# Scoping Exercise Report

## An overview of
## Advocacy Delivery in Relation to Personal Health Budgets
### and other health funded support

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# Introduction

This report outlines findings from a scoping exercise commissioned by NHS England and NHS Improvement exploring current arrangements for delivery of independent advocacy in relation to health funded care and support including:

- s117 aftercare (under the Mental Health Act)
- NHS Continuing Healthcare (adults) (NHS CHC)
- Children and Young People's Continuing Care (CC)
- Personal Health Budgets
- Personal Wheelchair Budgets

The primary aims of the scoping exercise were to:

1) Establish the baseline of current arrangements across England

2) Establish the training needs of advocates providing support in these settings

3) Establish how advocacy within the above processes and systems interact with other types of advocacy

## Approach and Methodology

Our approach included the following steps:

### 1) Freedom of Information Requests

In January 2020 we sent Freedom of Information Requests to all Local Authorities and Clinical Commissioning Groups (CCGs) across England to establish details of independent advocacy services commissioned to provide advocacy to people accessing support/services and through the above processes. The FOI asked to identify what services were commissioned, by whom and to which groups.

### 2) Advocate Survey

- We circulated a survey for advocates delivering all types of independent advocacy in England to complete. It aimed to establish a baseline in terms of what advocacy providers are already delivering in their areas in relation to the same processes outlined in the FOIs.

- The survey was open for one month, across February and March 2020.

### 3) Semi-structed telephone interviews

- We conducted semi-structured telephone interviews with Independent Advocacy providers who were identified through the FOI requests and survey responses. 7

individuals took part and their feedback has further informed this report. The services involved provided a diverse mix of experience including specialist health advocacy commissioned services and statutory providers who received no additional funding or support to advocate within these processes.

- Telephone interviews were delayed as a result of the Coronavirus Pandemic.

## 4) Desktop review of legislation and guidance

We completed a desktop review of legislation and guidance that refers to the delivery of independent advocacy, including:

- The Care Act and associated guidance
- The Mental Health Act and Code of Practice
- The National Framework for NHS Continuing Healthcare
- PHB guidance and information[1]

This identified where current provision should enable advocacy support to be provided and highlighted the potential shortfalls and gaps in current advocacy provision.

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[1] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/personal-health-budget-phb, https://www.england.nhs.uk/personal-health-budgets/

# The Definition and purpose of advocacy

***"Advocacy is taking action to support people to say what they want, secure their rights, pursue their interests and obtain services they need. Advocacy providers and Advocates work in partnership with the people they support and take their side, promoting social inclusion, equality and social justice."*** [2]

Independent advocacy is an essential component of local services and support for people who are at risk of exclusion. Having access to advocacy support will be important to many people in order to help them say what they want, secure their rights, represent their interests and obtain services they need – in relation to the health, social care, education systems and beyond.

Advocates help people to:

- understand, protect and promote their rights
- access information and advice to understand systems and processes for example in health and social care
- access services or support
- express their views about what is important to them or any concerns they may have
- be involved in and the centre of decisions about them and their lives
- explore choices and options to make decisions
- tell people what they want.

Advocates work in partnership with people who access the service. They aim to be 'instructed' or directed by the person at all times and to enable the person to 'self-advocate' as far as possible; it's an empowering relationship.

The advocate will always represent the person and their interests. Advocates don't do things or talk to people without their partner's consent and they don't withhold information that others have shared. They support people to get the information they need and to consider their options and make decisions. They support people to be listened to, respected and understood. Advocates seek to support people to have as much choice and control in their lives as possible. The provision of independent advocacy, in all its forms is based on a set of underpinning principles and values. These are set out in The Advocacy Charter which

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[2] The Advocacy Charter, NDTi 2018

was developed by Action for Advocacy and published in July 2002. This was then updated in 2014 and again in 2018 by NDTi[3].

## Statutory Advocacy

Advocates providing statutory advocacy have clearly defined roles and functions. They support specific people in pre-defined circumstances with particular decisions or activities. People accessing statutory advocacy have a legal right to do so.

Across England, local authorities have the responsibility for ensuring provision of a range of independent advocacy for adults and are required to commission:

- advocacy under the Care Act 2014 – supporting people who may have substantial difficulty to be involved in their Care and Support Assessments, Care and Support Planning, Care and Support Reviews as well as supporting people who are subject to Section 42 safeguarding enquiries, where there is no other appropriate individual available to provide support and representation.
- Independent Mental Capacity Advocacy (IMCA) – supporting people who don't have appropriate friends and family to consult and who lack the mental capacity to make decisions about where they live, serious medical treatment, deprivations of liberty (DoLS) and safeguarding.
- Paid Relevant Person's Representative – supporting people subject to DoLS authorisations, to understand restrictions and their rights and supporting them in all matters relating to the deprivation of liberty safeguards (DoLS).
- Independent Mental Health Advocacy – supporting people who are subject to the Mental Health Act 1983, to understand and promote their rights under the Mental Health Act and more generally, understand their care and treatment and express their views.
- NHS Complaints Advocacy – supporting people thinking about or making complaints about NHS services.

## Non-Statutory Advocacy

Advocacy providers may also deliver 'non-statutory' advocacy in a variety of forms. This could be called community advocacy, general advocacy, professional advocacy, issue-based advocacy, peer advocacy, volunteer advocacy, citizen advocacy as well as support to self-advocates.

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[3] https://qualityadvocacy.org.uk/resources/advocacy-charter/

Anecdotally, we understand that local authorities have decreased the amount of non-statutory, issue based, or community advocacy commissioned over recent years.

The lack of non-statutory advocacy may have an impact on the role advocates can play in the broader issues that people may face and in advocacy support needing to withdraw at certain points in an individual's journey through health and social care processes.

### Non-instructed Advocacy

Some people may lack the mental capacity to make some decisions or are unable to instruct their advocate in either some or all of the work that the advocate is undertaking with them. This is particularly the case in some forms of statutory advocacy, such as Independent Mental Capacity Advocacy (IMCA). Advocates still work hard to understand what is important to the person, ensure they are able to be a part of and influence decisions being made and that their rights are upheld.

In such situations, this is known as 'non-instructed advocacy', i.e. where a person is unable to instruct their advocate. The non-instructed advocate will still seek to uphold the person's rights; ensure fair and equal treatment and access to services; and make sure that certain decisions are taken with due consideration for all relevant factors which must include the person's unique preferences and perspectives.

