



# A review of advocacy

for people with a learning disability  
and autistic people who are inpatients  
in mental health, learning disability or  
autism specialist hospitals

**Full report**



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in partnership with:





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### **Acknowledgements**

With thanks to all those who have supported this review and in particular, all those who participated through sharing their personal and professional experiences. We recognise that many of these conversations were difficult and required honesty and bravery. We hope everyone's contributions will help to bring about the changes we all want to see.

I welcome this first in-depth review of advocacy for people with a learning disability and autistic people in mental health and specialist hospitals. Many of its conclusions chime with the findings in my forthcoming final report about the effectiveness of IC(E)TRs in reducing the use of Long Term Segregation in such hospitals.

The report clearly shows the importance of trusting relationships at the heart of successful advocacy, and how advocacy can change people's lives for the better. But clarity around entitlement to advocacy is needed, and this must not be based on a particular part of a person's journey - instead, to quote the report, "person-led advocacy for as long as it takes."

Advocacy has a key role at every stage, from ensuring that each person's physical and mental health is better supported, to how people are supported to leave hospital and live healthy and meaningful lives in the community.

From the accounts of the 500 plus people who participated in the review, we hear about the dedication of advocates and the skills and confidence they demonstrate in raising issues in a way that leads to real improvements in people's lives.

Sadly, the review clearly shows that people do not always receive the best possible support from advocacy. It shines a light on how advocacy is often misunderstood (at every level) and too frequently lacking in independence. The report also highlights that the inconsistent commissioning of advocacy, for example with short-term contracts, can be confusing for both the people receiving it and those providing it.

Family members have always been the main and natural advocates for people, especially when their relative lacks capacity or has additional communication needs that families can understand better than anyone. This review also considers how the advocacy sector can better work with families as well as considering the times when families may need advocacy of their own.

The ideas for improvement highlighted at the end of this report aim to ensure a multi-agency approach to improving advocacy for people with a learning disability and autistic people in mental health, learning disability and similar hospital settings. A co-ordinated approach across agencies is vital, if advocacy is to achieve its potential as a powerful voice in upholding people's rights, understanding people's experiences and improving the quality and safety of care received.



**Professor Sheila the Baroness Hollins**

I am a Peer Supporter with an NHS Foundation Trust. I help others to speak up using my own experience of being a self-advocate, having a learning disability myself.

When I was in a secure mental health hospital it was quite hard to speak up, when I asked to see an advocate people thought I wanted to make a complaint. But I wasn't complaining, I just wanted help to understand my rights and speak up in my meetings. Some of my advocates were alright but some were just a 'tick box exercise'. People also got confused between the advocates who worked for the hospital, the local authority and PALS (Patient Access and Liaison Service who work for the trust).

I think advocacy is so important in secure services and in the community to show the person that their voice and opinion is valued and listen to. When I had a good advocate they came to my meetings, valued my opinion, and put my views across to other people. People listened to my advocate.

Mental Health Advocates need to protect people's rights, not be afraid to challenge the hospital and not get too close to the service, so they stay independent. They should have an open mind and probably do need more training so they can support people with a learning disability and autistic people better.

I am out of secure services now and I do have an advocate in the community, but I don't rely on them. I use my Self Advocacy Group to give me strength to speak up for myself and this is really important especially for people who do not have close family or friends. I also help to run Focus Groups with patients in secure services, to help people to get their voice heard and talk together.

As well as more Independent Mental Health Advocacy, we need more peer advocates going into secure services who are valued, listened to and can help get patients' voices heard. I also know that not every area has a self-advocacy group to support peer advocates, local commissioners need to help with this. Self-Advocacy should be a priority.



**Stephen Ellis, Peer supporter**

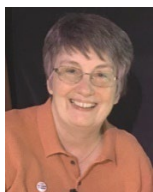
This report clearly shows that when the person, family, advocates and practitioners work together, they can really make a positive difference. Each brings their own knowledge and experience to ensure the person is able to realise their hopes, dreams and ambitions.

However, the report also shows that current provision can be disjointed, unreliable and even dysfunctional. We see examples of people not being supported to speak up or who do not have their rights explained to them in a way they can understand. And if they do speak up, they may be ignored or labelled a troublemaker. Some cannot speak up at all.

In many cases, it is family carers who end up advocating for their relative to get the support and services to which they have a right. After all, they provide the long-term love and support people need. They play a valuable role because they understand what's important to their relative, and what does and doesn't work for them. It can be daunting for families to become familiar with laws, guidance and policies however, as this report shows, family advocates are often ignored or excluded, or dismissed as difficult and interfering.

I welcome the report's call for a strategic approach to ensure that proper independent advocacy is funded and in place for people who want and need it. It should be available early (to get the right support) and for the long term (to make sure that support remains in place). It is not just for when things go wrong or for a few hours, as effective relationships are not built in a day. It should be truly independent and there should be escalation paths if things go wrong.

This report must be a catalyst for real action, otherwise, nothing will change and the Joint Committee on Human Rights' recommendation that families be seen as 'human rights defenders' will continue to be ignored.



**Julie Newcombe, Family carer advocate, Rightful Lives**



# Introduction to the review

Independent Advocacy<sup>1</sup> is a fundamental approach to supporting people throughout their lives to get the life they want, be heard and have their rights upheld. It is a critical safeguard for people when they are at risk of not having their rights upheld or being excluded from decision making about their lives. Access to independent advocacy is especially important when people are living and being supported in restricted settings. There are just over 2000 people with a learning disability and autistic people who are inpatients in mental health settings<sup>2</sup>.

Independent advocates are exclusively focused on ensuring people are being heard, included in decisions and that their rights are upheld. The support of an advocate should be reliable, easy to access, person-led and proactive.

Recently, inquiries and reports, [such as the independent report and recommendations from Baroness Hollins](#), CQC's [Out of Sight](#) and the [Safeguarding Adults Review on Whorlton Hall](#) have highlighted that the quality, effectiveness, and the independence of advocacy provision for people with a learning disability and or autistic people who are inpatients in mental health settings can and should be improved. If things are not improved, there is a risk that the 'illusion of advocacy'<sup>3</sup> will contribute to unsafe and risky environments. Advocacy services should not be failing people when they need that independent support, safeguarding of rights and amplification of voice the most.

Those reviews also highlighted the need for us to better understand what the barriers and enablers are to delivery of effective independent advocacy support. Whilst there have been broad criticisms on the quality, consistency, and availability of independent advocacy it's not always been clear what this looks like or what this means in practice for people with a learning disability and or autistic people who are in mental health settings. We know that reasonable adjustments must be made if advocacy is to be accessible to and effective for people with a learning disability and autistic people.

Transforming Care and Building the Right Support have highlighted the importance of planned and strategic approaches to support for people with a learning disability and autistic people who are inpatients or who are at risk of going into hospital. It's clear from these recent reports and this review that this approach must be extended to planning, commissioning and provision of independent advocacy also.

Whilst those with an awareness of advocacy provision in these settings recognise and rationalise these concerns, there has never been an in-depth review of the commissioning, delivery, or experience of independent advocacy in these settings.

NDTi, alongside partner organisations, [Bringing us Together](#), the [Challenging Behaviour Foundation](#), [People First Independent Advocacy](#) and [Speakup Self Advocacy](#), have

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<sup>1</sup> Definition of advocacy taken from the Advocacy Charter 2018: "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." [The Advocacy Charter, NDTi 2018](#)

<sup>2</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>

<sup>3</sup> [Safeguarding Adults Review on Whorlton Hall Executive Summary 2023](#)

undertaken a review of inpatient advocacy for people with a learning disability and autistic people who are inpatients in mental health, learning disability and/or autism specialist hospitals. This review was commissioned by NHS England (NHSE) as part of the Spending Review mental health recovery funding in 2021/22.

We were tasked with finding out what was getting in the way of people receiving effective and timely independent advocacy as well as identifying factors which enable advocacy to work well.

This review has provided an invaluable opportunity to explore and investigate people's views and experiences of accessing, commissioning, working alongside and delivering a range of types of independent advocacy to people with a learning disability and or autistic people who are currently being supported in inpatient mental health settings. It has provided an opportunity to highlight the systemic, legislative, cultural, service level and human issues which impact on people's experiences of independent advocacy while they are in hospital, as well as sharing ideas about how we can improve these.

The review has explored a wide range of advocacy provision from self, peer and group advocacy, general advocacy and statutory advocacy support that must be made available to people. It also explores family members role and experience as advocates for their relative.

Inevitably, much of the report is focused on statutory IMHA provision as this is the form of advocacy that most people are entitled to if they are inpatients and detained under the Mental Health Act. This focus does not diminish the value and importance of other types of advocacy. Much of the feedback from people who draw on advocacy support has highlighted the value and importance of access to peer advocacy and self-advocacy groups alongside statutory advocacy provision, in ensuring voices are heard and rights are upheld.

**Each of the partner organisations who worked on the review have had a particular focus within it. In summary and for the purpose of this report these were:**





The review report sets out the combined findings from each element of the review to provide a truly holistic and rounded perspective on the current provision and experience of independent advocacy to people in these settings.

Throughout this review we have been mindful of the human rights abuses that have been experienced by people in restricted settings and the absence of effective advocacy in preventing abuse and harm. What we have learnt through the review is that the issues impacting independent advocacy delivery and preventing advocacy from having the impact people need, are multifaceted, sometimes simple, sometimes complex, but often systemic and influenced by more traditional medical models of care and support.

The recently published Building the Right Support for People with a Learning Disability and Autistic People Action Plan highlights the need for the making of recommendations to improve advocacy support, based on this review.<sup>4</sup>

Through the review, we have also seen and heard about independent advocacy that was there at the right time for people, that has prevented abuse and ensured people's voices were heard and rights upheld.

We hope this report shines a light on both poor and brilliant independent advocacy, its impact on those who draw on it and that its findings and recommendations can be understood and adopted to make real improvements and people get access to the advocacy support they want, need, and are entitled to.

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<sup>4</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1092537/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1092537/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf)



# Defining advocacy and context for this review

## Terms and definitions used in this report

Throughout this report when we refer to ‘people’ we are referring to people with a learning disability and/or autistic people. When we refer to ‘these settings’ we explicitly mean inpatient mental health, learning disability and autism specialist hospitals.

When we talk about people, we don’t just mean people who are subject to the Mental Health Act; we also mean people who are in hospital under a Deprivation of Liberty Safeguard authorisation (a DoLS), as well as people who are in hospital voluntarily on an ‘informal basis’.

The review has explored a wide range of advocacy provision including:

- Self, Peer and Group Advocacy
- Non-statutory advocacy for individuals with a learning disability and or autism
- Statutory advocacy for individuals with a learning disability and or autism
- Advocacy support for family members in their own right
- Family members acting as an advocate for their relatives.

In the vast majority of this report, when we refer to ‘independent advocacy’ we mean advocacy support that has been arranged and provided to people, usually through a service or group that has been commissioned and then delivered by an advocacy provider.

We also specifically refer to families’ experiences advocating for loved ones.

## Different types of advocacy and people’s rights to access it

Reviewers found out that rights and entitlements to advocacy are complex and can be confusing; lots of people didn’t really understand advocacy and all the different types of advocacy that people can access. This section explains about different types of independent advocacy. Understanding these will help with understanding the findings of the report as well as helping people access the right advocacy when they need it.

