



Advocacy For People Accessing Health Funded Support

Executive Summary

This report outlines the findings of an NHS England and NHS Improvement funded scoping exercise exploring current arrangements for delivery of independent advocacy in relation to health funded care and support.

Methods included:

- Freedom of Information Requests to all Local Authorities and CCGs across England
- One month Advocate Survey in early 2020.
- Semi-structured telephone interviews with 7 individuals.
- Desktop review of legislation and guidance, etc., to identify the reach of current statutory¹ and non-statutory advocacy support along with the shortfalls.

The report covers the following **12 key findings** in detail, comes to **4 main conclusions** and highlights **areas for further consideration**.

Findings

1. Most 3rd party, one to one advocacy is provided under existing statutory duties.
2. Existing legislation, guidance and best practice advice does not ensure that advocacy services are available to people who are accessing or wanting to access health funded support.
3. Rights to advocacy under the Care Act, Mental Capacity Act and Mental Health Act enable some people to access advocacy support at various points in their care and support 'journeys' in relation to health funded support but, this can come to a 'sudden end' and feel quite rigid and or episodic.
4. There is nothing in current legislation or guidance which triggers a right to advocacy support for all individuals accessing NHS Continuing Healthcare (NHS CHC), Children and Young People's Continuing Care (CC), Section 117 mental health aftercare, Personal Health Budgets or Personal Wheelchair Budgets.
5. Joint strategic planning may not be taking place in line with the intentions set out in the National NHS CHC Framework.
6. Most Local Authorities and CCGs do not commission specialist advocacy for people going through NHS CHC, CC, PHB or PWB processes over and above the statutory roles introduced within the Care Act and Mental Health Act. Where they are

¹ Advocacy under the Care Act 2014, Mental Health Act 2007, Mental Capacity Act 2005

commissioned, these services are seen to be highly impactful, with positive outcomes for people.

7. Minimal data (if any) is being kept or recorded at a national level on what advocacy is being commissioned and on whether people are accessing or using advocacy, including in relation to young people.
8. Little evidence was found in relation to the commissioning or delivery of advocacy to children and young people in supporting them with Continuing Care, Personal Wheelchair Budgets, or S117 aftercare. Some local authorities identified that IMHA services are only commissioned for people over 18 which is worrying.
9. There is a lack of strategic commissioning of advocacy, across the country, for people accessing and using health funded support. Whereas some local commissioning arrangements ensure strong and robust advocacy provision is available, there is inconsistency across the country both in what is commissioned and by whom (CCG or local authority). There are examples of commissioners/local authorities believing that advocacy is available where it is not.
10. Advocacy accessed within NHS CHC and s117 aftercare processes through statutory advocacy can be restrictive and is limited by strict criteria resulting in 'episodic' 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). It also contradicts and undermines the principle of personalised care.
11. Where advocacy services hold IMHA, IMCA and Care Act Advocacy contracts and used 'multiskilled' advocates or integrated models of advocacy the advocate was able to stay with the individual for more of their journey through services, effectively moving from IMHA to 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.
12. Advocates and advocacy services didn't always have a good understanding of individual's rights and entitlements in relation to health funded support or where their current roles would allow them to provide advocacy support in this regard.

Conclusions and Considerations

1. There is a lack of strategic commissioning across England.

There is little evidence of joint strategic commissioning of independent advocacy services across England. However, where specialist commissioning of dedicated health advocacy has been arranged, advocacy is well embedded and is making a very real difference to individuals and to systems.

Consider:

- Explore co-producing updated commissioning guidance regarding advocacy for health funded support processes to address inconsistencies in commissioning arrangements and reemphasise the aspirations in Personalised Care and the NHS CHC framework in relation to joint strategic planning, commissioning, and joint working generally.
- In England there is no commissioning guidance that encompasses all types of advocacy delivery in one set of guidance. Any update should bring together all advocacy commissioning guidance.
- Evaluate the impact of specialist 'health' advocacy to better understand its benefits to individuals, potential improvement to personalised care, and the impact on the broader health and social care 'system'.
- Commission pilot projects and evaluate them.

2. Existing legislation and guidance often falls short in relation to accessing advocacy for health funded support. Guidance 'encourages' advocacy but there is no formal statutory guidance or expectation.

Whilst this remains the case provision of advocacy support is likely to remain 'episodic' and dependent on local awareness of its benefits.

Consider:

- Refreshing commissioning guidance to support more consistent approaches to advocacy available 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.

3. Lack of data about independent advocacy

There is a lack of data in relation to the commissioning and delivery of independent advocacy.

Consider:

- Developing and implementing systems for national data collection in relation to the commissioning of statutory and non-statutory advocacy, as well as key metrics

about delivery, including the impact of existing inequalities on uptake of and access to advocacy services.

4. There is a lack of standardised specialist training for advocates regarding health funding processes and current arrangements are haphazard

There was universal agreement from the advocacy sector that specialist training to support an effective advocacy workforce within health processes is needed and welcomed.

Consider:

- Develop and Deliver standardised training for advocates regarding health funding processes.
- Identify further measure to increase awareness of PHBs and personalised care across local authorities and CCGs



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