# The Legislative Context in relation to PHBs and health funded support

Across England, local authorities have the responsibility for ensuring the provision of a range of independent advocacy for adults and are required to commission:

- Advocacy under the Care Act 2014[4]
- Independent Mental Capacity Advocacy (IMCA)[5]
- Paid Relevant Person's Representative (Paid RPR)[6] [7]
- Independent Mental Health Advocacy (IMHA)[8]
- NHS Complaints Advocacy[9]

The above are the types of advocacy that people are entitled to and rights to advocacy are enshrined within legislation and guidance.

As previously mentioned, some local authorities continue to commission other types of 'community' advocacy.

Whilst none of the statutory 'rights' to advocacy specifically encompass Personal Health Budgets, some of the existing legislation enables advocates to work with individuals in:

- the journey to accessing health funded support
- care and support planning in some instances
- complaining about health funded services

The following section looks at this in more detail.

## The Care Act

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[4] Care Act (2014)

[5] Mental Capacity Act (2005)

[6] Mental Capacity Act (2005)

[7] Deprivation of Liberty Safeguards - Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice (2008)

[8] Mental Health Act (1983)

[9] The Health and Social Care Act (2012)

The Care Act[10] enshrines people's rights to independent advocacy with a range of Care Act Processes; Care and Support Assessment, Care and Support Planning, Care and Support Reviews (as well as with s42 safeguarding enquiries). This support is available to individuals with care and support needs as well as to carers. This advocacy support is available to people who are deemed to have substantial difficulty in being involved in the assessment, planning or review of their care and support package AND who do not have an appropriate person who is willing and able to support them through these processes. This is still the case when there is a **joint** package of care:

*This guidance applies equally to those people whose needs are being jointly assessed by the NHS and the local authority or where a package of support is, planned, commissioned or funded by both a local authority and a Clinical Commissioning Group (CCG), known as a joint package of care.*[11]

The guidance goes on to clarify:

*These processes and arrangements have historically been difficult for individuals, their carers, family or friends, to understand and be involved in. Local authorities (with CCGs) will therefore want to consider the benefits of providing access to independent advice or independent advocacy for those who do not have substantial difficulty and/or those who have an appropriate person to support their involvement. Effective joint commissioning arrangements would involve:*

- *dealing with the person holistically, providing a seamless service and avoiding duplication*
- *reducing communication break-down*
- *involvement of the person, family and carers*
- *effective partnership working for health and social care addressing needs together*
- *improved communication and continued care to achieve joint outcomes*[12]

The guidance further states that the local authority can request the involvement of an advocate, *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 4 weeks or*

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[10] Care and Support Statutory Guidance

[11] Care and Support Statutory Guidance 7.21

[12] Care and Support Guidance 7.22

*in a care home for a period of 8 weeks or more and the local authority believes that it would be in the best interests of the individual to arrange an advocate*[13]

It's important to note that this is limited to NHS funded placements and that in other circumstances, when it becomes clear that a person is eligible for full NHS continuing healthcare, the person is no longer eligible for support from a Care Act Advocate; Care Act Advocates often need to withdraw from supporting the person at this point in their journey unless the particular advocacy scheme has additional alternative advocacy services, such as Community Advocacy, where the advocacy support might be able to continue but under another guise (no longer Care Act Advocacy).

Mariah has a package of care and support from the Local Authority to help her manage her condition and do the things she wants to do. This package of support includes funding for a personal assistant. One of the impacts of her condition is that it can be hard to remember information and Mariah has used advocacy (triggered under the Care Act) to access services from a care agency who employs the PA on her behalf. The advocate has helped Mariah to explore how she would like her care needs met and has helped her to recruit a PA who understands her needs. Recently, the advocate has supported Mariah to request a new assessment for a wheelchair – her current chair is over 6 years old and is very heavy, meaning getting out and about is very difficult. The advocate has explained her rights to access a Personal Wheelchair Budget which can extend her options for an active lightweight chair and is now supporting her through this process.

## Mental Health Aftercare – The Care Act and Mental Health Act

Under section 117 of the Mental Health Act 1983 (the 1983 Act), local authorities together with CCGs have a joint duty to arrange the provision of mental health after-care services for people who have been detained in hospital for treatment under certain sections of the 1983 Act[14] After-care services must have both the purposes of 'meeting a need arising from or related to the person's mental disorder' and 'reducing the risk of a deterioration of the person's mental condition and, accordingly, reducing the risk of the person requiring admission to a hospital again for treatment for mental disorder.' The range of services which can be provided is broad and can be provided via a direct payment, PHB, a personal budget from the local authority, or directly provided services/supports.

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[13] Care and Support guidance 7.42

[14] These are patients who leave hospital after being detained on the basis of an application under section 3, a hospital order under section 37, or a hospital direction under section 45A, or a transfer direction under section 47 or 48

In relation to section 117 aftercare, the Care and Support Guidance clarifies that:

*Under the Mental Health Act 1983 (MHA) certain people, known as 'qualifying patients'*[15]*, are entitled to the help and support from an Independent Mental Health Advocate (IMHA). Section 117 of the MHA places a duty on the NHS and local authorities to provide aftercare and this will usually involve a joint assessment (often under the Care Programme Approach) including an assessment of the person's care and support needs, a care and support or support plan and subsequent review (which may reach a decision that a person is no longer in need of aftercare). Those people who do not retain a right to an IMHA, whose care and support needs are being assessed, planned or reviewed should be considered for an advocate under the Care Act, if they have substantial difficulty in being involved and if there is no appropriate person to support their involvement."*

Where the local authority is required to meet the needs of an individual under s.117 of the Mental Health Act, the Mental Health Act code of practice[16] must be followed in conjunction with the Care Act

Where advocacy services provide both IMHA and Care Act Advocacy there is an increased possibility of continuity of support from an advocate and the person is more likely to be supported by the same advocate, shifting their role from IMHA to Care Act advocate.

Tomas has been receiving care and treatment for his mental health in hospital. He has a diagnosis of severe depression and anxiety and has been detained under s3 of the Mental Health Act for 16 months. He has used IMHA support throughout his detention to request leave and to help him during ward rounds. Recently his IMHA supported him through his Tribunal which agreed he did not need to be detained and should be discharged. This triggered the LA and CCG working together to arrange aftercare for Tomas under s117. However, both the LA and CCG were in dispute over which parts of his care should be arranged and funded by health and adult social care. The IMHA helped Tomas to raise concerns and eventually write a complaint as the disagreements were causing delays to his discharge. The IMHA also supported Tomas to explore what type of aftercare would be beneficial in maintaining his mental health which led to Tomas requesting counselling support to him manage his anxiety and gym membership which was an important part of managing his wellbeing. After 10 weeks of planning, Tomas left the hospital with a robust package of aftercare support in place. At this point the IMHA signposted him to a different advocate who could continue to support him in the community (under the Care Act provisions).