Independent advocacy is generally understood as:

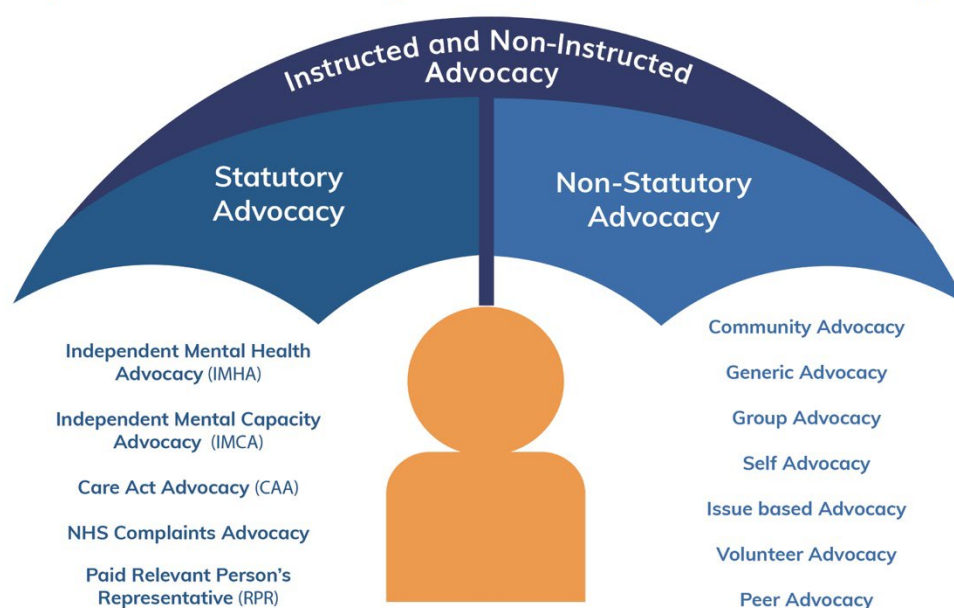
*“Advocacy is taking action to support people to say what they want, secure their rights, pursue their interests, and obtain services they need. Advocacy providers and Advocates*

*work in partnership with the people they support and take their side, promoting social inclusion, equality, and social justice.”<sup>5</sup>*

Advocacy has its roots in social models of disability, of social justice, inclusion, empowerment and of increasing citizenship. Advocates set out to support people to self-advocate; enabling the person to be heard and have increased agency, rights, choice, and control in their own life and essentially to get the great life they want.

Independent advocacy is an essential component of the health and social care system, offering support to people who are at risk of exclusion. Access to independent advocacy helps people 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. This is particularly important to people with a learning disability and autistic people who experience many barriers to inclusion and in accessing community services which can result in being detained in mental health inpatient settings where they experience a number of restrictions.

## (Commissioned) Independent Advocacy



Advocates work in partnership with people. 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 is an empowering relationship.

The advocate must always represent the person and their interests. Advocates don't do things or talk to people without their partner's consent, where the person is able to give this. They don't withhold information from the person that others have shared about that person. 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. People might have an advocate working with them who is able to provide all the different

<sup>5</sup> The Advocacy Charter, NDTi 2018 <https://qualityadvocacy.org.uk/resources/advocacy-charter/>

types of statutory and non-statutory advocacy, or they may have support from different advocates at different times.

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 was developed by Action for Advocacy and published in July 2002. This was then updated in 2014 and again in 2018 by NDTi<sup>6</sup>.

## Non-instructed Advocacy

Some people may not be able to 'instruct' their advocate in either some or all of the work that the advocate is undertaking with them; that is, they may not be able to consent to the advocate's involvement or tell the advocate what they do and don't want them to do. This is known as 'non-instructed advocacy'.

In addition, some people may be considered not to have the mental capacity to make some decisions – this doesn't automatically lead to non-instructed advocacy being provided but may be a trigger for ensuring that someone has access to independent advocacy to ensure their views, wishes and preferences are represented within decision-making processes.

The goal of the non-instructed advocate is the same as the instructed advocate: advocacy remains grounded in promoting the person's voice, choices, and rights. The non-instructed advocate must work on establishing what is important to and for the person and understand how they communicate their preferences. At times they are part detective and take a variety of approaches to build up their understanding of the unique person they are supporting; this might be through speaking with family, friends and members of the person's paid support network, who know them well, spending time with the person in different settings and with different people, observing the person from a distance, particularly when the person indicates they don't want the advocate in their close presence.

Non-instructed advocates may access the person's records and reports and attend meetings. They must maintain a level of professional curiosity throughout so as to ensure they are not taking information or other people's views and opinions at face value. In reality, advocacy with any one individual is often a mix of instructed, non-instructed or partially instructed advocacy. The advocate needs to be mindful of how they shift between approaches and be clear with others about how they are working with someone.

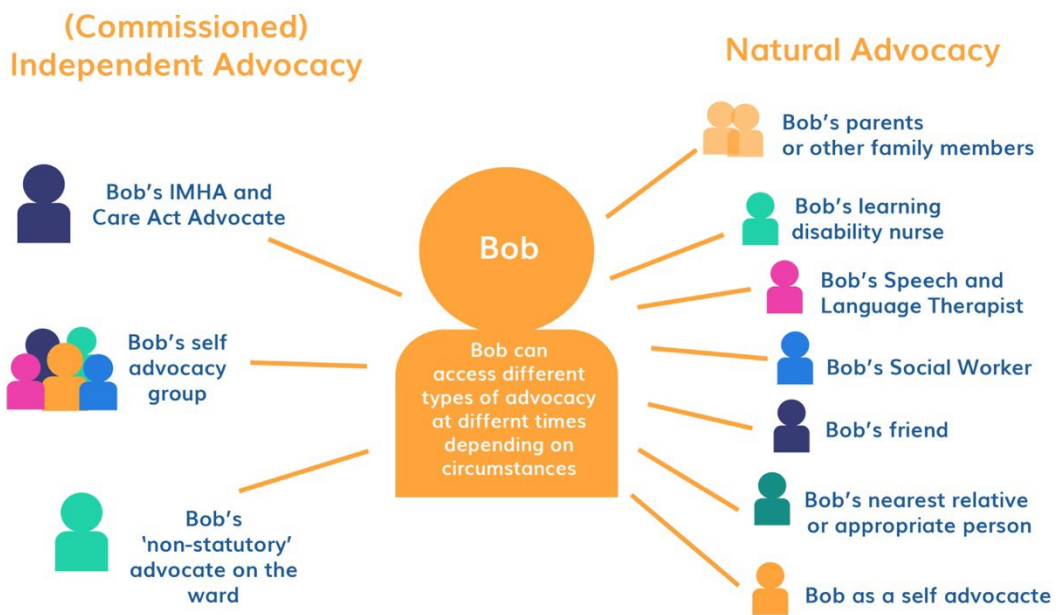
## Statutory Advocacy

Statutory advocacy describes the type of advocacy that a person has a legal right to access. People are entitled to access different types of advocacy support at different times and in different circumstances. People may have an advocate that supports them through providing all the different types of statutory advocacy as and when needed. People may have access to more than one type of advocacy support at the same time.

The graphic below shows the different advocates involved in support Bob, who is currently detained under the Mental Health Act.

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<sup>6</sup> Advocacy Charter, 2018 <https://qualityadvocacy.org.uk/resources/advocacy-charter/>



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

- Advocacy under the Care Act 2014<sup>7</sup>
- Independent Mental Capacity Advocacy (IMCA)<sup>8</sup>
- Paid Relevant Person's Representative (Paid RPR)<sup>9,10</sup>
- Independent Mental Health Advocacy (IMHA)<sup>11</sup>
- NHS Complaints Advocacy<sup>12</sup>
- Advocacy for Children and Young People<sup>13</sup>

The different types of statutory advocacy are explored in more depth in the chapter 2.4 of the findings section below, setting the legislative context for the review. In that section we explain what people's rights and entitlements are to different types of statutory advocacy. We also explain how current arrangements can lead to issues and challenges which can get in the way of person led advocacy.

Broadly and briefly, the different types of advocacy are available to people as follows:

7 Care Act (2014)

8 Mental Capacity Act (2005)

9 Mental Capacity Act (2005)

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

11 Mental Health Act (1983)

12 The Health and Social Care Act (2012)

13 The Children Act 1989

**Care Act Advocacy** is for people who have ‘substantial difficulty’ participating in Care Act process, who don’t have anyone else ‘unpaid’ to support them. Support is for care and support assessments, planning, reviews as well as safeguarding processes.

**IMCAs** support people who don’t have anyone unpaid to support or represent them and who lack mental capacity to make decisions about serious medical treatment, where they will live and when decisions are being made about potentially depriving someone of their liberty through the Deprivation of Liberty Safeguards (DoLS)<sup>14</sup>

**Paid RPRs** support people who are deprived of their liberty via a DoLs authorisation in all matters related to the DoL, including raising challenges.

**IMHAs** support people who are subject to the Mental Health Act, both in and outside of hospital.

**NHS complaints advocates** support people to make complaints about NHS care and treatment.

**Children and young people’s advocates** provide support to ‘Looked after’ children and young people, those going through child protection proceedings and those leaving care.

These are very brief descriptions. You can find out more about eligibility for the different types of advocacy in chapter 2.4 of this report.

## **Non-Statutory Advocacy**

Non-statutory advocacy may also be provided, and this can take many forms including general advocacy, community advocacy, one-to-one advocacy, peer advocacy, group advocacy, self-advocacy, and volunteer advocacy. Whilst recognised as highly valuable and good practice, there are no duties on any statutory body to commission these kinds of supports.

**General or Community Advocacy** is often provided on a one-to-one basis and is sometimes focused on a particular issue someone wants or needs support with or a particular circumstance someone is experiencing. This could be for people who are inpatients in mental health settings informally, people in care and health settings in the community, people needing support with benefits, housing, parenting etc.

**Volunteer Advocacy** Is advocacy provided by volunteers. It can be short or longer term, focused on an issue or situation or be more general and holistic.

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<sup>14</sup> The Mental Capacity Act

## Self-Advocacy<sup>15</sup>

Self-advocacy is speaking up for yourself. This can be with encouragement and support from someone you trust.

Self-advocacy is learning the skills to speak up confidently.

Self-advocacy is understanding who you are as a person.

Self-advocacy is knowing your rights and responsibilities.

Self-advocacy is about having self-respect.

Self-advocacy is about speaking out for what you believe in.

## Group Advocacy<sup>16</sup>

Group advocacy is where a group of people come together, to have their voices heard. This can be any group such as:

- A residents' or patients' group
- A self-advocacy group

All groups are made up of people with different skills and knowledge. People will all have a range of shared experiences as well.

In group advocacy everyone benefits from sharing and passing on information.

Group advocacy is about supporting each other (**peer support**)

Everyone is treated equally, and their needs are respected.

Group Advocacy can help build a person's confidence by knowing that their situation might not just affect them, it can affect other people too.

Group advocacy can inspire people to support others. People can then work together to achieve common goals.

## Peer Advocacy<sup>17</sup>

Peer advocacy is about one or more people with 'something in common'.

This could be having the same diagnosis or disability. This could be having the same experience. These people are called peers. The peers can help the other person to speak up for themselves.

A peer advocate really understands the other person's situation. They can use this shared understanding to provide information and support.

This can be either one to one or in a group.

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<sup>15</sup> Definitions from [People First Independent advocacy](#)

<sup>16</sup>, Definitions from [People First Independent advocacy](#)

<sup>17</sup> Definitions from [People First Independent advocacy](#)

Peer advocates can help the person 'speak up' for themselves. They can support them in meetings with professionals. They can speak with them. This helps others understand what that person is feeling or wants.

Peer advocates should have training to help them stay safe.

They should be provided with emotional support if they need it. They can be paid or volunteer. They can also be part of an advocacy group or an independent advocacy service.

A peer advocate can support someone in hospital. It is important that they are 'well' themselves and not in hospital. This is because if both people are unwell, it might make things worse for them.

