

# “SIGNPOST TO NOWHERE?”

The case for funded Independent Advocacy, Advice and Information for Patients & Families following Patient Safety Incidents

November 2022



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## Introduction

This report will explore the needs of injured patients or their loved ones for independent advocacy, advice and information when they have been involved in patient safety incidents that are believed to have led to harm; and to what extent this is available or resourced. The purpose of the report is to stimulate and inform a national discussion about this issue in England amongst key stakeholders. It will look at the historical context and both the moral and economic arguments and implications of resourcing these kinds of services. It will also propose potential ways of addressing this issue.

The report is written from the point of view of patients who have been harmed and their loved ones. It encourages stakeholders to understand the holistic needs of people who have been affected by harm in healthcare and to explore joined up, cross system solutions rather than be constrained by each agency's narrow perspective and needs.

Currently, many NHS bodies and regulators 'signpost' people affected by patient safety incidents to what they consider to be sources of independent advocacy, advice and support. No responsibility is taken for ensuring that support is actually available, and no funding is earmarked for specialist independent support for this group of people. The organisations 'signposted' to (mostly charities) therefore have extremely low capacity and can barely scratch the surface of the unmet need. Hence the name of our report "*Signpost to Nowhere*". Harmed Patients Alliance would like to thank Peter Walsh, ceo of Action against Medical Accidents for his work on this report on our behalf.

## About the Harmed Patients Alliance

We are an informal group of people with lived experience of healthcare harm founded by James Titcombe OBE and Joanne Hughes and with an advisory group of individuals with expertise in patient safety. Our aim is to enhance understanding of the experience of harmed patients and families, the needs that emerge for them from being harmed by their healthcare and how these can best be met. We do not provide independent advocacy or advice ourselves and have no intention to do so. We are not seeking funding for ourselves, but we recognise the vital importance of independent advice, advocacy and information for harmed patients and their families and that they currently do not have guaranteed access to a service that can meet their needs.

## What do we mean by "advocacy", "advice", "information" and "independent"?

**"Advocacy"** is sometimes used in a generic sense, covering the provision of advice and information as well as someone actually acting as an independent "advocate" for another person. For example, Independent NHS Complaints Advocacy is funded in England in order to help people navigate the NHS complaints procedure. This service (described in more detail later) does not always need to provide an individual advocate for complainants, but sometimes it does.

One general definition of 'advocacy' is:

*"Advocacy means giving a person support to have their voice heard. It is a service aimed at helping people understand their rights and express their views."*<sup>1</sup>

Advocacy in terms of providing an advocate often involves supporting a vulnerable person or person with special needs:

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<sup>1</sup> Advocacy Focus <https://advocacyfocus.org.uk/services/understanding-advocacy/>

*“Advocacy services help people – especially the most vulnerable – to be involved in the decisions that affect their lives.”<sup>2</sup>*

Advocacy in its purest sense does not involve giving people ‘advice’ on what to do or what decision to make.

**“Advice”** is defined as:

*“an opinion that someone offers you about what you should do or how you should act in a particular situation”<sup>3</sup>*

However, giving advice does not always necessarily mean offering an opinion about how people should act. For example, patients can be advised of their rights or options. In this context, giving advice can be more about providing information and *explaining* what it means to help someone make an informed decision.

**“Information”** in this context is information that is made available to patients and families who have been affected by a patient safety incident. This could be about their rights; about the different processes or organisations that they may want to discuss their incident or concerns with; or about where to get other types of support. Many people when provided with the right information, are able to help themselves without having to access advice or advocacy.

**“Independent”** in this context means independent of the NHS or the Department of Health & Social Care; the organisation responsible for the care or treatment where the incident occurred; regulators who may or may not have to make decisions about what action to take; or anyone else with a conflict of interest. Whilst this report is about “*independent* advocacy, advice and information” it is not intended to imply that none of the above can provide information or advice that is helpful to patients or families. (PALS for example). Only, as explained later, that it is widely accepted that in the case of incidents that have led to significant harm, many people would also want, expect and benefit from information, advice or advocacy that is fully independent.

### What independent information, advice or advocacy needs do people have when they have been harmed or affected by a patient safety incident?