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[15] These are patients who leave hospital after being detained on the basis of an application under section 3, a hospital order under section 37, or a hospital direction under section 45A, or a transfer direction under section 47 or 48.

[16] Mental Health Act Code of Practice chapter 34

## Independent Mental Capacity Advocacy

Independent Mental Capacity Advocates (IMCAs) have very clearly defined roles and remits as set out in the Mental Capacity Act and Code of Practice. The IMCA role is to support and represent people through decision making processes, specifically people who are deemed to lack capacity to make their own decisions when they have no suitable friends or family to support and represent them in relation to those decisions.

Individuals have a statutory right to IMCA support when decisions are being made about Serious Medical Treatment and about where someone should live. IMCAs can also get involved in care reviews and in relation to decision being taken as a consequence of safeguarding situations.

IMCAs need to be ‘instructed’ by the local authority or by a medical professional.

## Deprivation of Liberty Safeguards (DoLS)

IMCAs also get involved when decisions are being taken about whether someone should be under a DoLS authorisation and can also provide support to those undertaking the relevant person’s representative role

The case study below gives an example of how IMCAs may get involved in decisions in relation to NHS CHC and PHBs.[17]

Phillipa is 89 and lives with her husband Patryk. 4 years ago, she had a heart attack which left her with a brain injury: she requires 24hr care and is receiving end of life care at a hospice funded through Continuing Health Care. As she lacks capacity to consent to these care arrangements a DoLS has been authorised. Her husband acts as her unpaid Relevant Person’s Representative and has a 39d IMCA to help him understand the Deprivation of Liberty Safeguards. Patryk believed that Phillipa would not want to die in the hospice but would want to return home for her last days and weeks. The advocate working in the IMCA role supported Patryk to request a Personal Health Budget to help him to care for Phillipa at home. The advocate challenged the DoLS as there was evidence Phillipa wanted to go home and would want to appeal. The advocate was also concerned that the current arrangements were not the least restrictive option, which was returning home with support. With the support of the advocate, Patryk requested adaptions were made to the home and nursing care was arranged and organised through a Personal Health Budget. Phillipa spent the last 6 weeks of her life at home, with her husband, which is what she wanted.

## NHS Complaints Advocacy

Those wishing to make a complaint about NHS funded services, (including, for example, NHS CHC and PHBs) are able to make complaints about care, treatment and/or services received as well as processes and decisions that are made.[18] Complainants are entitled to the support of independent complaints advocates[19] (sometimes referred to Independent Complaints Advocates, NHS complaints advocates or health complaints advocates) to support them in the making of their complaint. People using NHS CHC and PHBs can access health complaints advocacy if they need support to challenge decisions being made about the amount of money they receive.

## NHS Continuing Healthcare

The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care refers to advocacy in a number of regards:

In completing the NHS CHC checklist: The amount of notice given should take into account whether the individual wishes to have someone present to act as an advocate for them or represent or support them, and the reasonable notice required by the person providing that support. It is the responsibility of the person completing the Checklist or coordinating the discharge process to make the individual aware that they can have an advocate or other support (such as a family member, friend or carer) present and of the local arrangements for advocacy support.[20]

In describing the role of NHS CHC coordinators: supporting the person (and those who may be representing them) to play a full role in the eligibility consideration process, including ensuring that they understand the process, they have access to advocacy or

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[18] The NHS Constitution for England

[19] Handbook to the NHS Constitution for England

[20] The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care 1.11

other support where required, and organising the overall process in a manner that maximises their ability to participate.[21]

In identifying an example of good practice in partnership working being: Joint funding of advocacy services by CCGs and LAs[22]

The section on Advocacy[23] goes further in explaining the potential role for advocacy in NHS CHC processes and in how arrangements should be made. It reiterates people's right to advocacy support under the Mental Health and Mental Capacity Acts as well as people's right to support under the Care Act as set out above. It does make clear that there isn't a broader statutory right to advocacy for people being assessed for NHS Continuing Healthcare beyond joint assessment, although it recognises an individual's entitlement to engage an advocate:

"57.1 Any individual is entitled to nominate a person to represent their views or speak on their behalf and this could be a family member, friend or peer, a local advocacy service or someone independent who is willing to undertake an advocacy role. It is not appropriate for either a local authority or NHS member of staff to act as a formal advocate in this sense as there could be a conflict of interest, although staff should always seek to explain the individual's views alongside their own. Local authorities and CCGs may have varying arrangements to fund advocacy services in their locality, some being jointly funded whereas others are funded by a single agency or rely on voluntary contributions."

It also makes clear that whilst CCGs aren't required by law to provide advocacy services, they should consider planning strategically with local authority partners in relation to statutory and non-statutory advocacy services provided within their area.[24]

It also states that: For advocacy in relation to independent review panels (IRPs), CCGs should ensure that there are agreed protocols as to how the provision of advocates will operate and the circumstances in which they may be made available. CCGs could link such protocols with the strategic development of advocacy services discussed above.

Findings from the Freedom of Information Requests and the advocates survey and subsequent telephone interviews indicates that the joint strategic planning may not be taking place in line with the intentions set out in the National Framework.

The guidance goes on to clarify the IMCA role and further states that:

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[21] The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care 20.1

[22] The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care 48.1

[23] The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care PG 57

[24] The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care 57.4

Even if an individual does not meet the criteria for use of the IMCA service, and regardless of whether or not they lack capacity, they may wish to be supported by an advocate to help ensure that their views and wishes are represented and taken into account. Any person may choose to have a family member or other person (who should operate independently of local authorities and CCGs) to act as an advocate on their behalf. CCGs should ensure that individuals are made aware of local advocacy and other services that may be able to offer advice and support and, in conjunction with local authority partners, may wish to consider whether there are any joint commissioning opportunities to enhance general advocacy services in their local area[25].

and

Although not related to the eligibility decision-making process, local authorities have a duty under the Care Act 2014 to promote the well-being of the individual at all times. Where relevant, this includes making arrangements for independent advocacy in relation to safeguarding enquiries relevant to the individual.[26]

In Summary, whilst the guidance refers to good practice in the involvement on advocates, it does not 'trigger' advocacy being put in place for individuals beyond, IMCA, IMHA and Care Act Advocacy.

## Children and Young People's Continuing Care

The National Framework for Children and Young People's Continuing Care states that:

The CCG must ensure that the child or young person and their family being considered for continuing care should understand the continuing care process, receiving accessible advice and information in a timely and clear manner. Their views should be documented and taken into account and considered alongside the benefits and risks of different types of provision as part of the assessment. Where the views of the child or young person are different from those of their family, the possibility of advocacy should be discussed.[27]

It does not go further to ensure that advocacy should be arranged and there is no mention of a duty to commission advocacy.