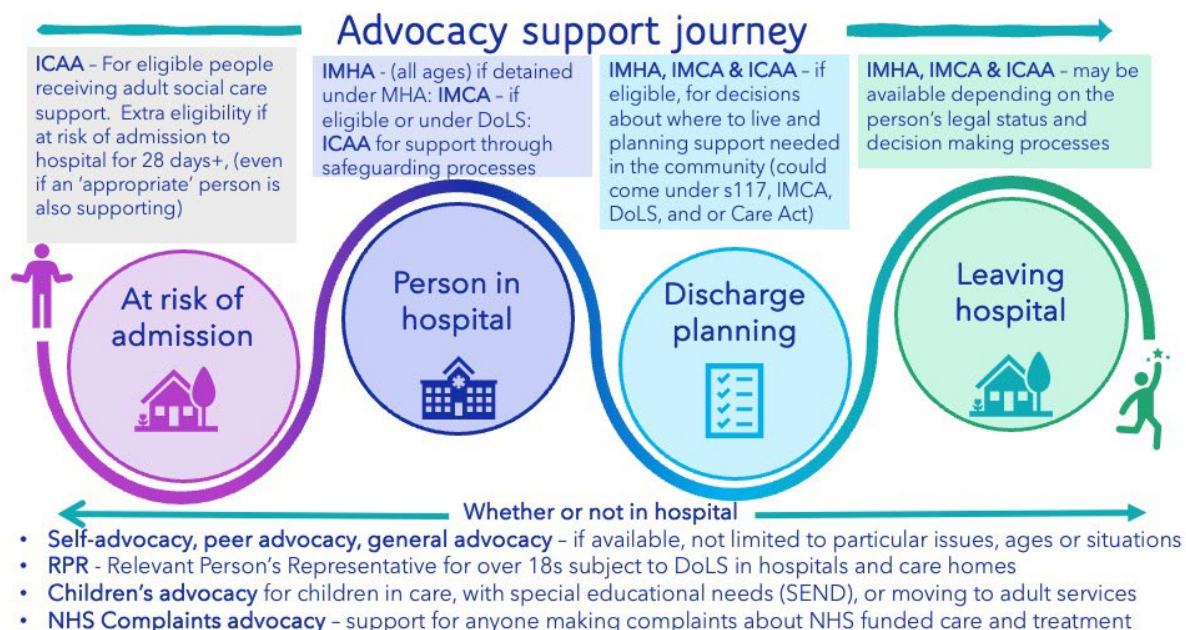
### **Informal Advocacy**

Many people have friends and family who are natural allies in their lives. The term informal advocacy can be used to describe the advocacy role that people's friends and family members can take in their lives. Just because this advocacy isn't commissioned, doesn't mean it isn't highly important. It is. Friends and families are the people who know the individual best and are able to instinctively put forward what is important for the individual.



# When to access different types of advocacy

This graphic illustrates someone's journey from before they are admitted until after they leave hospital and shows what types of advocacy can be accessed and when.



Chapter 2.4 of the findings in this report explores in depth the different eligibility and entitlements to independent advocacy and how these can pose challenges for people with a learning disability and or autistic people who are inpatients.

## Different types of advocacy in action

Here are some examples of how different types of advocacy can support people with a learning disability and autistic people who are inpatients.

This first story shows<sup>18</sup> how continuity and consistency can be achieved when one advocate provides all the one-to-one advocacy someone draws upon. It also shows how people can access different types of statutory and non-statutory advocacy at different points in their life.

*James is 28, loves football and goes to the park on most days to kick a ball about. His friends are also important to him, and he sees them 3-4 times a week.*

*He lives in a residential home with four other young people who have a learning disability and/or autism. James has a Deprivation of Liberty Safeguard because he cannot consent to his care arrangements and has at least one member of staff supporting him twenty-four hours a day. James has an advocate, Nadia, who acts as his paid RPR and visits him once a month in this capacity. When James has his Care Review, Nadia is also asked to be his Care Act Advocate to support him through the review and share his views about his care and support.*

<sup>18</sup> This story came from an advocacy provider who took part in the focus groups. Some details have been changed to protect anonymity.

*James experiences some unsettling changes and finds it hard to cope with these which causes his mental health to deteriorate. The staff where James lives are worried about him and James is admitted to hospital under a section of the Mental Health Act for support and treatment. A referral for an IMHA is made to the local advocacy IMHA service and Nadia is able to be James' IMHA, visiting him in hospital and ensuring he is okay. She helps him understand what is happening and helps him talk to the doctors and nurses. She can also help him to appeal his section if he wants to.*

*While he is in hospital James joins the patient's advocacy group that meets once a month.*

*When the time comes for James to be discharged from hospital Nadia is able to be James' IMHA and Care Act advocate during the discharge planning process. A decision is being made about where James should live after he is discharged and as James may move to live somewhere other than his previous home, an IMCA referral is made for James. Nadia is able to stay supporting and representing James as his IMCA in this decision. The decision is made for James to move to a new residential home where he will be under a DoLS. Nadia will be James' IMCA39A and continue to be James' RPR in the new home. She is also able to be his Care Act Advocate at his 6-week review.*

*After he has been discharged, James needs some advocacy support in relation to his finances and as the local advocacy services has some non-statutory advocacy funded, Nadia can support James with this too.*

*There is a self-advocacy group that meets near his new home and James joins the group.*

This next example shows what Peer Advocacy for someone in hospital can look like:

*"A **peer advocate** came to visit me in hospital.... every week.*

*They..... took time to get to know me.*

*They talked to me about how I was feeling and how things were going.*

*They understood how I was feeling and what changes I wanted to make.*

*They helped me talk to the staff on the ward and helped them see things differently.*

*They talked to me about when they were in hospital and what their life is like now.*

*When I leave hospital, I want to be a **peer advocate**."*



# How the review was carried out

## What the reviewers wanted to find out

We wanted to find out what was working and not working in the commissioning and delivery of independent advocacy to people who are inpatients. We wanted to understand this from the perspectives of lots of different groups of people to make sure we understood the full picture.

We wanted to:

1. Understand how statutory advocacy, non-statutory advocacy, peer, group, and self-advocacy was being accessed and delivered in mental health settings and how this is experienced by people with a learning disability and autistic people, their families and support networks.
2. Identify factors which impact on the quality and availability of independent advocacy to people with a learning disability and autistic people who are inpatients.
3. Find out how much people in a variety of roles, understand about independent advocacy and people's rights to access it.
4. Find out what it is like for family members when they are acting as their relatives' advocate.
5. Find out what the law and guidance say about independent advocacy in hospitals to understand the impact this has. We also wanted to see what other people had found out and written about advocacy for people with a learning disability and autistic people who are inpatients, including in recent reviews, to see if there was anything important we can learn.
6. Capture positive examples where advocacy has impact.
7. Identify areas for improvement.

Much of the review focuses on statutory Independent Mental Health Advocacy (IMHA) provision as this is the main form of advocacy that people are entitled to if they are detained under the Mental Health Act. This focus does not diminish the value and importance of other types of advocacy.

Feedback from people who draw on advocacy support has highlighted the value and importance of access to peer advocacy and self-advocacy groups alongside statutory advocacy provision, in ensuring voices are heard and rights are upheld.



## What the reviewers did

Each of the partner organisations in the reviewing team led on their own lines of enquiry. In total there were 562 responses from individuals and groups, directly in providing evidence for the review. The graphic below shows the consolidated information about the work undertaken by the reviewing team as a whole.<sup>19</sup>



We wanted to identify factors which impact on the quality and availability of independent advocacy, including self and peer advocacy, to people with a learning disability and autistic people who are inpatients as well as what people and their families said was important about the advocacy support, they access. We also wanted to understand families' experiences of advocating for their relatives.

<sup>19</sup> All lines of enquiry were undertaken between August 2021 and March 2022

The next graphic shows who responded and participated in the review. The wide range of participants helped us to understand what things are like:



### Freedom of Information Requests

Partners worked together design a '**Freedom of Information Request**' (FOI) which went to all local authorities and all CCGs in England. This was sent out in October 2021. It asked for information about the advocacy that is commissioned for children and young people, adults, and families, including statutory and non-statutory advocacy and self-advocacy groups. It specifically asked if any advocacy was separately commissioned for children and adults with a learning disability and autistic people in the community and in inpatients settings. It sought information about how many people with a learning disability and or autism had accessed the commissioned IMHA service between 1st April 2019 and 31st March 2020.

### Surveys

Reviewing partners designed and launched **8 different surveys** (September-November 2021). Surveys were for: parent carers of children and young people, parent carer forums, children and young people, family members of adults, independent advocates, managers of advocacy providers, local authority commissioners of advocacy, self-advocacy organisations and learning disability and mental health hospitals.

### Focus Groups and individual discussions

Reviewing Partners set up **38 online and face to face focus groups**. Focus Groups were for parent carers and relatives of children, young people and adults, people with a learning disability and or autistic people who were or had been inpatients, self-advocacy organisations, advocates and advocacy managers, local authority commissioners of advocacy, other professional stakeholders including staff from CQC, mental health and learning disability hospitals, C(E)TRS panel members and chairs, solicitors, health commissioners, NHSE commissioners and more.

### Deep Dive case studies

In 3 local authority areas we have spoken with: The local authority commissioned advocates, the commissioner, professional stakeholders from NHS and independent hospitals within that area. This was important as it provided detail about arrangements in the same area from different perspectives.

NDTi also undertook a [Literature Review](#)<sup>20</sup> and [Review of legislation and guidance](#).

### How we analysed the evidence

The reviewing team at NDTi reviewed and analysed all of the evidence from each strand of the research to identify themed findings from the different partners.

The partners then reviewed the findings and developed the recommendations for creating change.

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<sup>20</sup> [You can read the literature review as a stand-alone document here](#)



# Review findings and discussion

All the lines of enquiry outlined in the section above that were undertaken by the different reviewing partners produced findings that independently aligned, providing strong, corroborative evidence that further validate the findings in this review. For brevity we cannot provide all the supporting evidence for each finding, however the [literature review can be accessed here](#) and additional quotes from [advocate's surveys are here](#).

The review findings set out in this chapter are often interlinked and overlap; some areas impact on others, some issues cause others and as such we have tried to present the findings in a way which demonstrates the intercausal nature of the issues and how so many are inextricably linked.

Throughout the review, we heard from people with a learning disability and autistic people who draw on independent advocacy services, and their families, about what is and isn't working from their perspectives. It's clear that for many people, the experience of advocacy is disjointed and not led by the person. In addition there's a lack of clarity in the advocacy role, and its boundaries which have been observed across the system and professionals around the person. People and families were clear about what they want and need from the advocacy support available to them.

The reviewers identified that the way that advocacy is arranged, funded, and delivered is complicated and unclear. There is little co-ordination of the different types of advocacy, no consistent mechanism for commissioning advocacy, or for explaining it. On top of this there is an additional layer of complication as rights to advocacy are interpreted differently by different local authorities, hospitals, advocacy providers and other people and organisations. Navigating through this complexity is very often unnecessarily difficult for people who need advocacy, their families, professionals, and advocacy providers. This key point must be addressed.

As we reviewed all the different sources of evidence from different groups of people, we observed that the findings and issues related to 6 different areas; what people want from advocacy, accessing, arranging, providing, and facilitating independent advocacy as well as examples of advocacy working well.

We are using these areas to group our findings and will explore each area in the following chapters:

1. What people and families want from independent advocacy
2. How independent advocacy is arranged and commissioned
3. How independent advocacy is provided
4. How independent advocacy is accessed
5. How advocacy can be supported and facilitated by others
6. Examples of effective advocacy



In this section we explore the core themes and findings of the review. Given the systemic and multifaceted, multifactorial nature of these, there is inevitably an extent of overlap. The same issue may appear in more than one 'theme' area and be explored from a different angle.

We will discuss each group of findings in turn.