When faced with the aftermath of a patient safety incident and the harm it has caused, people are often traumatised and confused. Most people struggle to make sense of the situation they are in and understand the needs that are emerging. They do not have a clue about their rights or their options. They may be invited to take part in patient safety investigations, which they have no experience or understanding of, and need help to describe and ask for what they need in the process. They may be faced with the possibility of various other processes or procedures such as making a formal complaint; reporting concerns to a professional regulator; an inquest; or legal action if there is potential clinical negligence involved. Often times they are forced into ‘processes’ that don’t quite fit with their needs. An opportunity to have a more person centred conversation with the help of a skilled advocate could help support collaborative versus adversarial relationships.

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<sup>2</sup> Independent Age <https://www.independentage.org/get-advice/health-and-care/taking-action/independent-advocacy>

<sup>3</sup> Cambridge University Dictionary <https://dictionary.cambridge.org/dictionary/english/advice>

Individuals' needs and preferences of course vary. However, our collective experience and discussions with people who have experienced patient safety incidents tells us that:

- **Anyone** affected by a patient safety incident would benefit from being able to access good quality, easily understandable written/audible independent **information and advice** about what their needs might be, their rights and options. This would include all the various processes which might be appropriate for them. Some people will be content and able to help themselves with the help of this information .
- **Most people** would benefit from being able to speak to someone independent and specialist enough to listen and understand their needs, explain in more depth about their rights and options and offer **advice** where appropriate. This can take account of the individual's actual experience and circumstances.
- **Some people** would benefit from having a person to support them in person. This might be to help them compose and deliver communications; understand reports or communications they receive; accompany them to meetings providing moral support, advice and where appropriate acting as an **advocate**.

We encourage all stakeholders to think of the holistic needs of the injured patient or their family, rather than simply how these people can be supported through each organisation's own process. This not only deals with people's actual needs better but can result in economies of scale if a system wide approach is taken. The kinds of issues that we believe harmed patients and their families most often need advice, information or advocacy to deal with include:

- Ability to understand what they are experiencing, the needs emerging and how to get those responded to in a non-adversarial way
- Understanding their rights under the Duty of Candour
- Taking part in a meaningful way in a patient safety investigation under the Patient Safety Incident Response Framework (PSIRF)
- Help with the NHS Complaints procedure, and how this relates to other processes
- Access to Medical Records
- Death certification, need for a postmortem, role of the coroner and inquests
- The system of health professional regulation and how to raise concerns
- Potential legal action re clinical negligence and/or human rights (what is involved and its interface with other procedures)
- Bringing concerns to the attention of other bodies such as the CQC or Integrated Care Boards or reporting incidents to the National Reporting and Learning System
- Sources of other support such as counselling
- Sources of specialist legal advice/representation

Some readers may question the benefit for their own organization or the appropriateness of people receiving support on some of these issues, paid for with public funding. However, these are all issues that people affected by healthcare harm are faced with and struggle to deal with. They perceive the difficulties they face to understand and navigate the system and the lack of support available for this as evidence their needs are not considered important. This leads to feelings of abandonment and betrayal, and ultimately compounded or 'second harm'. It not only benefits their wellbeing, trust, and relationships with services by having these services 'under one roof'. Well advised and supported people are more likely to take an active part in investigations without suffering compounded harm; know when it is appropriate or not to bring concerns to the attention of regulators, and in a way that is clear; and have confidence with different parts of the system. This approach can help avoid people feeling they have to make a formal complaint or to take legal action. It is far better that people are supported well from the beginning rather than them feeling they have

to go straight to a lawyer. Many people go to a lawyer because they are looking for an independent ‘advisor and advocate’ to take an interest in their needs and help them get what they need, and a lawyer is all that is on offer in their regard. Economies of scale also come with this joined up approach, and the ability to pool budgets. Dealing with the holistic needs of people affected by patient safety incidents, rather than just thinking of how they can be ‘processed’ through each part of the system’s procedures is better for everyone.

What services of this kind are currently made available by the NHS / healthcare system specifically for patients/families affected by patient safety incidents?

**The simple fact is that no services of this nature are currently funded by the Department of Health & Social Care; the NHS; regulators or other parts of the healthcare system.** For the most part, injured patients and families are left to fend for themselves apart from whatever information and advice they receive from the organisation where the incident occurred or the regulatory or other body they take their concerns to. If they are lucky, they may be given information about how to contact a small number of independent charities who may be able to help them, but as discussed below, (apart from Independent NHS Complaints Advocacy) these rely on their own fundraising and lack capacity to help more than a small fraction of the people that would benefit.