## Personal Health Budgets and Personal Wheelchair Budgets

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[25] The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care 307

[26] The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care 308

[27] National Framework for Children and Young People's Continuing Care, 67

A personal health budget is an amount of money to support a person's health and wellbeing needs, which is planned and agreed between the person and their local NHS team. It is not new money, but it may mean spending money differently so that people can get the care and support they need.

People have a legal right to have a personal health budget if they are eligible for:

- NHS Continuing Healthcare (adults)
- Children and Young People's Continuing Care
- Personal Wheelchair Budgets
- Section 117 aftercare

Other people also have a right to ask for PHB; there is nothing to stop CCGs giving PHBs to wider groups e.g. people with a learning disability etc.

The joint LGA and NHS paper, Community capacity and peer support - Summary guide[28], refers to the need to "Promote self-advocacy, provide advocacy support or enable access to independent advocacy as required." However, this is best practice advice and not statutory guidance.  Existing guidance and legislation do not trigger the involvement of advocacy for PHBs or PWBs.

## Summary

Whilst existing rights to advocacy under the Care Act, Mental Capacity Act and Mental Health Act are enshrined in the NHS constitution and enable some people to access advocacy support at various points in their care and support 'journeys', there is nothing which triggers a right to advocacy support for all individuals accessing NHS CHC, CC, s 117 aftercare, PHBs or PWBs.  Existing guidance and best practice advice recognise the important role advocacy can play as well as people's rights to choose a representative of their choice, however it does not go further to ensure that advocacy services are available.

The National Framework for NHS Continuing Healthcare & NHS-funded Nursing Care sets out clear intentions in relation to joint strategic planning, partnership working between local authorities and CCGs as well as siting the joint funding of advocacy as being an example if good practice.  More evidence is needed to understand how these intentions are applied in practice. However findings from the advocacy survey and FOIs suggest that

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[28] https://www.england.nhs.uk/publication/community-capacity-and-peer-support/ 2017

not all areas are working in this way. This may impact on people's experience of services and their access to advocacy.

## Findings from the Freedom of Information Requests

We have analysed data received following the submission of Freedom of Information Requests (FOIs) to all Local Authorities and Clinical Commissioning Groups (CCGs) across England. These FOIs asked what, if any, independent advocacy is currently commissioned to support people going through the following processes:

- s117 aftercare (under the Mental Health Act)
- NHS Continuing Healthcare (adults)
- Children and Young People's Continuing Care
- Personal Health Budgets
- Personal Wheelchair Budgets

Most Local Authorities and CCG's do not commission specialist advocacy for people going through NHS CHC, CC, PHB or Personal Wheelchair Budgets over and above the statutory roles introduced within the Care Act and Mental Health Acts. There are a few examples where local commissioning arrangements ensure strong and robust advocacy provision is available. There are also examples of commissioners believing that advocacy is available where it is not.

Minimal data (if any) is being kept on whether people are accessing or using advocacy. The Department of Health used to collect data in relation to IMCA provision, however this ceased some time ago. Increased, systematic data collection in relation to advocacy commissioning and delivery would be extremely beneficial; it would enable a greater understanding of the national picture of delivery and the 'postcode' lottery of provision that we think exists.

## Summary of findings

### 1) Statutory advocacy

The overwhelming majority (94) of Local Authorities were able to tell us who they commission to provide statutory advocacy. For people going through the processes focused in the scoping report, this specifically included:

- Independent Mental Health Advocacy (IMHA) services. IMHAs are able to support a person through discharge planning where they will receive s117 aftercare whilst they are detained in hospital, receiving it whilst on a Community Treatment Order, or to those people who are conditionally discharged.
- Care Act Advocacy. Care Act advocates can support an eligible person[29] once they are discharged with a package of s117 aftercare. They can also support anyone going through a joint Care Act and NHS CHC assessment/receiving a joint package of care.

## 2) Community based advocacy

20 Local Authorities identified community-based advocacy services which may be able to meet the advocacy needs of people going through these processes but there is no data kept on whether community advocacy is being used to support people going through health led processes and decisions.

Just one area commissioned a self-advocacy network to support people going through the above processes.

## 3) Specialist advocacy

- There are a very small number of local authorities who commission specialist one to one 'health' advocacy provision to meet the advocacy needs of people going through the above processes. (Devon, Cheshire, Hampshire, Islington, Knowsley, Newcastle, Norfolk, Milton Keynes, Stockport, Stockton and Surrey were all able to identify advocacy for some of the above processes). This is non-statutory advocacy and the model of delivery, eligibility criteria etc varies from area to area.
- Some areas (4) identified that statutory advocacy was jointly commissioned by the CCG and Local Authority. This is somewhat unusual, given the public duties to commission statutory clearly lie with the Local Authority. It may be that this was misreported, and the joint commissioning extended the non-statutory advocacy available in an area.
- A small number of CCGs identified a specialist provider 'Beacon' was available to support people going through NHS CHC processes. Upon further research it became evident that NHSEI had previously commissioned Beacon to provide 90 minutes of advocacy and advice to people going through NHS CHC

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[29] This is where a person faces substantial difficulty at being involved in the assessment, planning or review of their care and support package AND does not have an appropriate person who is willing and able to support them through these processes.

processes. This contract ended approximately 2 years ago and is no longer available. However, it appears that Beacon do still offer support with NHS CHC processes that people need to pay for privately. This may mean that people are being referred to a service mistakenly.

## 4. Commissioning advocacy

- Commissioners responses show confusion as to whether IMHAs or Care Act Advocates are supporting people with planning (discharge or support) or receiving s117 aftercare: some areas suggest one or the other, but this is inconsistent.
- The FOI highlighted a significant lack of detail regarding young people accessing IMHA support and s117 aftercare which could mean that little or no advocacy is being offered to these young people.
- There is a risk that some commissioners may not fully understand their duties to commission advocacy. These specific examples stand out:

**Example 1:** Some commissioners responded 'none' when asked if they commission advocacy for people going through NHS CHC processes. This is significant as they should ensure that eligible people who qualify for support from a Care Act Advocate access it. This could suggest they are not.

**Example 2:** One respondent told us commissioning advocacy for people going through these processes is the "remit of the NHS and CCG and therefore advocacy is not in the Local Authority's remit". This is simply inaccurate.

**Example 3:** One CCG responded: "In adults if someone expresses an interest in a direct payment or third party PHB they generally have a representative to begin with if they do not have capacity that acts as their advocate, and therefore we would as a general rule not be required to commission an independent advocate". This reflects a lack of understanding and therefore potential lack of support being offered to anyone who has capacity but wants advocacy help, as well as for those people who lack capacity and do not have an appropriate representative.