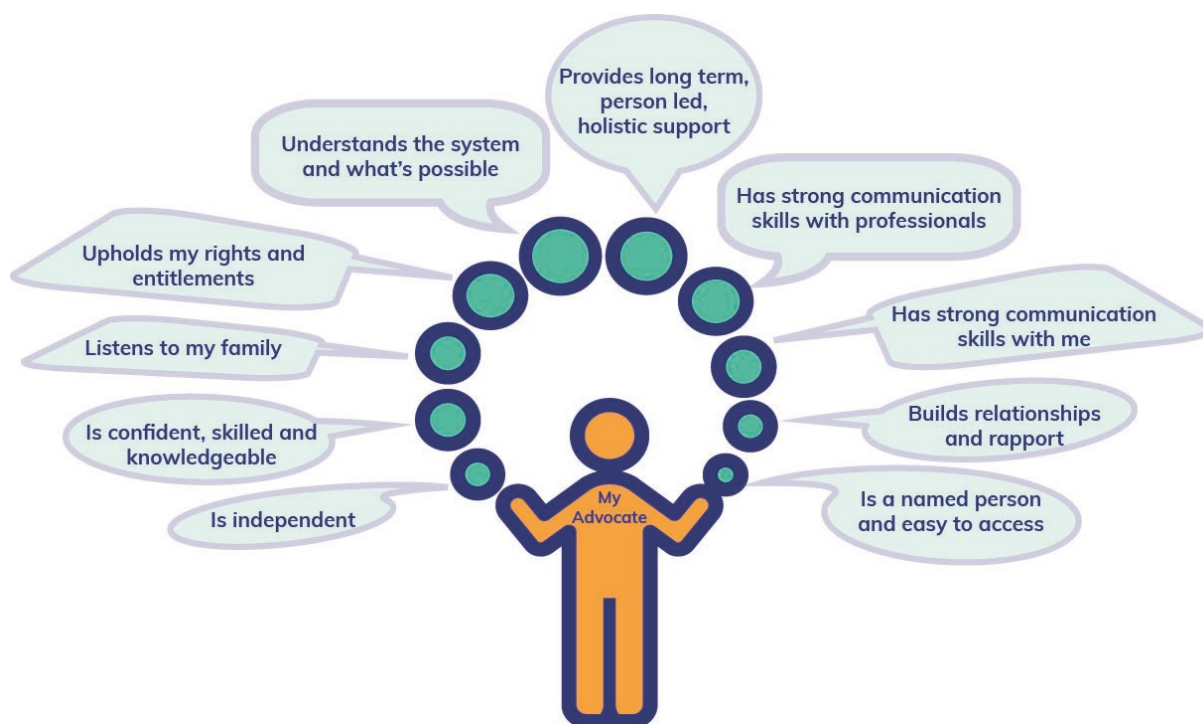




# What people and families want from independent advocacy support

In this section we have summarised the findings about what people with a learning disability and autistic people as well as family members said was important about the advocacy support they draw on and access.

We hope this information can be used as a blueprint when commissioning, delivering, and monitoring advocacy support.



## 1. Easy access, named person

People were clear that advocacy needs to be easy to find and easy to access. This means being able to find an advocate quickly and effortlessly. Far too many people experience far too many barriers when finding and accessing advocacy. Reviewers heard it is often extremely time consuming and that people are 'passed from pillar to post' trying to find an advocacy service they were eligible for and that could meet their needs.

Reviewers heard that people typically wanted a single named advocate to contact and a straightforward method of contacting them. People didn't want to always call central referral or help lines, which could be seen as a disincentive - they want to be able to contact their local advocate directly.

## 2. A range of longer term, person led, holistic and proactive advocacy support

People described that they needed access to longer term and more holistic advocacy than they were currently experiencing. People said they want their advocate to be there for as long as they need and have enough time to get to know, understand and value them. Advocates don't need to be around for every single decision, but it's important that the person can draw on an advocate at times when they do want advocacy, it is critical that the advocate is available to offer person led support and can respond to any request for support at the point the person wants or needs it. Statutory advocacy can't always respond in the way people want, but there sometimes isn't any non-statutory advocacy available.

People said they want to access a range of types of advocacy including access to self-advocacy groups and independent peer advocacy. Self-advocates who fed into the review highlighted the importance of being listened to and the valuable role that peer advocacy and access to self-advocacy groups had for them.

## 3. Independence

The independence of the advocate was felt to be of paramount importance by people and their families. They want to see advocates retain their independence from hospitals and consistently said that advocacy must be separately commissioned; not commissioned by the hospital and not part of the hospitals.

People want advocates to behave in ways that communicate they are not part of the health or care system, whilst still working effectively within hospital settings.

*“Really good support can only be offered by well-informed, qualified individuals who are independent of the responsible agencies”. Family Carer*

Advocacy providers also need to support advocates to maintain, protect and promote their independence.

Commissioning arrangement and contracts need to support advocacy providers to maintain their independence so they can align themselves fully with the person being supported.

## 4. Understanding of the system and what's possible for people

People and families said they want advocates to have greater insight and awareness into the different ways that people can live and be supported, beyond the hospital setting. They want advocates who can push for person led solutions and know about the different ways people can live full lives whilst being supported in their communities. Sometimes this is about advocates having technical knowledge about things like Personal Health Budgets, tenancies, and section 117 aftercare and sometimes it's about the advocate maintaining their independence and their professional curiosity, really getting to know and understand the person and questioning the status quo.

People told us they want their advocate to be ambitious and have high expectations for the person:

*“Advocates need to come from a can-do perspective not a cannot! People need advocates he will stand up for them and not judge them based on other people they have supported or what the advocate feels the person is able to do.” Self advocate*

## 5. Relationship, rapport and working together

People and families are clear that they want advocates to have the time and ability to build effective working relationships and rapport with individuals and their families. It takes time to build up trust with new people, including advocates. It also takes time to understand the advocacy role and advocates must be supported to have the time needed to revisit and re-explain how advocacy can help as well as to get to know people. People with a learning disability and autistic people said good advocacy is:

- *“Trusting and kind”*
- *“Tells me how it is and honest”*
- *“Tells me what I need to do to move on”*
- *“Meets me as soon as I move into Hospital”*
- *“Someone I can see easily”*
- *“Someone I trust”*
- *“They fight your corners”*
- *“They listen”*

The time someone has with their advocate should be decided by the person, their needs and at least give them enough time to:

- Get to know the advocate well
- Be able to see them when they need to
- For the advocate to listen and understand what is important for the person
- For the advocate to have the time they need to communicate properly with the person
- Have their advocate at every hospital meeting
- Have pre-meetings before EVERY meeting to find out what they want to say and what they need support with to speak up
- Talk about what went well and what happened at meetings after they happen

## 6. Strong communication skills with individuals with a learning disability/autistic people

People wanted advocates to develop strong communication skills and be trained to provide effective support and make appropriate reasonable adjustments when working with people with a learning disability and or autistic people and their families. Advocates need to know

how to communicate with people and have a range of knowledge, skills, and tools to support effective communication, particularly when people don't use words to let people know what's important to them.

Similarly, it means advocates need to understand that everyone will experience learning disability and/or autism differently and need to be confident in getting to know how to communicate with each individual they support.

## **7. Families and advocates working together**

Many family members expressed that they want to play a part in the advocate's involvement with their relative, but that they are often ignored or excluded.

Families told reviewers that they want to know about advocacy and want the advocate to listen to what they know about their loved one. They also want the advocate to feed back to them about what is happening and share information where possible.

*“(Advocates) work on certain agendas. If they think what you are raising is irrelevant, they don't listen to you.” Family carer.*

## **8. Strong communication skills with staff, professionals, commissioners**

People and families want advocates to be effective in their relationships with other professionals. They want the advocate to be skilled in communication so they can ensure the person's voice, views and preferences are heard. It's vitally important that the advocate has strong communication skills to represent the person and influence the paid support team that surrounds someone. People also want advocates who are confident to raise challenges and ask important questions of professionals and commissioners.

## **9. Confident, skilled, knowledgeable advocates**

People said advocates need to be well trained, well supported, and knowledgeable in order to be effective in their roles. They need to be qualified and have access to ongoing support and supervision, reflective practice and continued professional development.

## **10. Upholding rights and entitlements**

People and families said they want advocates to be vigilant and persistent in ensuring people's rights and entitlements are upheld. Advocates therefore need to have a working knowledge of the Human Rights Act, the Mental Health Act, the Care Act, the Mental Capacity Act, the Equality Act as well as policies which impact people, e.g., Dynamic Support Register and Care (Education) and Treatment Review policy and guidance<sup>21</sup>.

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<sup>21</sup> See [NHS information on Care \(Education\) and Treatment Reviews](#)

*“Knowledge of the law and rights for advocates is a problem. The advocates in the hospital might be mental health advocates and not know much about the Care Act. To get a successful discharge this is really important!” Self advocate*

### **11. Families must be included and listened to**

Families said they want to be heard, valued and to participate in decision making. Regardless of whether family members are acting in an advocacy role for the relative, family members want health and social care professionals must proactively include family members in discussions and decisions about their relatives.

They highlighted the need for professionals and advocates to take a trauma informed approach and be compassionate and open to the experiences and views of family members.



# Arranging independent advocacy

## Key Messages

In this section you will read about a lack of joined up strategic approaches to arranging advocacy which has created significant differences from area to area in what advocacy is commissioned and for whom.

The advocacy support that is available to people varies considerably from local authority to local authority throughout the country. This inconsistency threatens the accessibility, effectiveness and efficacy of advocacy and causes difficulty for people who access advocacy services.

This can be seen through short-term contracts, un-costed models of advocacy and an absence of funding for self and peer advocacy groups.

There are four sub-headings:

1. Commissioning
2. Funding
3. Support for self and peer advocacy
4. Legislation, guidance and best practice

## 2.1 Commissioning independent advocacy

**The way independent advocacy is commissioned varies considerably from local authority to local authority and throughout the country. This inconsistency threatens the accessibility, effectiveness, and efficacy of advocacy and causes difficulty for people who access advocacy services.**

In England local authorities have legal duties to commission and arrange Independent Advocacy for people, including people with a learning disability and autistic people who are subject to the Mental Health Act, Mental Capacity Act including the Deprivation of Liberty safeguards (DoLS) and those with 'substantial difficulty' in being involved in accessing/receiving adult social care as defined in the Care Act. This advocacy is generally accessed through the statutory roles of Independent Health Advocacy (IMHA), Independent Mental Capacity Advocacy (IMCA) and advocacy under the Care Act as set out above and explored in section 2.4 below.

Reviewers found evidence that there are substantial differences in the ways that advocacy is commissioned, monitored, delivered, costed and funded, across the country and from local authority to local authority.

This has created:

- significant confusion for people, families and professionals as to who an individual's advocacy provider should be
- inequity of access for people who draw on advocacy services
- inconsistency of provision in terms of what is commissioned and for whom
- disparities and inconsistencies in how advocacy services are monitored

Reviewers also heard concerns that there are no legal or policy requirements to monitor or publish data about commissioned advocacy services and therefore no national data regarding:

- the amount of advocacy support that might be available to a given population
- the extent to which that service is drawn upon
- how people access that service
- the nature of advocacy services delivered
- the quality of the advocacy provided
- the outcomes achieved and impact of the advocacy provided

This lack of data means it is very hard to generate an accurate understanding of the advocacy that is available and/or delivered to people in any given area or the impact that this has.

Whilst the reviewers found examples of strong and thoughtful advocacy commissioning, we also saw the following commissioning themes impacting the variability of good quality and effective advocacy.

### **2.1.1 Different understanding and interpretation of who should commission advocacy services**

Reviewers heard from commissioners representing a wide variety of local authorities and geographical and socioeconomic regions, e.g., urban, and rural, more, and less affluent, county councils and unitary authorities as well as from authorities with varying levels of NHS and independent mental health inpatient provision, through the Freedom of Information request (FOI), a survey, focus groups and individual discussions.

Despite the Mental Health Act 2007 and the associated Code of Practice being explicitly clear that IMHA services must be arranged and paid for by the local authority where the hospital is<sup>22</sup> regardless of whether the hospital is NHS or independent provision, some local authority commissioners can be seen to put forward different interpretations of their commissioning responsibilities for independent advocacy, specifically IMHA. Some local authority commissioners told reviewers they did not need to commission advocacy within

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<sup>22</sup> "To ensure that IMHA services reflect the diversity of the local population and that they are as independent as possible, they are commissioned by local authorities, as follows:

- for detained patients, by the local authority for the area in which the hospital in which they are detained is located
- for community treatment order (CTO) patients, by the local authority for the area in which their responsible hospital is located
- for people subject to guardianship, by the local authority which is acting as the guardian or, if the patient has a private guardian, by the local authority for the area in which the private guardian lives. (6.6 CoP)

independent hospitals whilst others believed that Independent Mental Health Advocacy should be funded through health.