Many harmed patients themselves become the ‘harmed helping the harmed’, with no support, funding or training. People seek out harmed patients who have gone before them on social media and beg them for support, recognising their knowledge from lived experience is often more valuable than generic ‘complaints advice’. When capacity does not allow for this, it creates moral distress for everyone involved and some people attack other harmed patients over their perceived ‘lack of care’. James and Jo from HPA have both experienced extremely distressing scenarios where this has occurred and know that most others have too.

There are a small number of cases where independent advocacy for individual patients or families is commissioned by the NHS trust who is conducting an investigation, or a Clinical Commissioning Group (Integrated Care Board) or NHS England. At the time of writing, we are still awaiting a response for information about this from NHS England.

What help is available?

Whilst there is no service funded specifically for people who have been affected by patient safety incidents, there are a number of services that are funded either by the Department of Health & Social Care; NHS or local authorities which may address one part of their needs. The most relevant in this context is Independent NHS Complaints Advocacy.

Independent NHS Complaints Advocacy:

Local Authorities have a statutory duty to provide funding for Independent NHS Complaints Advocacy in England. The amount of funding available for this service for the whole of England was £15.1 million in 2021-22.<sup>4</sup> Funding is distributed to local authorities who then commission a service for their area. Local authorities do not have to spend all of the money they receive on this service. The contract specification is limited to supporting people with navigating the NHS complaints

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<sup>4</sup> Department of Health and Social Care <https://www.gov.uk/government/publications/adult-personal-social-services-specific-revenue-funding-and-grant-allocations-2021-to-2022/adult-personal-social-services-specific-revenue-funding-and-grant-allocations-for-2021-to-2022#annex-a-specific-grant-resources-allocated-by-dhsc-in-2021-to-2022>

procedure. It can be any complaint including about car parking; quality of food; rudeness; waiting times; as well as complaints about treatment. Some people who are affected do benefit from this service but only if they want to make a formal NHS complaint. The service is not contracted to help people with other issues or processes that they are faced with and staff running the service do not necessarily have the knowledge or skills to do this anyway. Because of the way commissioning of this service is handed over to local authorities, much of the funding is used up on the commissioning process and local authorities 'top-slicing' the budget for other uses. This also leads to a variation between providers of this service across the country.

**SIMPLE FACT: The government accepts the need for independent advocacy for anyone who wishes to make a formal complaint about any aspect of the NHS. Someone with a complaint about hospital car parking or food is guaranteed access to an independent advocacy service, but someone who has experienced harm has no access to a funded service to meet their specialist needs.**

#### Charitable Help:

Injured patients or their families can request charitable help from a number of charities, but none of them receive public funding for this work and have to rely on their own fundraising, without any public funding<sup>5</sup>. The services they provide are free. Their capacity is therefore very limited. For example:

- Action against Medical Accidents (AvMA) runs a specialist helpline and casework service specifically for people affected by patient safety incidents. **Amount of public funding: NONE**
- The Patients Association runs a helpline covering all aspects of health and social care. **Amount of public funding for the Helpline: NONE**
- Various health charities provide support as best they can to service users within their area of health who have experienced patient safety incidents. Maternity charities for example. However, they do not claim to be expert and tend to refer to other sources of specialist advice. **Amount of public funding for this: NONE.**
- Citizens Advice bureaux give general advice and information on issues such as making a complaint. Beyond that, they tend to signpost to sources of more specialist advice. **Amount of public funding for this particular work: NONE**

#### Individual providers of advice or advocacy:

There are a small number of private individuals who offer these services to a small number of people for a fee or in some cases for free.

#### Specialist Advocacy Services:

Local authorities commission different types of advocacy for vulnerable people to assist them with NHS and social care services. For example, Independent Mental Capacity Advocacy (IMCA); Independent Mental Health Advocacy (MIHA); and Care Act Advocacy. None of these are directly relevant to addressing the needs of harmed patients or their families.

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<sup>5</sup> 'Public funding' is funding from central or local government or their agencies/authorities including the NHS

NHS Maternity services – “Independent Senior Advocates”:

Although not currently available, NHS England/Improvement plans to pilot the roll out of the role of ‘Independent Senior Advocates’ which were recommended by Donna Ockenden in the report of her investigation of Shrewsbury & Telford NHS Foundation Trust maternity services. The proposals are currently under review due to widespread concerns over the proposal for the advocates to be employed and managed by Integrated Care Boards (part of the local NHS itself). It is also not clear whether there will be recurring funding for this initiative or if so, how much. Notwithstanding the current controversy about what constitutes ‘independence’, the fact that there is now an acceptance on the part of the system to fund advocacy for injured mothers and their families strengthens the argument for funding it for injured patients and families across the NHS. Incidents are more numerous and just as serious outside of maternity care.