- There are concerns that IMHA services are not being commissioned for children and young people. Significant numbers of commissioners identified the IMHA service as being available only for adults over the age of 18.
- Some commissioners suggested that NHS complaints advocacy would be available if a person wanted advocacy support to complain if things were going wrong. It is interesting and concerning that in some areas, advocacy is viewed through a lens of complaints rather than being an integral part of

personalisation and ensuring people are fully supported and involved through decision making processes.

- Some commissioners rely on charities providing non-commissioned services: "The Continuing Health Care Team use the services of Disability Sheffield, mental health citizens' advice advocacy service and The Carers centre. As these are voluntary independent bodies, Sheffield CCG does not commission these services".

## 5. Spot purchasing advocacy

- Some areas fed back that they spot purchase independent advocacy for people going through these processes. However, we do not know whether this advocacy is actually arranged as no data is kept. There was little evidence from the FOI that people actually access advocacy under spot purchasing arrangements.

## 6. Advocacy in Continuing Care

- There is generally little evidence of commissioning advocacy for young people. Kent was one example who had made some arrangements for young people going through Continuing Care, accessing PHBs or wheelchair budgets, although it is vague and not monitored: "Kent County Council contracts the Young Lives Foundation to provide a Rights, Representation & Advocacy Service for Children in Care and Care Leavers. The advocacy service does not deliver in isolation the specific areas of advocacy asked for in your questions. If a child or young person is accessing s117 aftercare (under the Mental Health Act), Continuing Healthcare (NHS CHC), Continuing Care, personal wheelchair budgets and/or personal health budgets then advocacy would continue to support this. This is though not something monitored by the Young Lives Foundation."

## 7. Wheelchair Budgets & Advocacy

- One area (Surrey) openly admitted they do not yet offer personal wheelchair budgets which could be against the current requirements. "Currently Adult Social Care do not support personal wheelchair budgets and therefore do not commission Independent Advocacy Support for this at present. We are working in partnership with the CCG to develop a process for personal wheelchair budgets. This may therefore change in the next 6 months".

## Findings from the advocates survey

An invitation to complete the survey was sent out via the NDTi's advocacy and Quality Performance Mark mailing lists. It was further promoted by Kate Mercer Training and by both organisations on social media. Despite this we had a relatively low response rate with 24 individuals completing the survey. It may be that the timing of the survey promotion, coinciding with the start of the coronavirus pandemic impacted on the response rate. It may also indicate that advocates don't naturally associate their roles with supporting people in relation to PHBs and other health funded support and so felt that the survey wasn't relevant to them.

### Respondents

Tables 1 shows the geographical area that the responding organisations indicated that they cover. Please note that some respondents stated that they were part of more than one organisation. Responding organisations represented a wide range of advocacy providers; there was a mix of national, regional and smaller, local providers. They also had a range of experiences and provision, with some providing all types of statutory and non-statutory independent advocacy, some with just one 'strand' of statutory advocacy, e.g. Care Act Advocacy and some with specific NHS CHC advocacy projects. Some organisations provide support to self-

| Location | Respondents |
|---|---|
| **Across England** | 1 |
| **Dorset** | 3 |
| **Isle of Wight** | 1 |
| **Lancashire** | 2 |
| **Leeds** | 1 |
| **Liverpool** | 2 |
| **London** | 2 |
| **North East England** | 2 |
| **Oxford** | 1 |
| **Shropshire** | 2 |
| **Staffordshire** | 1 |
| **Stockport** | 1 |
| **Wiltshire** | 3 |
| **Worcester County (Dudley)** | 1 |

*Table 1. Areas covered by respondent organisation*

100% of respondents said that their organisation provides independent advocacy services.

14 (58.3%) respondents said that they were responding to the survey as individuals and 10 (41.7%) were responding on behalf of an organisation.

## Advocacy Delivery

Respondents were asked whether their advocacy provision enables them to provide independent advocacy to people during different processes related to health funded support, and if so, how these are funded. Table 2. shows the number of respondents who selected each option.

*Table 2. advocacy delivery and funding sources, as reported by respondents*

| Type of health funded support process | Funded by LA | Funded by CCG | Jointly funded by LA & CCG | Funded by another source | I don't know how the support is funded | Not delivered |
|---|---|---|---|---|---|---|
| **Aftercare Support under Section 117 of the Mental Health Act to children and young people** | 3 (12.50%) | 1 (4.17%) | 3 (12.50%) | 0 (0%) | 3 (12.50%) | 14 (58.33%) |
| **Aftercare Support under Section 117 of the Mental Health Act to adults** | 11 (45.83%) | 2 (8.33%) | 3 (12.50%) | 0 (0%) | 1 (4.17%) | 7 (29.17%) |
| **NHS CHC to Adults** | 11 (45.83%) | 5 (20.83%) | 4 (16.67%) | 0 (0%) | 1 (4.17%) | 3 (12.50%) |
| **CC to Children and Young People** | 1 (4.17%) | 0 (0%) | 0 (0%) | 0 (0%) | 3 (4.17%) | 22 (91.67%) |
| **PWCB to Children and Young People** | 1 (4.17%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (8.33%) | 21 (87.5%) |

| | | | | | | |
|---|---|---|---|---|---|---|
| **PWCB to Adults** | 3 (12.50%) | 2 (8.33%) | 1 (4.17%) | 0 (0%) | 1 (4.17%) | 17 (70.83%) |
| **PHB to Children and Young People** | 1 (4.17%) | 0 (0%) | 0 (0%) | 0 (0%) | 3 (12.50%) | 20 (83.33%) |
| **PHB to Adults** | 5 (20.83%) | 2 (8.33%) | 2 (8.33%) | 0 (0%) | 3 (12.50%) | 12 (50.00%) |

According to these responses, most of this advocacy was funded by local authorities (LAs) rather than clinical commissioning groups (CCGs). In particular, the responses suggest that less was known about the processes relating to children and young people. Responses mirror findings in the FOI regarding limited provision of advocacy to children.