*“The contract is commissioned by ‘x’ CCG”*

*“The CCG commission CTRs”*

*“You will need to contact NHS as this is not held by us [local authority]”*

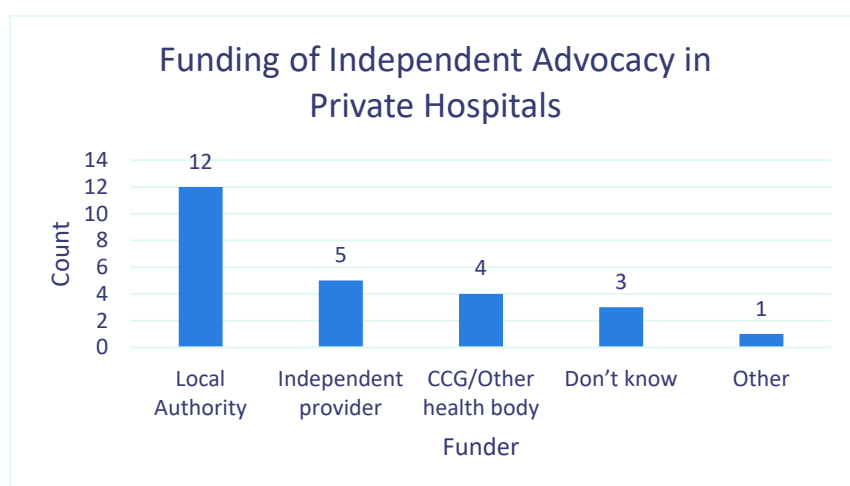
*FOI responses*

Indeed, some focus group participants attended the sessions explicitly to seek clarification about where commissioning responsibility should lie.

The survey asked local authority commissioners whether the IMHA service they commissioned provided advocacy within independent hospitals. There were four responses to this question; one ‘yes’ response, two ‘no’ responses and one ‘don’t know’. When asked who commissioned the IMHA service in these settings if it was not the local authority, one replied, *“the independent provider”* and another stated, *“there are other arrangements”* although did not elaborate.

Reviewers believes the misunderstanding of commissioning responsibility, has contributed to a number of *different* commissioning approaches, funders and commissioners emerging. This is especially the case within independent hospitals where arrangements are particularly varied; some have local authority commissioned services; others were arranged by the CCG (now integrated care boards) and others by the independent hospital itself. This variation contributes to a lack of consistency in the availability and access to independent advocacy.

In the survey to advocacy providers and separately to advocates, we asked who is responsible for funding their advocacy service in independent hospitals:



*Figure taken from responses from Advocacy Providers Survey which asked who is responsible for funding independent advocacy in private hospitals.*



## Funding of Independent Advocacy in Independent and Private Hospitals

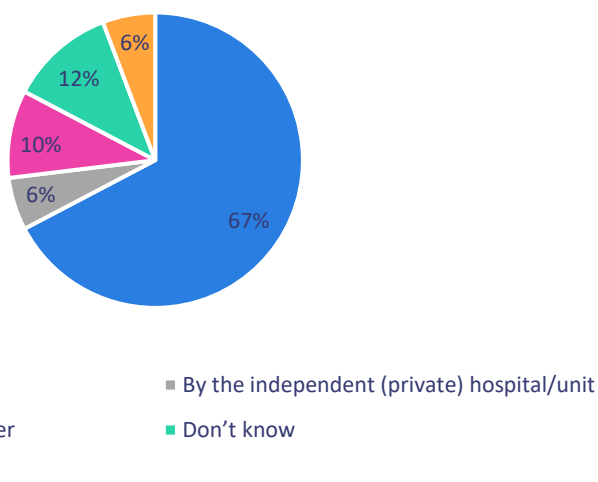


Figure taken from responses from Advocates Survey which asked who is responsible for funding independent advocacy in private hospitals.

in focus groups and individual discussions, we also heard about NHSE commissioners, social workers and others commissioning an advocacy service for an individual within an inpatient setting.

*“The local authority commissioned IMHA doesn’t have much time on the ward and hasn’t been able to build a rapport with the person; engagement is very hit and miss with them. I’ve commissioned another advocate to support the person – they have the rights skills and right approach and has a good relationship with the person as well as being respected by the multi-disciplinary team.” NHSE Commissioner*

When exploring where this misunderstanding about commissioning responsibility may have come from, the review team heard a variety of reasons from participants:

- Pressure or encouragement from CQC to ensure advocacy is available in independent hospitals
- A belief that the local authority can’t, won’t or don’t need to fund advocacy in independent hospitals
- NHS commissioning guidance, service specifications and contracts requiring independent low, medium, and high secure hospital providers ‘to make advocacy available’
- Previous Mental Health Act regulations
- Local authorities do not commission the levels of service needed and often don’t commission any non-statutory advocacy to be delivered alongside IMHA so other funders ‘plug’ this gap.

On being asked why they commissioned independent advocacy, one hospital director said:

*“We’re required to – it’s in our contract with NHSE. The funding for advocacy is built into the bed fee”*

There are also logistical considerations with one independent hospital group believing it was easier and preferable for them to arrange their own advocacy as it avoided multiple complex relationships with each local authority.

*“Should the local authority be commissioning [advocacy]? It might be quite messy if we did it that way, but I’m open to it, I think it’s a good idea. It might get complex – with lots of contracts if coming through the local authority. We’re in multiple areas and there will be multiple providers” Independent Hospital Manager*

The impact of this lack of clarity has created multiple providers within single hospital sites (see also 2.1 and 3.2), as different agencies believe they have commissioning responsibility. This also leads to confusing access arrangements as well as gaps in provision as different commissioners believe it is someone else’s responsibility to commission advocacy.

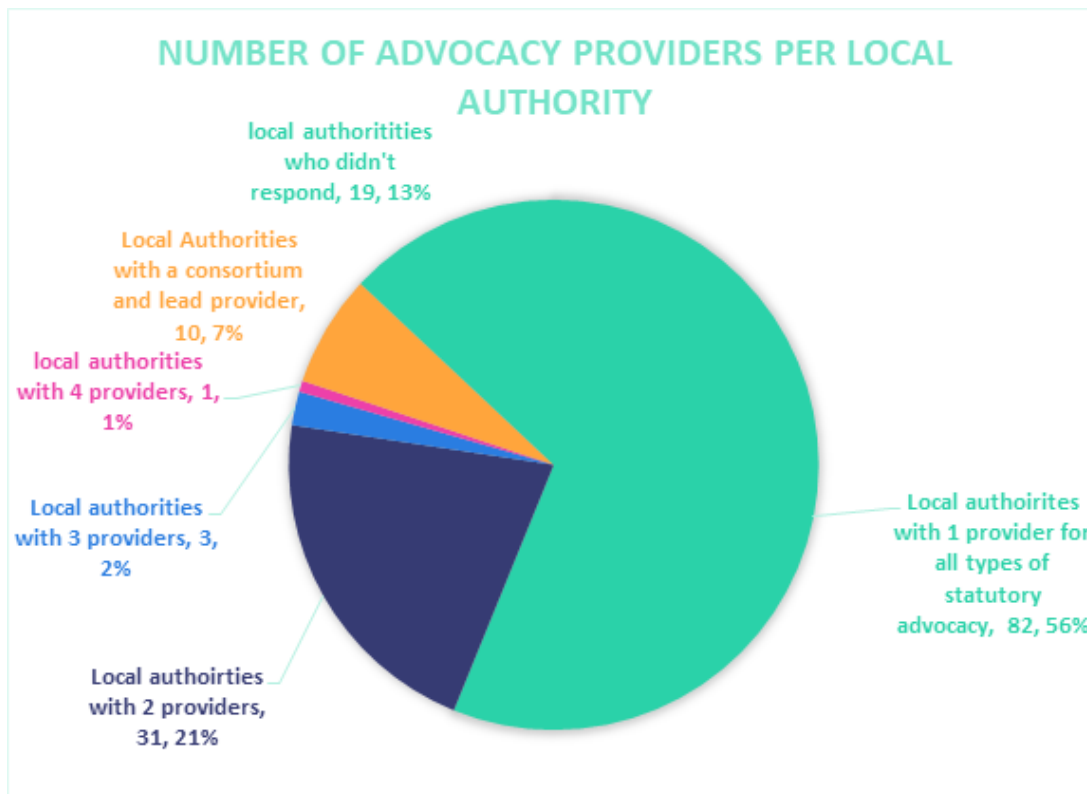
Providing clarity about who should commission advocacy can only improve current access arrangements.

### **2.1.2 Different commissioning models are used across the country**

Reviewers learnt that a variety of commissioning models are currently used. This includes arrangements where, within one local authority area:

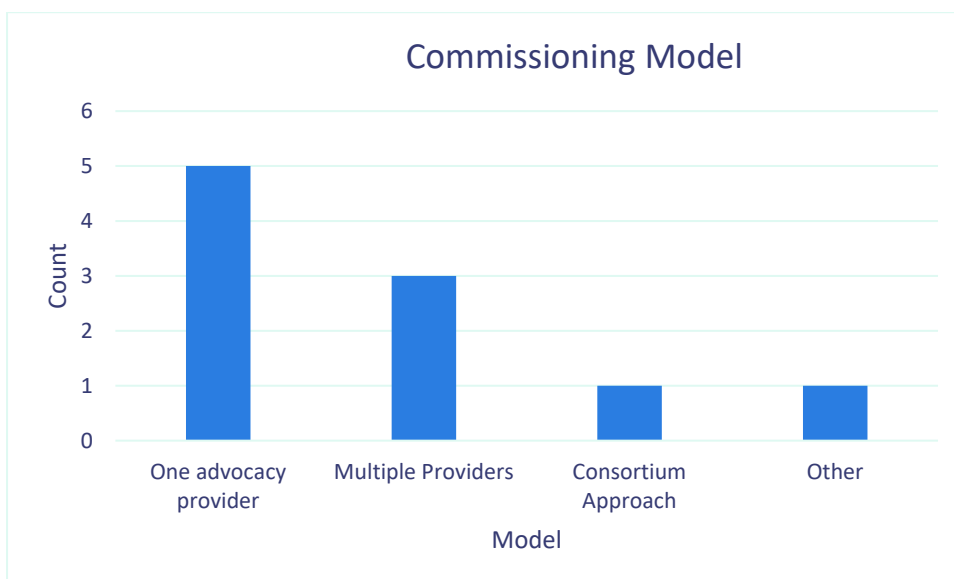
- one advocacy provider delivers all types of advocacy
- one advocacy provider delivers advocacy to adults, and one delivers to children
- there is a consortium approach with one lead provider
- multiple providers provide different advocacy services, either to different groups of people or different types of advocacy
- the local authority uses a ‘dynamic purchasing system’
- spot purchase arrangements supplement commissioned services
- services are modelled on subcontracting work to self-employed advocates

Most Local authorities favour commissioning one advocacy provider for all types of statutory advocacy, others opt for a consortium model (this involves a number of providers working together, usually with a lead agency) and others may separately commission the different statutory advocacy roles.



The figure reflects the findings from our Freedom of Information Request (FOI).

It is largely mirrored by the findings in our survey to local authority commissioners:



The choice of models may allow commissioners to respond to the local need of their population, support a range of community advocacy providers within an area, gives flexibility in how services are commissioned and might reduce risk or increase ease of access. However, as described below, where there are multiple providers, this can have an impact on how advocacy is accessed: complicated processes created by multiple providers can make it unclear where to go for different types of advocacy.

This was particularly observed when a person received in-patient care out of area; there was a lack of clarity over who should be their advocate. Or where a person is entitled to different

types of advocacy; in some areas a person would have an IMHA from one provider but then have to go to a different advocacy service for their IMCA or Care Act advocacy support leading to multiple advocacy relationships and a lack of consistency and continuity for the person.

Reviewers heard about one commissioning area using a 'dynamic purchasing system' where advocacy organisations are invited to 'advertise' their services and a commissioner can choose which provider to use. The information the commissioner has available to them is essentially location and cost – quality and experience does not feature in the decision making about where to go for advocacy support.