### What do the Government, NHS bodies and regulators say about Independent Advocacy, Advice & Information for harmed patients / their families?

The Government already accepts that anyone with a complaint about the NHS, no matter what the complaint is about, should be able to access independent help and advocacy and significant funds are allocated to local authorities to commission this. However, this only addresses one small part of harmed patients’/families’ needs, and only if they want to make a complaint. This begs the question:

***“If independent advocacy for anyone who makes a complaint to the NHS of any kind is funded, how can it be right that no funding is allocated to ensure independent advocacy, advice and information is available specifically for patients who experience harm as a result of patient safety incidents?”***

NHS England/Improvement already accepts that patients/families should be meaningfully involved in patient safety investigations, and this is a major theme in the new Patient Safety Incident Response Framework. NHS Trusts are told they should signpost people to sources of independent advice and support:

*“You should inform those affected of sources of independent advice at the earliest opportunity”<sup>6</sup>*

The Care Quality Commission regulations for the Duty of Candour require that people who are subject to the Duty of Candour process are provided with support. The CQC guidance for the Duty of Candour goes on to be more specific about signposting to sources of independent advice and other support, telling registered providers they should be:

*“drawing their attention to other sources of independent help and advice such as AvMA (Action against Medical Accidents) or Cruse Bereavement Care”<sup>7</sup>*

NHS Resolution recommends that people contact Action against Medical Accidents or Citizens Advice for independent advice.

Most Health Professional Regulators, many of whose cases involve suspected harm as a result of poor care, point people to sources of independent advice.

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<sup>6</sup> NHSE, PSIRF, *Engaging and Involving patients, families and staff following a patient safety incident* <https://www.england.nhs.uk/wp-content/uploads/2022/08/B1465-2.-Engaging-and-involving...-v1-FINAL.pdf>

<sup>7</sup> CQC, *Duty of Candour Guidance*, <https://www.cqc.org.uk/guidance-providers/all-services/duty-candour-what-you-must-do>



The Parliamentary and Health Service Ombudsman (PHSO) acknowledges there is an unmet need:

*“We have also heard about some concerning gaps in access to more specialist services. While it is important that individuals are supported to navigate the NHS complaints process, they may also need other forms of support and advice.”<sup>8</sup>*

The Learning from Deaths Guidance on working with bereaved families says that people should be provided with details of where they can access independent advice and advocacy. It also says:

*“The Learning from Deaths programme board is reviewing how advocacy services might be commissioned in future.”<sup>9</sup>*

The Learning from Deaths programme board never carried out this review and neither has the National Quality Board who took over the programme board’s responsibilities.

**Whilst it is only right that people are told about organisations that *might* be able to help them, little comfort can be taken from this. In effect, the Department of Health and Social Care; NHS bodies and regulators are washing their hands of any responsibility for ensuring people can actually get the specialist independent help they need. Basically, they are just being advised to go and ask charities if they can help them. With the limited resources available to them, these charities will never be able to do more than scratch the surface of the unmet need.**

What are the moral, patient safety and financial arguments for funding independent Advocacy, Advice and Information?

***Does the NHS / healthcare system in England have a ‘just culture’? Does it owe a moral duty of care to meet the needs it created for injured patients and their families?***

The Patient Safety Strategy for England stresses the importance of a ‘just culture’ in the NHS for patient safety. It is widely accepted that such a culture has to include being fair to patients/families. The Harmed Patients Alliance and Action against Medical Accidents have published recommendations for a “Harmed Patient Care Pathway”<sup>10</sup> which has been widely welcomed and is being piloted in a number of NHS trusts. Elements of it have already been incorporated in the new PSIRF. At the core of the concept is the assertion that NHS bodies owe a specific ‘moral duty of care’ to patients who have experienced harm as a result of patient safety incidents, and their families, in a similar way to the duty of care they owe current patients. It identifies a set of needs created by the harm experienced for this group of people, which they should be entitled to expect are met if they have that particular need. Access to independent advocacy, advice and information is just one, but a

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<sup>8</sup> PHSO, Making Complaints Count (2020):