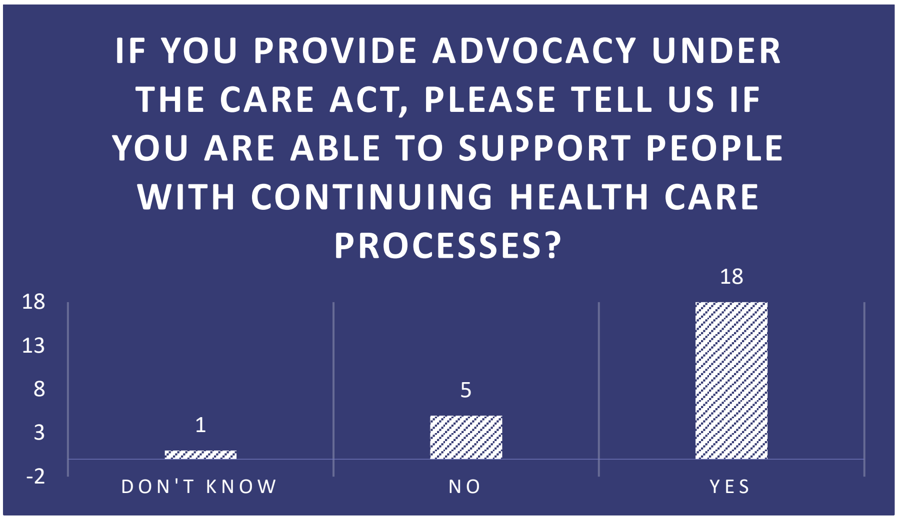

*Figure 1. Provision of CHC support through Advocacy under the Care Act*

Respondents were also asked to indicate which 'strands' of their advocacy delivery enabled them to provide advocacy in relation to health-funded support. Figure 3. shows their responses. The most common strand was Advocacy under the Care Act, followed by Independent Mental Health Advocacy (IMHA) and Independent Mental Capacity Advocacy (IMCA). Some community advocacy projects also supported people, for instance Newcastle and Gateshead CCG fund community-based health and social care advocacy. There were some specific projects identified in the survey that enabled advocates to support people:

- Dorset Advocacy has a specific NHS CHC Advocacy project
- Southern Advocacy Service are 'separately' funded to support people with NHS CHC appeals

Even with a relatively small sample size there is a clear disparity in provision from area to area, which indicates discrepancies in the ways that commissioners and advocacy organisations have interpreted statutory guidance.

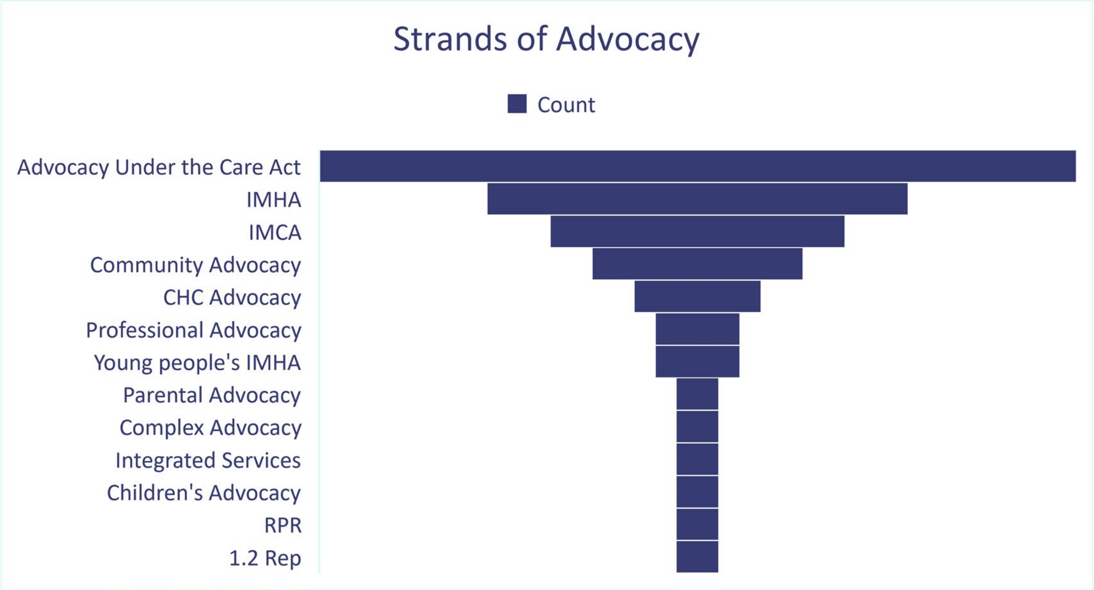

*Figure 2. Strands of advocacy that provide support relating to health-funded support*

## Further Comments

Respondents were asked to tell us more about the independent advocacy support that they had provided in relation to accessing, planning or reviewing health-funded support. Their comments are summarised below.

## Experience of providing advocacy relating to health-funded support

Some advocates said that they had provided specific advocacy for the NHS CHC process, which tended to be provided under the Care Act. They said that they had supported people through various aspects of the NHS CHC process, including preparing applications for NHS CHC support, completion of the Decision Support Tool (DST), assessments, planning a package of care, review meetings and appealing NHS CHC decisions.

Others said that this support was provided under broader advocacy arrangements for an individual, such as Community Advocacy. This includes people who did not meet the Care Act criteria. Another respondent said that their organisation generally doesn't provide support with NHS CHC processes under the Care Act but would consider doing so based on individual circumstances.

Regarding the Mental Health Act, some respondents had provided support with planning for Section 117 aftercare. Another had attended care and treatment reviews (CTR) and s117 discharge planning meetings on with or on behalf of individuals.

As above there was variation in responses across respondents, potentially indicating a lack of clarity and consistency across areas.

## Barriers

The respondents discussed barriers they had encountered in providing advocacy to people in relation to health-funded support. For example, one person said that they do not always receive referrals from health-care professionals which leaves them unable to provide support. Another respondent said that NHS CHC tends not to be provided in their local area.

A lack of integration between health and social care was thought to limit provision, particularly when there isn't an integrated approach to commissioning independent advocacy.

Another respondent said that they had turned down referrals for Care Act advocacy for someone going through the NHS CHC process, because the process was not led by the local authority. They would only be able to accept the referral if the person had a joint package of care including a local authority social worker. They acknowledged a lack of clarity when interpreting the guidance, which led them to wonder whether the guidance was being applied inconsistently.

## Funding

Respondents wrote in more detail about the funding arrangements in their areas. Some reported that this was funded jointly by local authorities and CCGs. Another said that NHS CHC advocacy was generally not commissioned in their area but could on rare occasions be funded through spot-purchasing. Another said that advocacy for support with PHB and PWB processes could be provided under generic or community advocacy arrangements. Individual contracts could be used in selected local authorities or on a CCG contract to deliver health planning, including Emergency Healthcare Plans.

Another respondent reported an agreement with their commissioner that they would support people who are being assessed for NHS CHC funding if a social worker was involved. If the individual was not eligible for NHS CHC funding, then the local authority would be required to provide support or agree joint funding.