### 2.1.3 Disjointed commissioning arrangements between children and adult settings make it more difficult to get an advocate

The Mental Health Act 2007 is not age restricted – so entitlements to access an Independent Mental Health Advocate are not dependent on the person's age. In most areas across England, we found that the local authority believed that the IMHA service they commissioned is available to everyone with a learning disability and autism regardless of age. However, there were several areas where one advocacy provider had been commissioned to work with young people and another service to support adults<sup>23</sup>.

The risk with this approach is that it can make it more difficult to access an advocate and introduce uncertainty as to who is responsible.

*“There are commissioning gaps – we had a referral for one young person who was in hospital. They were 15 years old. They couldn't get an IMHA for love nor money. I went to the local provider who were adamant that they wouldn't support because they weren't commissioned for anyone under 18. All of that working out who should be doing what, takes time. It takes my time away from managing advocacy but most important it meant that 15-year-old went without advocacy for about 3 weeks until it got sorted”*  
Advocacy manager

In some other areas, commissioners did not realise they were responsible for ensuring eligible young people in their area had rights to access IMHA and simply did not commission for young people.

*“We do not commission for children”*

*“This contract excludes children”*

*“Only for adults”*

*“Our Children's Service does not provide an advocacy service”.*

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<sup>23</sup> A total of 12 Local authorities responded they commission different services for children and adults via the FOI request

The consequence of this often means the children and young people are losing out on their statutory right to access advocacy.

*“Two young people (aged 13 and 16) were in a [independent] unit. They were placed out of area. There was an advocate from ‘x’ local authority but they wouldn’t advocate for these children as they were out of area. I didn’t understand. I didn’t think there was anyone battling for him”*  
*Professional Stakeholder*

Reviewers also learnt about local arrangements that have evolved over time which relied on different organisations and bodies commissioning advocacy.

*“The child/young person would have access to [an advocate] via either through the Clinical Commissioning Group (NHS) or via education (sic) as part of their EHCP. This is not specifically part of their care package, as the parents will request the support on behalf of their child”* Professional Stakeholder

*“Children and young people who are in inpatient settings are placed through NHS Specialist Commissioning. Advocacy is provided by various organisations, depending on needs, location, and type of setting, commissioned by NHS Provider Trusts and others”*

*“We [local authority], do not commission anything for children or young people locally as the offer is commissioned nationally by NHS England”*

*FOI Responses*

All of these statements are concerning; children and young people who are detained under the Mental Health Act should absolutely have access to their local IMHA service. Instead, there are overly complicated, disjointed, and hard to understand commissioning arrangements, which don’t make sense in terms of the legislative requirements or in meeting the advocacy support needs of children and young people.

#### **2.1.4 Commissioning using short term contracts**

Independent advocacy is overwhelmingly commissioned for short-term periods, with many providers we spoke with reporting feeling they are on a merry-go-round of constant re-tendering. This can prevent investment in the future of the advocacy organisation, impact on job security, recruitment, and makes systemic advocacy very difficult. Advocacy providers also described that short-term contracts can also drain management time of small organisations towards tendering processes and away from focusing on high quality service delivery:

*“It shows the value that is placed on services and the people they support – it [procurement process] is last minute, with no recognition of the needs of the organisation and how they manage / pay / recruit staff and it is detrimental to the needs of people. It is impossible to plan and therefore we cannot progress work that is needed”. Advocacy Provider*

Reviewers heard from some commissioners who understood the risks of short-term commissioning and valued contracts that allowed organisations to “get on with the job”.

*“For smaller organisations it is crippling to keep doing bids. If you don’t have a back office with a big management team, you just can’t do this. We run a 3 + 2 + 2 year contract – and I would consider extending this if things are going well”. Local authority commissioner*

*“If I could change two things I would say more money, longer contracts. There is too much emphasis on short term contracts that don’t go anywhere. I know regulations have to be followed, that goes without saying, but why would we have a strong provider on a string for 3 years to retender for just a year. Why can’t we have a 10-year contract? You can always get out if it goes wrong but having something long really helps with this and is much smarter”. Local authority commissioner*

Advocates further expressed concern and frustration at projects receiving short term funding, sometimes for just a few months at a time, as it severely restricts the impact advocacy can have. Some advocates felt short term commissioning actually made things worse:

*“Where the advocacy is short term, there is a danger that we help but then leave with a sense of giving people false hope”. Advocate*

One obvious improvement to improve the stability and longevity of services is to offer longer contracts that allow investment into services and ensure management time is focused on service delivery, not diverted to constant tendering processes.

### **2.1.5 Non-Statutory Self, peer, family and community advocacy is not consistently commissioned**

Non-statutory, self, peer, family and community advocacy is commissioned in *some* areas. Where they are commissioned, these organisations mostly shared some similarities in that they are traditionally smaller services, are likely to be user led and have a local focus.

Similar to the experience of statutory advocacy services, there are huge inconsistencies in how they are commissioned. Reviewers heard about:

- local projects with a local reach – for instance in one hospital or one authority area.
- one off commissioned pieces of work with a specific focus. This could be from local commissioners, hospitals, or national bodies such as NHS England. They were sometimes described as pilots, or short-term projects (sometimes as short as 3 months).

- Advocacy that features as part of a larger piece of work (such as an expert by experience programme, or coproduction).

Participants described that despite these services being highly effective, they are routinely threatened by inconsistent or non-existent funding. There is a belief shared by many that this is because commissioners have a finite pot of money and have to prioritise statutory advocacy services:

*“Part of the funding problem is that statutory advocacy (that has to be provided in law) takes most of the share of available funding. Even though it is known that self-advocacy is very important”. Self-Advocacy Provider*

Smaller self-advocacy groups said they felt unhappy about losing out and being ‘starved of funding’.

*“The funding for self-advocacy has always been quite poor and there isn't much evidence of self-advocacy taking place within the borough. There is now only one paid member of staff at our organisation.” Self-Advocacy Provider*

Some self-advocacy providers told the reviewers their views that they lamented the ease in which contracts were lost and won with new providers taking over which led to inevitable loss of local knowledge and relationships that can be critical to the person and in providing effective advocacy:

*“We were commissioned to provide self-advocacy in the assessment and treatment unit, but this work has now been given to another organisation. We need further funding to do this work and all our practitioners have skills to do this.” Self-advocate*

*“We lost the advocacy contract to XXXX organisation, which means that the local knowledge and experience is lost within a larger organisation.” Self-advocate*

Self-Advocacy groups also raised concerns about local services losing out on contracts to larger or national organisations *“who are very good at infrastructure, business planning and writing tenders”*, but who may lack local knowledge and don't have the local relationships needed nor an authentic commitment to activism that is often a fundamental feature of self, peer, and community groups:

*“I think it is important that advocacy for inpatients is provided by a local organisation that has strategic relationships with the local authority and CCG NOT a national advocacy provider” Self-Advocacy Provider*

*“Funding for any form of advocacy is very difficult to obtain and even when it becomes available, it is quickly oversubscribed, and larger groups or organisations are always more successful in the tender / bidding process. I think small local groups have lost out to large companies / charities and whilst some may be very good, there are others that are not so great. Larger groups win contracts but can't always deliver across all groups or work effectively and this means that people lose access to services” Self-Advocacy Provider*

The Open University and Learning Disability England publication, [Funding The Gap](#) further explores these issues as well as providing suggestions to self-advocacy organisations and commissioners about how to support the growth of self-advocacy.

## 2.2 Funding

**Advocacy is routinely underfunded. There is not enough available resource to support effective advocacy – which is causing advocacy to be limited**

Throughout the review, all stakeholders expressed the opinion that advocacy is underfunded and ill-equipped with the financial resources required to fulfil statutory duties and have the impact people need. Put simply; many local authority commissioners are unable to access the necessary funds that are required to support quality advocacy, which can then be exacerbated by an absence of strategy in working out how to fund advocacy. Add to this a lack of national monitoring and accountability, and the result is significant and consistent underfunding.

The consequences are obvious: advocacy services reported they have to limit what support advocates can offer in terms of the nature of the support, the types of ‘issues’ or situations the person wants help with, the number of people they work with or the length of time available to support someone. The impact of this is potentially greater for people with a learning disability and or autistic people who may want and need to spend more time with their advocate as well as accessing a broader range of advocacy support, including access to peer and group advocacy. This is compounded further for people in secure settings and those in long terms seclusion. The cumulative barriers will become increasingly significant.

It also has consequences for the recruitment, retention and development of advocates and the longevity and impact of the advocacy service. Nowhere is this more keenly felt than within self and peer advocacy groups who suffer disproportionately from short-term, uncertain, and even non-existent funding.

### 2.2.1 Advocacy is underfunded

Advocacy managers expressed exasperation at what they were expected to deliver on the budgets they receive:

*“Our constraints mostly come from time and funding” Advocacy manager*

*“Due to funding issues and the demand, I don't feel we have enough staff. Most of us have to work unpaid hours in addition to keep up with the demand” Advocacy manager*

*“I reckon we support between ½ and 1/3 of the people on the wards – I would need more funding to support everyone”. Advocacy manager*

*“No wonder there are criticisms of advocacy when advocacy is not resourced to provide a decent level of service to the majority of people and especially to people with a learning disability and autism who may have additional*



*communication, sensory and mental health support needs". Professional stakeholder*

*"Advocacy is utterly, utterly underfunded" Professional stakeholder*

In our survey only 25% of advocates felt there was an adequate level of resource for independent advocacy.

Commissioners equally identified financial resources as a key problem within advocacy. Across the commissioners' survey and focus group interviews, funding was consistently identified as having a detrimental impact on service delivery, with lack of time and lack of funding being the most frequently cited issues.

*"Funding. We need more funding to put into preventative support. Did Care Act go far enough for wellbeing? Its watered down. We see transactional advocacy within very specific decisions and that's it." Commissioner*

*"The restrictions are placed upon the service by funding restrictions" Commissioner*

### **2.2.2 There is no strategy in how to cost and fund advocacy**

Reviewers found that there is no consistency in how to cost advocacy provision. In 2014 the Care Act Impact Assessment costed advocacy at £30 per hour (at 2012-13 prices); the Impact assessment of the Mental Capacity (Amendment) Act 2019 costed advocacy at £35 per hour (at 2019 prices). However, Reviewers found little evidence of these figures translating into contracts with the primary driver appearing to be whatever funds are available: funds that are under constant pressure to be reduced.

*"When I came to look at advocacy, I was told to bear down on the cost as much as possible. When Care Act advocacy was commissioned, it was during austerity, and this was the message so I had to have this as the main focus" Commissioner*

*"Services are retendering for ever decreasing pots of money". CQC lead*

*"Every year we are asked to do more for less money" Advocacy manager*

Some commissioners confirmed they undertake needs analysis to inform how much advocacy is arranged, however reviewers did not see any evidence of this informing how much financial resource was made available.

### **2.2.3 Underfunding impacts delivery**

Advocacy providers identified the lack of funding as the main barrier to delivering effective advocacy. There are concerns that because advocacy is underfunded it means there are not enough advocates to work with people and there are limits to what advocates can do.

*“We are limited due to funding; our contract is very flexible but due to limited funds it is very difficult to manage the waiting list and promote the service”.  
Advocacy manager*

*“Our constraints mostly come from time and funding. We would like to have more of a presence on wards” Advocacy manager*

*“I keep going back to ask for more money. You can guess the answer I get”.  
Advocacy manager*

*“Our main issue is time. We want more time on wards, but the budget will not allow for our advocates to visit as frequently as they would want to build those relationships and gain the trust of the patients”. Advocacy manager*

*“Having funding available to provide a specific service for these patients, who are often around for a longer period than patients without Learning Disabilities and/or Autism and often need more time with an advocate than other patients” Advocate*

*“We only have one advocacy for all the wards” Self Advocate*

Reviewers heard that advocacy services have to respond by limiting what actions they take, how long they can work with people, and what types of support they can offer. There are concerns that these restrictions in funding can create a culture where advocates believe they are limited in what they can and cannot do. They have to choose between spending 10 hours with one person or 5 hours with two people.