<https://www.ombudsman.org.uk/sites/default/files/%28HC%20390%29%20-%20Making%20Complaints%20Count-%20Supporting%20complaints%20handling%20in%20the%20NHS%20and%20UK%20Government%20Departments.pdf>

<sup>9</sup> NHS England/National Quality Board: <https://www.england.nhs.uk/wp-content/uploads/2018/08/learning-from-deaths-working-with-families-v2.pdf>

<sup>10</sup> Harmed Patients Alliance and AvMA; *Harmed Patient Care Pathway* <https://www.avma.org.uk/policy-campaigns/patient-safety/harmed-patient-pathway/>

major one of these needs. **The NHS cannot claim to be operating a 'just' 'restorative' or 'patient safety culture' if the patients and families affected by patient safety incidents within NHS services are unable to access the support they need.**

Inquiry after inquiry into NHS scandals have identified that patients and families affected by healthcare harm have not been seen, heard, listened to or understood and have had to fend for themselves. In many cases the problems at the respective trusts only came to light as a result of individuals' efforts. This was the case at Mid Staffordshire; Morecambe Bay; Shrewsbury and Telford and East Kent. The CQC report 'Learning, candour and accountability' (2016)<sup>11</sup> depicted a widespread situation even in fatal cases, where families had no access to independent advice or support. In the ensuing Learning from Deaths Programme overseen by the Department of Health and Social Care and the National Quality Board, the evidence that families needed independent advice and support and recommendations by the family engagement group that this must be addressed went unheeded. Many individuals and families all over the country still suffer the same challenges. Without specialist independent help even the most educated of people can feel lost and unable to make sense of and articulate their needs; participate meaningfully in investigations; or raise concerns with the appropriate bodies. AvMA report that even health professionals who contact them for advice following being involved (as a patient) in patient safety incidents, or a family member having been, don't know their rights and the various procedures that might be followed. **It cannot be right that patients and families affected by patient safety incidents in the NHS should be left to fend for themselves.**

***Better informed, and better supported patients / families help identify problems and drive improvement in patient safety***

The lack of access to specialist independent help can mean not only that the affected people do not get the support, information or outcomes they are seeking, but also that serious failures or risks are less likely to be identified and acted upon. This is the case whether it is learning through a patient safety investigation; helping health professional regulators identify a health professional who is a risk to patients; or bringing wider concerns to the attention of bodies such as the CQC, NHS England/Improvement's reporting system or Integrated Care Boards. **Empowering patients and families who have been affected by harm makes it more likely lessons will be learned and action taken to improve patient safety. It can help avoid 'second harm' being caused by the way incidents are handled after the event (as opposed to the original incident). The saving in human costs of this are enormous, but so are the financial savings.**

***Having better informed, and better supported patients / families helps save time and money***

Having good advice or an advocate makes it easier to understand and be understood and the right process for your needs, which can save huge amounts of staff time (whether in patient safety investigations, or complaints investigations). With NHS complaints, complaints staff and the Parliamentary and Health Service Ombudsman (PHSO) report that when complainants can access the independent complaints advocacy service it makes the handling of complaints go better. However, as explained elsewhere not every injured patient/family wants to or should have to make a complaint. It is just one small part of what injured patients/families are faced with. No independent service is funded which helps people through patient safety investigations or other procedures. **If patients/families were receiving independent advice and support in patient safety**

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<sup>11</sup> CQC, Learning, Candour & Accountability: <https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf>

**investigations, it would lead to better investigations, help avoid compounded harm, and could avoid complaints being made unnecessarily and even avoid litigation (see below).**

Health professional regulators have to spend huge amounts of money in dealing with reports of concerns which turn out not to meet the criteria for a full fitness to practice investigation. Most of this could be avoided if people were better informed and advised as to where and how to raise their concerns. When concerns are raised with the regulator by patients/families, they would be easier to understand and investigate which would save more time and money. Appropriate advice and support would also help people raise valid concerns who otherwise may have been too daunted to do so. Following a wide-ranging review of health professional regulation led by the Department of Health in 2009, there was consensus among stakeholders who recommended that patients/families with concerns have access to:

*“advice and clearer signposting for those considering raising a concern; support in articulating the concern, including advocacy support for vulnerable people”<sup>12</sup>*

**This recommendation has never been acted upon. There is no funding available to ensure people who may be considering bringing a concern to a health professional regulator or who are doing so, get independent advice and support.**

***Access to independent information, advice or advocacy can help avoid unnecessary costs involved in litigation***

Action against Medical Accidents reports that most of its beneficiaries do not want to take legal action and when they do, it is often that they feel forced to because earlier investigations have not led to acknowledgement that harm has been caused; witnessed and acknowledged what the event has meant for them and all the impacts; apologies; and commitments to put problems right. This tendency is also confirmed by research commissioned by NHS Resolution.<sup>13</sup> The involvement of an independent advisor or advocate can make it much more likely that a patient/family gets their needs satisfied without the need to take legal action at all.