# Findings from telephone interviews

Advocates who completed the survey self-identified as being available for follow up interviews. Contact was made with all positive respondents and a total of 7 people confirmed they would be available for further contact. The group included representatives from:

- One of the largest national providers of independent advocacy
- Small local charities who deliver community-based independent advocacy
- Small and medium size organisations who deliver community and statutory based independent advocacy
- Specialist providers of NHS CHC advocacy

## Most advocacy is provided under existing statutory duties

Overwhelmingly, most of the advocacy services interviewed only work with people within NHS CHC and s117 aftercare processes under their statutory IMHA, IMCA or Care Act contracts. Advocates described these arrangements as very restrictive and limited as it meant people could only access advocacy if they met strict criteria. It also meant 'episodic' advocacy was frequently used – advocacy which focuses on single issues rather than holistic person-centred approaches. This results in people having access to advocacy for some part of their journey (i.e. assessment) but not others (i.e. planning).

> *"Under the Care Act we get involved in CHC for the assessment meeting - we would do the prep work with the person. We don't get involved in the screening - but the assessment. It would then end - we don't stay for the planning or review"*

> *"We would help the person understand the outcome - we don't help them to appeal or to ask for a review. But we could raise a complaint (this is easy as we do the NHS and social care complaints). This is only for jointly funded/assessments - we don't get involved in fully CHC processes".*

Where the advocacy service held IMHA, IMCA and Care Act Advocacy contracts and used 'multiskilled' advocates or integrated models of advocacy – that is advocates who were trained to undertake the different statutory roles – the advocate stayed with the individual effectively moving from IMHA/IMCA to Care Act Advocate. This was helpful particularly when the advocate was already present to support the individual to access NHS CHC or PHB processes:

> *"There is lots of cross over - lots of our people have a DoLS. If a person has an IMCA and then it becomes apparent that they need a CHC assessment, we would*

> *then be looking at advocacy care and support under the Care Act - but if its full CHC they wouldn't be Care Act"*

There is very little data to demonstrate how frequently this happens, and there is anecdotal evidence to suggest this is more likely to take place where the larger or national advocacy providers are commissioned as they are often better placed to offer integrated or multi skilled advocates.

## Spot purchasing arrangements

In some areas advocacy providers have negotiated spot purchasing arrangements for decisions that fall outside of statutory duties. This was often with the CCG (for NHS CHC) but also with the local authority or even private hospital provider (for s117 aftercare). There is very little data available on the frequency of these arrangements being put in place or which groups of people are benefitting. Where this was identified as a real option, it was generally as a result of enthusiastic or strong advocacy leadership, rather then commissioners seeking to make advocacy accessible.

## Squeezing advocacy in (although technically not allowed)

Some services described informal arrangements where they would endeavour to support a person going through these processes despite the person not technically qualifying for help: *"this is us pushing on the door - not the commissioned service letting us in" and "There is nothing specifically commissioned – but we make it fit the statutory work".*

Similarly, some areas use funding allocated to community advocacy to provide advocacy within NHS CHC processes. Although this funding stream may not have been sourced with NHS CHC or s117 processes in mind, given the parameters are wider, advocacy services find they can access this to enable advocacy in these processes. Having said this, anecdotally we understand that community (non-statutory) advocacy has been commissioned to a lesser extent in recent years and it is likely that there will be some areas across England where there isn't any non-statutory, community advocacy available. Where there is unmet need within a locality, advocacy providers may highlight this to commissioners, but the extent to which this happens is unknown.

## Private hospitals commission advocacy too

Within private hospitals (St Andrews, Cygnet, Priory, Huntercombe etc), IMHA support has been commissioned by the hospital, separately from the local authority. At least one these contracts provides advocacy *"on top of the IMHA commissioned. So, the advocate might stay with the patient once they are back in their community. But its only for people in area - if they are returning to their home area then we would end"*. This potentially increased the level of advocacy support for people going through s117 aftercare as the advocate would be available whilst the person was detained and once they were discharged. When people are placed out of area and then return to another area their access to advocacy support may be disjointed.

## Evidence that specialist commissioning produces positive results

Areas that had specialist commissioning arrangements reported positive relationships with the CCG and a history of supporting people through NHS CHC and PHB processes. These pockets of dedicated advocacy appeared to be well established and embedded locally.

Services that received dedicated funding to support people through NHS CHC processes reported much stronger success in supporting people: open referrals and strong relationships with the CCG meant people could easily access the services. In one area the CCG informs every person of the advocacy service at the point they are notified of the NHS CHC decision.

One service reported working very closely with family members – particularly where the person lacked capacity. This group of people are usually well supported by family members so are not entitled to statutory advocacy under the Mental Capacity Act or Care Act, but by having access to specialist advocacy they are able to secure better outcomes. For instance, the advocacy service reported that *"family often contact us following a 'non-eligible' decision and they want help to understand the decision, understand their rights and challenge. People find it very confusing and once they have spoken to our advocate, they are better informed. We have found that fewer appeals are made – it's almost like once things have been explained properly the decision becomes more acceptable. This is a good thing as it prevents people from challenging decisions that aren't going to change"*

## Specialist services support people placed out of area

One of the specialist commissioned services visit people who are placed out of area. The advocacy service reported that visiting people from this group provided many benefits including helping the CCG with the annual review – particularly if the person didn't have family members or friends – as they knew the person well and it also afforded benefits in safeguarding as an independent advocate would visit the person and would be well placed to raise any concerns should they arise. This was important as many people were not supported by natural allies or accessed other types of advocacy.

## Variation in advocacy offered to people looking at PHBs

Most services do not actively provide advocacy to people accessing PHBs. This is mostly because they are not commissioned although there is some evidence that advocacy services are not confident or knowledgeable about PHBs: some interviewees did not know whether they were commissioned or not and seemed to have a lack of insight into the process: *"people who use PHBs don't tend to use advocacy" "We focus on people who lack capacity who wouldn't take on PHBs"*

## Low awareness of personal wheelchair budgets

The services we spoke to, generally knew very little about personal wheelchair budgets: both in relation to advocacy, *"don't know if we are commissioned*" was the most common response, and in understanding the right of people to use personal wheelchair budgets, "*I haven't heard of these, what are they?"*

## Very little specialist training available

In areas where advocacy is contracted to deliver dedicated support within NHS CHC processes, there was much evidence of additional training being available. This was mostly arranged with the CCG so that advocates effectively joined CCG arranged NHS CHC training aimed at staff implementing NHS CHC processes. Advocates reported this worked well. Others had utilised free resources made available from organisations such as Social Care Institute for Excellence, but most relied on the current Qualifications in Independent Advocacy supplemented with support through supervision.

There was universal support for specialist training to be available for advocates and everyone interviewed agreed this was a gap.

