumer's Council (2015) Annual Report 2015. Perth: Health Consumer's Council. http://www.hconc.org.au/wp-content/uploads/2015/10/Annual-Report_2015_Website-copy.compressed.pdf

Appendix 1

List of resources consulted to answer Question 1

Inclusion Ireland (2015) *Discussion on advocacy services*. Written submission to the Joint Committee on Health and Children

<http://www.inclusionireland.ie/sites/default/files/attach/news-item/1379/written-submission-final.pdf>

Institute for Research and Innovation in Social Services (IRISS) (2013) *Advocacy: models and effectiveness*. IRISS: Glasgow. www.iriss.org.uk/sites/default/files/iriss-insight-20.pdf

Keenan, O and Keogh, F (2011) *Scoping study for a National Intellectual Disability Advocacy Initiative*. A Report for Genio

http://www.genio.ie/system/files/publications/genio_national_intellectual_disability_advocacy_initiative_-_final_report_nov_11.pdf

Forum of People with Disabilities (2001) *Advocacy: a rights issue: a reflection document, 2001*. Dublin: Forum of People with Disabilities.

<http://lenus.ie/hse/bitstream/10147/560487/1/advocacy-arightsissue.pdf>

Scottish Independent Advocacy Alliance (2008) *Principles and Standards for Independent Advocacy*. Edinburgh: Scottish Independent Advocacy Alliance.

http://www.theadvocacyproject.org.uk/wp-content/uploads/2012/07/SIAA_Principles_and_Standards.pdf

Joseph Rowntree Foundation (2005) *Information, advice and advocacy for older people: Defining and developing services*. York: Joseph Rowntree Foundation.

<https://www.jrf.org.uk/report/information-advice-and-advocacy-older-people-defining-and-developing-services>

Social Care Institute for Excellence (2014) *Care Act 2014: Commissioning independent advocacy*. London: Social Care Institute for Excellence. www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/files/commissioning-independent-advocacy.pdf

Health Consumers Queensland (2011) *Health Advocacy Framework*. Brisbane: Health Consumers Queensland.

www.health.qld.gov.au/hcq/publications/hcq_framework_may11.pdf

Joint Committee on Health and Children (2016) *Report on the Role of Advocacy in Health and Social Care Services in Ireland*

<http://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2015/JC-HC-Report-on-Advocacy.pdf>

Macadam, A, Watts, R and Greig, R (2013) *The impact of advocacy for people who use social care services*. London: School for Social Care Research.

<http://www.sscr.nihr.ac.uk/PDF/ScopingReviews/SR7.pdf>

<http://www.hdc.org.nz/> Website of the Health & Disability Commissioner in New Zealand