Some independent advocates reported working arrangements that restricted time within the contract, for example, a set amount of advocacy time per hospital/setting and per ward/unit. This was more prevalent in independent hospitals but was evidenced throughout all types of hospital.

*“I had 3 hours per fortnight for the whole site. It was a 6 bedded unit. Step down setting – people getting ready for discharge. They would condense the hours into one day a month. If we had a request for a meeting, there was zero flexibility in these hours”. Advocate*

Advocates reported being restricted in how much time was available per person (21% of advocates reported in the survey they had a set number of hours available per person, 23% of advocates reported they had set hours per ward), and managers reported there were caps on how much advocacy is available.

*“The amount of time I have with each person has decreased. This is really not great. It’s not great for anyone but especially for this group of people as you need more time to build up trust and get communication. More and more it seems to be commissioned as get in and get out. I’m getting more and more frustrated with this”. Advocate*

Advocates felt they did not have enough time to offer support on the full range of issues facing people and did not have enough time to get to know people well.

*“We have huge waiting lists for IMHA support due to not enough funding for advocates so sadly we can’t support everyone who needs the support meaning*

*those we work with we do our best to support but there are many people let down by the waiting and lack of advocacy support too”*

Significantly, reviewers did not find many examples of actual limits to advocacy imposed through contracts or acted upon through management directives. Advocacy managers gave examples of contracts suggesting a limit on average hours available, but reviewers found no evidence of local authority commissioners actually withdrawing or stopping advocacy. This is not to say these demands do not exist and that advocacy providers and advocates aren't under pressure to limit the time they spend with people, just that reviewers did not find any overt evidence within local authority contracting arrangements.

There could be a legacy of poor commissioning arrangements which have previously limited and capped advocacy availability. This quote from one advocacy manager spoke of a previous contract that they had since withdrawn from:

*“They had a matrix that equated how many people were in that site to how many hours of an advocate. And it was in minutes, for example so many beds led to so many minutes of advocacy being available. Complexity of need was totally ignored.” Advocacy manager*

*“With the perception that hours are capped there can be the development of a culture of ‘we can't’ – people presume a lack of resource, creativity is stifled, people stop asking, they get used to doing the bare minimum, it becomes normalised” Professional stakeholder*

Underfunding causes obvious problems within service delivery, but it also prevents advocacy services from retaining and developing advocates:

*“Sustainability and stability are really important – investment in training and support of advocates – I want them to stay!” Advocacy Commissioner*

This is also linked to short-term contracts negatively impacting on a service's ability to grow, offer stability, invest in its people, and have longevity.

#### **2.2.4 Self and peer advocacy groups suffer disproportionately**

The problem of chronic underfunding was keenly felt within self and peer advocacy groups with all the groups involved in the review highlighting problems within inconsistent and unreliable funding as:

*“We used to get...150k for the whole of county (2006-2010). From 2010 to 2017... the contract was just over 100k. We now get £20k per year to cover four districts. The whole grant is worth 60K. This is in a grant form from social services, and we are unsure if this funding is continuing after March 31st. If this happens our Advocacy groups will cease. Many of the people who come to our meetings are not in receipt of other services and often have no meaningful activities to do during the day, we find this group of people the most vulnerable group”. Advocacy Provider*

*“Preventative approach makes sense, but the local authority don't have the funding to invest in non-statutory advocacy”. Commissioner*

*“We have lost substantial amounts of funding over the past five years. We were originally funded through Local Authority contracts which reduced over time but then the contracts were moved to Healthwatch via their engagement requirement and funding stopped over a two-year period. We have some funding to support the work of the Learning Disability Partnership Board but no other work, other than a few ‘one off’ pieces of work.” Advocacy Provider*

In the more extreme cases, self-advocacy groups reported they do not receive any funding:

*“We have not had any funding for self-advocacy work for over 10 years”.*

A further issue is the focus and prioritisation of funding statutory advocacy, over the range of different types of advocacy that people want and need.

Unless adequate funding is secured to support the full range of advocacy support, it is unlikely advocacy will be enabled to have the impact it could.

## 2.3 Very little support for self, group, and peer advocacy groups

**Self, group, and peer advocacy services all have an important part to play in realising the impact of advocacy - but they are currently not joined up and frequently unavailable.**

There is very little self, group, or peer advocacy arranged and commissioned that is delivered in inpatient settings. Out of 44 self-advocacy groups who took part in the review, only 10 offered any type of self, group, or peer advocacy in inpatient settings.

- 1 for children and young people
- 7 provide self, group or peer advocacy after people have been discharged
- had been involved in inpatient advocacy in the past but had lost their funding.

There were a number of different approaches to the work:

- Some organisations ran pilot projects on behalf of NHS England to gather people’s experiences of advocacy in hospitals.
- Some organisations ran focus groups inside inpatient settings.
- Sometimes people were chosen by staff to go to a separate room for a focus group rather than people choosing themselves.
- One organisation was involved in PLACE assessments (Patient Led Assessments of the Care Environment).
- Many organisations had very talented people working as experts by lived experience for CETRs.

Whilst people thought a lot of the projects were good, they were mostly funded for a short period of time. Smaller groups particularly said they felt unhappy about losing out and being “starved of funding”. This created major worry that projects give people hope and support but is then removed, leaving people in vulnerable situations without support.

There is also a complete absence of any joined-up peer advocacy support for family members. Reviewers found it was very difficult to even find out about advocacy support organisations for family carers. This reflects the lack of specially commissioned services, but it is further complicated because organisations that do offer peer or advocacy support for family members, often do not call themselves advocacy organisations. For example, the Challenging Behaviour Foundation (CBF), Mencap and National Autistic Society (NAS) support family carers in a variety of different ways, and this support may aid carers when advocating with their relative, but none of these organisations described their support as advocacy or ‘support for family carers to advocate for their relatives’ as part of their offer.

### 2.3.1 Peer and self-advocacy can do things statutory advocacy just can't

Reviewers heard about the power in being able to access peer and self-advocacy support. People with a learning disability and autistic people want to access support from people who have been in the same situation and can relate. This is not instead of statutory rights to advocacy, but in addition to. This type of advocacy which supported people to talk together about their own experiences with other people who have had the same or similar experience was crucial.

*"When I moved out of hospital, one of the biggest things I struggled with is not having to ask for things and just being able to do things. Because I was no longer on a section it felt so different. It would have helped to have the reassurance from other people who have been through this to know it is ok to feel like this, what is ok to do and what is not ok (simple things like drinking alcohol!) and get reassurance with these feelings". Self-advocate*

*"Being an advocate, you need that life experience, especially here. Some of the guys are not well. You can't be offended or get upset by behaviours." Self-advocate*

Self and peer advocates may also be much more aware of unspoken issues that are important; issues that are obvious when the advocate has lived experience.

*"Because I have autism, I see things straight away from the person's perspective. I know immediately that that light is going to cause them distress, or the hum from the kitchen is going to be a problem" Advocate.*

*"I supported an autistic person in a ward round once and something happened that I didn't immediately challenge. When we were leaving my partner turned to me and said 'if you were autistic you would never had let that happen'. It really struck me that I just didn't 'get it' because I'm not autistic and I don't know what it's like". Advocate*

Reviewers also heard that peer and self-advocacy organisations are often better able to respond to pressing issues that have a massive impact on people with a learning disability and autistic people. This can be the difference between offering timely support and problems being missed. One such example is the anxiety that people might feel at the point of discharge. Many professionals are excited at the idea of the person leaving, but for the individual this can be overwhelming.

*“Thinking about leaving hospital can make people feel so anxious that they don’t want to leave. This is called “Gate Fever”. People needed to hear from other people saying how they had managed, positive stories.” Self-advocate*

### **2.3.2 Funding for peer and self-advocacy groups is the biggest problem**

As explored previously, underfunding is preventing all advocacy services from having the impact they need. Nowhere is this more acutely apparent than within peer, group, and self-advocacy organisations.

Reviewers heard how peer and self-advocacy make a huge difference to people having a voice, but Reviewers also heard that it is not financially supported on a regular basis. Most of the peer and self-advocacy organisations identified adequate funding as was one of the biggest problems they faced.

*“To make this work self-advocacy groups need money so they can support peer advocates going in to support patients to speak up and it needs to be independent!”. Peer advocate*

*“We have the skills and experience, but would need some funding as it is not part of any commissioned advocacy service by the local authority or CCG” Self-advocate*

*“Funding for any form of advocacy is very difficult to obtain and even when it becomes available, it is quickly oversubscribed, and larger groups and organisations are always more successful in the tender / bidding process.” Self-advocate*

The absence of long-term funding was equally a problem for most groups:

*“Funding can stop at any time. They are continually working with local MPs to put pressure on the government to increase or at least sustain funding”. Advocate*

*“Short term can be anything from 12 weeks to 12 months but is rarely longer than this. We have tried to work with this as best as we can, but it is not sustainable, is unrealistic and damaging to smaller groups who may not have extensive reserves to ‘carry’ the lack of good practice which often comes from local authority commissioning. Self-advocate*

*“Short term for us is a year and it is not an adequate time frame to offer a quality provision.” Self-advocate*

## **2.4 The legislative framework**

This section explores the context of the legislation and guidance which frames the commissioning and delivery of advocacy for people in inpatient settings.

It is somewhat different from the previous findings sections. It reflects on some of the challenges presented by the legislative framework and explores how different types of advocacy, underpinned by different legislation interplay and impact on individuals' rights and entitlements. The section illustrates how complex the frameworks are and how piecemeal access to advocacy has become over time.

### 2.4.1 Rights to advocacy

As previously mentioned, in England, local authorities have the responsibility for commissioning statutory independent advocacy, and people have a legal right to receive:

- Independent Mental Health Advocacy (IMHA)
- Advocacy under the Care Act 2014
- Independent Mental Capacity Advocacy (IMCA)
- Paid Relevant Person's Representative (Paid RPR)
- NHS Complaints Advocacy
- Advocacy for children and young people

In this section we look in more depth at what these types of advocacy offer, when and who to.

We reflect on the complexities of people's entitlements in different circumstances, and how these can pose a challenge to the person, their family and the commissioning authorities.

We also note what we heard from Freedom of Information requests and participants during the review.

#### Independent Mental Health Advocacy (IMHA)

The Mental Health Act 2007, brought about changes to the 1983 Act, including introducing a duty on the 'appropriate national authority' (the Secretary of State) to make arrangements for help to be provided by independent mental health advocates (IMHAs) for those detained under sections of the Mental Health Act.

The purpose of the IMHA is to make sure that the person who is subject to significant restrictions on their freedom has access to independent support. The IMHA can support on any issue connected to the persons mental health, care, support and treatment that is authorised under the Mental Health Act. IMHAs:

*"Provide an additional safeguard for patients who are subject to the Act. IMHAs are specialist advocates who are trained specifically to work within the framework of the Act and enable patients to participate in decision-making, for example, by encouraging patients to express their views and supporting them to communicate. their views.*

*They are commissioned by the relevant local authority as identified under the Act.1 IMHAs should be independent of any person who has been professionally involved in the patient's medical treatment<sup>24</sup>."*

This right to an IMHA is not impacted by whether someone has a family or friend who might also advocate for them. However, the right is linked to people being detained under the Act

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<sup>24</sup> 6.3 MHA Code of Practice

and people in England are not currently legally entitled to an IMHA if they are in hospital informally. If people are no longer under a section of the Mental Health Act, but remain in hospital, IMHAs will most likely need to stop working with them at that point, unless the local authority commissions non-statutory advocacy. The draft Mental Health Bill 2022 sets out an intention to extend IMHA to informal patients.

The Mental Health Act 1983 requires local authorities to commission IMHA services for everyone, regardless of age, in their area who is eligible for IMHA services. The Act, associated Regulations, and Code of Practice clarify that commissioning bodies need to be mindful of arranging advocacy that meets the needs of all people who may need to access it, including people with a learning disability and autistic people.