## Difficulties in local authority and CCG relationships impact on people's ability to access support

A number of interviewees commented on the challenging landscape of NHS CHC processes: many find it complex, lengthy, jargon heavy, hard to understand and harder for people and their families to access and navigate. There were also reports of the local authority and CCG disagreeing with who is responsible and so the inevitable ping pong of decision avoidance begins: *"CHC is incredibly difficult to access - you get health and Local Authority literally fighting across the table"*.

This was further echoed when people are placed in mental health hospitals and eligible for s117 aftercare: there are significant problems in establishing who is responsible for discharge arrangements, something advocacy could help with:

*"One of our units is a rehab unit for mental health - the patient could have come from anywhere in the UK. No-one from the placing authority is available to attend meetings. We are there as advocates constantly battling with the authority to do some things. There is complete lack of clarity on who is responsible, they are really difficult to get hold of and pin down. It's meant people lose their placements which is massively frustrating and upsetting"*.

# Conclusions

## Current arrangements across England

This scoping exercise has identified a lack of strategic commissioning across the country for people accessing and using health processes. This is exacerbated in some areas by staff not being fully aware of what advocacy provision is commissioned. There is inconsistency across the country both in what is commissioned and by whom (CCG or local authority). It is clear that there is a real 'postcode' lottery when it comes to being able to access independent advocacy in relation to health funded support, with local authorities and CCGs commissioning different 'community' advocacy provision and there being a lack of clarity and consistency in interpreting statutory guidance.

This must surely impact on people's uptake of and access to PHBs, particularly where people require additional support to navigate systems and realise their entitlements.

Where advocacy is used by people accessing NHS CHC processes and PHBs, it is through one of the following ways:

1) Overwhelmingly, the majority of advocacy support is delivered through existing statutory duties – but only where the advocacy service is confident and competent in undertaking these roles. The scoping exercise found that not all advocacy services are responding fully to people who may be entitled to advocacy.

2) Through spot purchasing arrangements – that is the local authority or CCG pays an agreed hourly or set fee per person using advocacy.

3) Through community advocacy (i.e. non statutory advocacy). This is where the service is able to use resources with broad parameters to support people who may need advocacy in a range of settings. This may be funded by the local authority or CCG or potentially grant funded.

4) Through specialist commissioning of dedicated health advocacy. These specialist services are extremely limited, however where this has been arranged, advocacy is well embedded and is making a very real difference – both to individuals and to systems.

The scoping exercise found no evidence of specialist advocacy being used to support people using Personal Wheelchair Budgets.

Considerations:

- It would be interesting to explore how co-producing updated commissioning guidance regarding advocacy for health funded support processes could address some of the current inconsistencies in commissioning arrangements. It may also help to reemphasis the aspirations in Personalised Care and the NHS CHC framework in relation to joint strategic planning, commissioning and joint working generally.
- In England we don't have commissioning guidance that encompasses all types of advocacy delivery in one set of guidance. Any update considered should take into account a need for all of our advocacy commissioning guidance to be updated and brought together.
- It would also be valuable to evaluate the impact of specialist 'health' advocacy to further understand its benefits to individuals, potential improvement to personalised care, and the impact on the broader health and social care 'system'.
- Commissioning pilot projects to evaluate could ensure a level playing field from the outset.

## Constraints with legislation and guidance

Whilst existing legislation and guidance goes some way in enabling advocacy to be provided to support people through NHS CHC and other health funding processes, it often falls short. This potentially leads to 'episodic' advocacy provision that has to start and stop in line with the requirements of different types of statutory advocacy.

Guidance 'encourages' advocacy support to be considered or arranged for people accessing NHS CHC, CC or PHBs. However, whilst there is no formal commissioning guidance or expectation in this regard, provision of advocacy support is likely to remain patchy and dependent on local awareness of the benefits of advocacy involvement in achieving better outcomes with and for individuals.

Personalised care is about what matters to people and about people having increased choice and control over how their health and care needs are met. It recognises that people themselves can design their own health and care support and enables people to live as they wish.

An aspiration of personalised care is that people are more involved in the decision-making process and should be supported to talk about the outcomes that matter most to them and what is the best course of action to achieve these outcomes. Advocacy can and should be a key part of this support.

Personalised care also recognises the importance of better joint working at the health and social care interface is vital to improving outcomes for people[30].

The findings within this report show that there is more to do for this to be realised.

**Considerations:**

- As above – refreshing commissioning guidance could support more consistent approaches to advocacy availably across the country.
- Establishing a statutory right to advocacy for people accessing or wanting to access health funded support would potentially fill the 'gaps' and lead to less episodic and more holistic advocacy being available to people.
- Establishing recognised standards and/or best practice guidance in relation to the delivery of specialist health funded support could support more consistent approaches across the country.
- Developing a shared understanding of how the gaps in legislation and guidance impact on people's experiences of advocacy and other health and care services would provide a basis for mitigating any issues arising.

## Lack of data

As previously mentioned, there is little, if any data collected, nationally or locally, in regard to the commissioning and/or delivery of independent advocacy in England. The lack of data means we don't have the ability to baseline what is being delivered where, examine the take up of advocacy or ensure that inequalities are addressed or understand the potential impact that advocacy can have.

It also means we are unable to establish the true extent of the 'postcode lottery' in terms if advocacy services that are available to people in a locality.

**Considerations:**

- Design and implement standardised national and/or local data collection in relation to the commissioning and delivery of independent advocacy. In particular, ensuring that data supports an understanding of how existing inequalities impact on take up of or access to independent advocacy along with mitigating factors.

## Specialist training

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[30] https://www.england.nhs.uk/personalisedcare/making-the-case-for-a-more-personalised-care-approach/

There is a lack of standardised training for advocacy regarding health processes. Current arrangements are haphazard with most services relying on the following training opportunities:

- accessing CCG delivered training on NHS CHC processes.  This is excellent at covering content connected with NHS CHC processes, for example, completing the Decision Support Tool and appeal processes but offers nothing on the advocacy role in these processes
- internal knowledge being shared and utilised through supervision or internal training
- using resources provided by organisations such as Social Care Institute for Excellence.  These tend to focus on NHS CHC processes in general and do not address the advocacy role within the health systems

This scoping exercise found universal agreement from the advocacy sector that specialist training is needed and welcomed to support an effective advocacy workforce within health processes.

The FOI also indicated a low awareness in local authorities and CCGs in relation to PHBs and PWBs and this may highlight a broader training need across health and social care.

**Considerations:**

- Design and implement specialist training for independent advocates in relation to NHS CHC, CC, PHBs and other health funded support processes.
- Identify further measure to increase awareness of PHBs and personalised care across local authorities and CCGs