Even if an incident does result in legal action, if there has been a better-informed investigation through empowerment of the patient/family through independent advice / advocacy, it is more likely the NHS will recognise it was at fault earlier and save the high legal costs of prolonged litigation when meritorious cases are defended but ultimately settled. Access to independent advice and advocacy for injured patients/families would also support efforts by NHS Resolution to avoid litigation where possible and seek early resolution of cases when they do arise. For example, the Early Notification Scheme for serious birth injuries and also mediation of cases more generally. **Collectively, independent advice and advocacy being available could save the NHS millions of pounds in litigation costs.**

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<sup>12</sup> Department of Health, ‘Tackling Concerns Locally’

[https://webarchive.nationalarchives.gov.uk/20130103005754/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_096492](https://webarchive.nationalarchives.gov.uk/20130103005754/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096492)

<sup>13</sup> NHS Resolution: Behavioural insights into patient motivation to make a claim: <https://resolution.nhs.uk/wp-content/uploads/2018/10/Behavioural-insights-into-patient-motivation-to-make-a-claim-for-clinical-negligence.pdf>

***Access to independent information, advice or advocacy can also help avoid compounded or “second harm”. As well as this unnecessary human cost, this would help avoid costs to the NHS and the economy through ongoing treatment and lost work and benefit payments.***

## Conclusion

Addressing the unmet need for independent advice, information and advocacy when things go wrong and cause harm in healthcare has been left in the ‘too difficult’ box for years. This is unacceptable and a start has to be made in addressing this. The need for doing so is compelling for moral, patient safety and also financial reasons. It would support the NHS work on creating a just culture; support the new approach using the PSIRF; support efforts by NHS Resolution to find alternatives to costly litigation; support health professional regulators by ensuring people get to the right place; and lead to better investigations and better learning to improve patient safety. It would stop harmed patients’ and families’ sense of bewilderment, abandonment and frustration after events that currently causes more harm on top of the original event.

We believe the problem is partly due to the fact that most healthcare system stakeholders only see their own specific areas of responsibility which makes the prospect of funding advice and advocacy solely for their area seem very daunting. Account has not been taken of the financial as well as moral arguments for investing in this. Also, for the Department of Health and Social Care, there is naturally a concern about the financial cost and lack of appreciation of the potential benefits of investing in independent advice and advocacy both in terms of reducing the financial costs as well as the human costs of not doing so.

However, we believe the answer lies in an approach which looks at the needs of injured patients and their families holistically and across the whole healthcare system. This brings simplicity and economies of scale as well as better meeting the needs of injured patients and their families.

Below, we set out a potential way forward to aid discussion and debate.

## A POTENTIAL WAY FORWARD

We do not propose a single, set plan for addressing this real and pressing unmet need, but rather an acknowledgement from key stakeholders that these needs have to be addressed and the start of a conversation as to how best to do this.

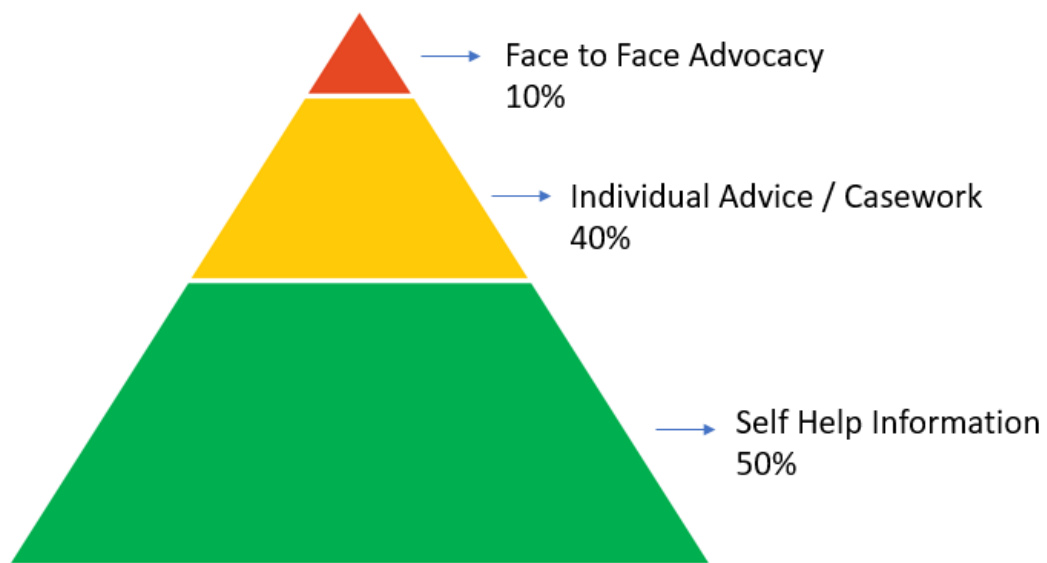
We do suggest a way forward which:

- Addresses the holistic needs of injured patients and families
- Works across the whole system
- Brings economies of scale
- Is independent and free of real or perceived conflicts of interest

We estimate that the split between needs for information for self-help; advice and advocacy is roughly as follows:

- **Anyone** involved affected by a patient safety incident would benefit from being able to access good quality, easily understandable written/audible independent **information and advice** about their needs, rights and options. This would include all the various processes which might be appropriate for them. Some people will be content and able to help themselves with the help of this information.

- **Most people** would benefit from being able to speak to someone independent and specialist enough to explore their needs and explain in more depth about their rights and options and offer **advice** where appropriate. This can take account of the individual's actual experience and circumstances.
- **Some people** would benefit from having a person to understand and support them in person. This might be to help them compose communications; understand reports or communications they receive; accompany them to meetings providing moral support, advice and where appropriate acting as an **advocate**.



These needs could be met by a combination of the following types of services:

**A. A COMPREHENSIVE WEBSITE WITH EASY-TO-UNDERSTAND INFORMATION GEARED SPECIFICALLY FOR PEOPLE WHO HAVE BEEN AFFECTED BY A PATIENT SAFETY INCIDENT**

This would need to be regularly updated and maintained. As well as information about all the key issues and procedures faced by people following a patient safety incident, other support available including those below plus other sources of support such as counselling that people may need to access. This would be geared to making it easier for people to self-help without the need for the services below where possible.

**B. A SPECIALIST ADVICE SERVICE DELIVERD PRIMARILY THROUGH A SPECIALIST HELPLINE, PLUS THE CAPACITY TO PROVIDE MORE DETAILED CASEWORK FOR MORE SERIOUS OR COMPLEX CASES**

The Helpline number together with the Website above should be the single main points of contact for independent advice and support given in any information produced for harmed patients and their families. This builds on the concept of a "single portal" which has been discussed many times with regard to getting people the right information and helping to get them to the most appropriate bodies, rather than being passed from pillar to post. It is anticipated that the Helpline would be staffed by specialist staff and trained volunteers. It is possible for this service to be provided

remotely, nationally. Together with the Website self-help information it should be able to give the vast majority of people the help they need. However, it would also 'triage' cases for those needing additional support through: (a) the more in-depth casework advice and/or (b) the face-to-face advocacy service described below.

**C. A FACE-TO-FACE ADVOCACY SERVICE FOR THOSE WHO NEED ADDITIONAL SUPPORT – INCLUDING ATTENDANCE AT MEETINGS /INQUESTS**

This service would be for people who would find it particularly hard to cope on their own, for any reason. Criteria would need to be thought about in more detail, but it could be argued that anyone who had lost a loved one due to a patient safety incident, or anyone who had experienced severe harm should be able to access this service if they feel they need it. It would still only be a small proportion of the total number of people who suffer harm following patient safety incidents. The service would be able to provide face to face advocacy all over England, so would probably need some form of regional structure or contracts with various different providers of this service across the country working to a common specification.

The above is not intended to be prescriptive, but rather to serve as an example of how these needs can be addressed in a cost-efficient way. We are more concerned that there is formal acknowledgement of the unmet need and appreciation that addressing this is doable. There may be other approaches which can be explored. Equally, within this overall approach there can be different ways of handling this.