The associated Code of Practice outlines the arrangements by which this can be achieved, including which commissioning body should commission in which circumstance or location. Put simply, the local authority where the hospital is situated has responsibility for commissioning the IMHA service.

However, we found that this was poorly understood by many, and reviewers heard a plethora of examples of differing arrangements, and of hospitals also commissioning their own 'IMHA' and advocacy services. Confusion about commissioning responsibility may arise from:

- practice dating from older commissioning regulations,
- a genuine desire from hospitals to ensure advocacy is available,
- misunderstandings about who is responsible to commission advocacy,
- potential ambiguity within the service specifications for low, medium, and high secure mental health services<sup>25</sup> which require that an independent advocacy service including IMHA must be provided for patients. It does state that this should be commissioned independently to ensure patients' rights are safeguarded but does not go further to clarify who should commission the advocacy.

Eligibility for IMHA support from the local authority commissioned advocacy service should not be restricted by age, nor dependent on where the person is from. However, within the Freedom of Information Requests, reviewers heard of many local authorities only commissioning services for people over 18, over 14, or only for the people whose ordinary residence was within the local authority. This is contrary to the requirements of the legislation.

### **Care Act Advocacy - The Care Act 2014**

The Care Act 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, Safeguarding Adult Reviews (SARs) as well as s42 safeguarding enquiries. This support is available to individuals with care and support needs as well as to carers.

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<sup>25</sup> <https://www.england.nhs.uk/publication/service-specification-low-secure-mental-health-services-adult/>  
<https://www.england.nhs.uk/wp-content/uploads/2018/03/Adult-Medium-Secure-Service-Specification-SCFT-WSBS-addendum-version.pdf>  
<https://www.england.nhs.uk/wp-content/uploads/2021/02/service-specification-high-secure-mental-health-services-adult.pdf>  
<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-c/c02/>



The Care Act advocate role is to support people's involvement and participation in Care Act processes and ensure their voice and preferences are central to planning and decision making and to raise challenges as needed.<sup>26</sup>

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. People who are being jointly assessed by the NHS and local authority are also eligible for the support of a Care Act Advocate<sup>27</sup>.

A further entitlement is triggered when there is a disagreement between the local authority and the 'appropriate person', if both agree that advocacy support is in the person's best interest.

If people are receiving adult social care arranged by the local authority, then they may already have a Care Act Advocate. If the person doesn't and the Care Act process might result in the person being moved to an NHS funded placement<sup>28</sup>, they have an additional right to access advocacy, even if there is an appropriate person, if the local authority deems it to be in the person's best interest. Importantly, this includes people with adult social care needs at risk of being admitted to a mental health hospital.

It is important to note that this is limited to NHS funded placements. In other circumstances, where a person receives full NHS continuing healthcare, the person is no longer eligible for support from a Care Act Advocate, meaning the advocate would withdraw, unless the particular advocacy scheme has additional funding to deliver non-statutory advocacy. If the person is detained under the Mental Health Act, they will become eligible for IMHA support, or if under a DoLS Authorisation they may be able to access support from a paid RPR.

The Care and Support Statutory Guidance describes how advocacy should be made available to 'people in the area' (para 7.59-6W), making it clear that ordinary residence applies. "The advocate should, wherever possible be from the area in which the person is ordinarily resident at the time of assessment and review."

This is problematic and reviewers found issues with Care Act Advocates being unavailable due to how the legislative framework for the different types of advocacy interact: The duty to provide IMHA and IMCA is based on where the person currently is; Care Act Advocacy is based on where the person is from. This impacts on continuity of advocacy support as the local provider may not be able to provide Care Act Advocacy alongside IMHA and IMCA and the advocacy provider where the person is from, may not be able to work out of area. The person may have existing relationships with one advocate and prefer to receive support from that person, however current requirements for commissioning may make that challenging to achieve.

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<sup>26</sup> [Providing Independent Advocacy Under the Care Act – Self Study Pack](#)

<sup>27</sup> [Care and Support Statutory Guidance](#)

<sup>28</sup> This includes a hospital for a period exceeding 4 weeks or in a care home for a period of 8 weeks or more (Care and Support Statutory Guidance 7.42)

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

Under section 117 of the Mental Health Act 1983, local authorities together with integrated care boards (ICBs)<sup>29</sup> 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.<sup>30</sup>

Aftercare services must have the purpose 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.’<sup>31</sup> The range of services which can be provided is broad and can be provided via a direct payment, personal health budget, a personal budget from the local authority, or directly provided services/supports.

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’<sup>32</sup>, 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.”*

When an individual’s discharge is being planned, they could be entitled to IMHA, Care Act Advocacy and potentially other advocacy support, such as IMCA, if a decision is being made about where someone will live.

However, reviewers found that few people received advocacy support of any kind during s117/discharge planning processes. IMHAs did not always see it as part of their role and referrals were not always made for Care Act advocacy. The issue of ordinary residence further complicated what should be a simple decision about who should be the person’s advocate.

## Independent Mental Capacity Advocacy – The Mental Capacity Act 2005

The IMCA role is to support and represent people aged 16 and over who don’t have appropriate friends and family to consult **and** who lack the mental capacity to make decisions about where they live<sup>33</sup>, serious medical treatment, deprivations of liberty (DoLS)

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<sup>29</sup> ICBs replaced CCGs in July 2022

<sup>30</sup> 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

<sup>31</sup> Mental Health Act 1983

<sup>32</sup> 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.

<sup>33</sup> This includes, long term change of accommodation decisions and reviews of these decisions.

and safeguarding<sup>34</sup>. When someone has a right to IMCA support, there is a duty on statutory bodies to instruct an IMCA. IMCAs must be 'instructed' by the professional who is responsible for making the decision.

Independent Mental Capacity Advocates (IMCAs) have very clearly defined roles and remits as set out in the Mental Capacity Act and associated Code of Practice. The IMCA role is to support and represent people through specific decision-making processes and ensure their rights are upheld. IMCAs tend to only be involved for very short periods of time. They are there to support the person just whilst a decision is being made.

IMCAs provide support in relation to where people may live, including a proposed move organised by the NHS or local authority, where that accommodation is not arranged under the Mental Health Act.

Reviewers did not hear many of examples of IMCAs providing this support to people when their move out of hospital was being planned.

#### Deprivation of Liberty Safeguards (DoLS) IMCA 39a, 39c and 39d IMCA

Where a person is staying in a care home or a hospital and they can't consent to that arrangement, a deprivation of liberty will need to be considered. This relates to when a person is not free to leave, and they are under continuous supervision or control.

IMCAs can get involved when decisions being made may amount to a deprivation of liberty. This is known as IMCA 39a or IMCA DoLS and the role is to:

- support the person to understand what is happening in relation to the deprivation of liberty
- represent them through the assessment process
- raise concerns or challenges.

A person can also have an IMCA DoLS following the authorisation, where there is a gap in the person's RPR support (39c IMCA) or where their representative or the individual needs support through the process (39d IMCA).

Some people with a learning disability and or autistic people will be in hospital under a DoLS authorisation. They have different rights to advocacy and different rights to appeal to those who are detained under the Mental Health Act. You cannot be under a section of the Mental Health Act and a DoLS authorisation.

Reviewers heard a level of confusion, from all stakeholders, about which legal framework for authorising detention was most appropriate. This subsequently impacts on the type of advocacy people can access. This is important because it demonstrates inequities in access to advocacy and in people's rights to appeal and challenge their detention.

We heard from some advocates that they had had more success in supporting the person to be discharged in timely fashion via the Court of Protection rather than the First-tier tribunal (Mental Health).

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<sup>34</sup> It's important to note that the Care Act 2014 introduced stronger rights to advocacy for people subject to safeguarding processes. The Mental Capacity Act 2005 powers to instruct an IMCA are therefore 'overtaken' by the Care Act. The exception to this is where a person who lacks capacity is the alleged perpetrator.

We also heard concerns about people being held under the DoLS process due to long delays to DoLS authorisation which effectively results in some people spending a significant amount of time detained in hospital, but not under a legal framework, the impact of this is that the individual does not have recourse to legal safeguards such as 21a challenge, review, appeal and/or advocacy.

#### **Paid Relevant Person's Representative (RPR or Paid RPR)**

Paid and unpaid RPRs support people subject to Deprivation of Liberty Safeguard (DoLS) authorisations, to understand the restrictions imposed on them and their rights in relation to these. RPRs support people in all matters relating to the deprivation of liberty safeguards (DoLS), including challenging it and ensuring that any conditions to DoLS are met. As above an unpaid RPR can be supported in their role by an IMCA.

Those who are in hospital under a DoLS authorisation, and not the Mental Health Act, will have the right to a Relevant Person's Representative, an RPR, for the duration of their DoLS. This will either be someone who they know, or a paid RPR (usually from an advocacy organisation).

At the time of writing, the new Mental Capacity Act Code of Practice has been out for consultation. The new legislation will introduce the Liberty Protection Safeguards (LPS), which will replace the Deprivation of Liberty Safeguards. Under the new legislation the RPR role will no longer exist. However, the implementation of the Liberty protection Safeguards is currently paused and it's unknown if or when the scheme will be implemented

#### **NHS Complaints Advocacy - Health and Social Care Act 2012**

NHS complaints advocacy is also relevant to those who are in inpatient settings. Those wishing to make a complaint about NHS funded services, including Mental Health Services are able to make complaints about care, treatment and/or services received as well as processes and decisions that are made. Complainants are entitled to the support of independent complaints advocates (sometimes referred to Independent Complaints Advocates, NHS complaints advocates or health complaints advocates).

People who are inpatients under a section of the Mental Health Act may sometimes be supported by their IMHA if they are needing to make a complaint about NHS funded care and treatment.<sup>35</sup>

#### **Advocacy for Children and Young People**

The [Children Act 1989](#) gives the right to 'looked after children' and young people leaving care, to make representations and complaints to the Local Authority regarding their care arrangements.

The [Adoption and Children Act 2002](#) also places a duty on Local Authorities to assist looked after children who want to make a complaint. This duty is interpreted in the [Advocacy Services and Representations Procedure \(Children\) \(Amendment\) Regulations 2004](#) to mean that the Local Authority **must** provide advocacy services to looked after children who wish to make a complaint about their care.

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<sup>35</sup> Section 4.66 of the Mental Health Act Code of Practice

Children and Young People's Advocates provide support to children and young people in care, or those who are leaving care and enables children and young people to express their views or make a complaint.

Advocacy is often available for children and young people who:

- are Looked After Children (LAC)
- live in a secure children's home
- are going through Child Protection process
- have Special Educational Needs (SEND)
- are in transition to adult care and support services

However, our Freedom of Information Request responses show that available support varies from area to area.

Children's advocacy isn't always provided by independent advocacy providers; local authorities sometimes decide to deliver this type of advocacy themselves. This limits the independence of the advocates. [The National Advocacy Standards](#)<sup>36</sup> set out how advocacy should be delivered for children and young people.

#### **2.4.2 Entitlements to Independent Advocacy for people with a learning disability and autistic people who are inpatients**

As already explained, people with a learning disability and autistic people who are inpatients have different rights to advocacy support depending on whether or not they are detained under the Mental Health Act, are under a DoLS authorisation, or are in hospital 'informally'. Whether or not people have friends and family involved in their life and supporting them to be involved in decision making will also have an impact.

Rights to advocacy have evolved over time: legal frameworks have meant rights to advocacy changed and been added to in 2002, 2007, 2009, 2010 and 2015. The consequence of this is that instead of an advocacy service that meets the needs of the person, people can only access short term, episodic, process led advocacy. The absence of a joined-up framework hinders many commissioners and advocacy providers in arranging and delivering person led, holistic advocacy.

Reviewers heard this is the exact opposite of what people want and need.

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<sup>36</sup> National Standards for the Provision of Children's Advocacy Services 2002

The table below attempts to capture people’s circumstances and the type of advocacy they may have a right to receive.

<b>Legal status in hospital</b>	<b>Friends or family involved</b>	<b>Type of Statutory Advocacy</b>	<b>For support with...</b>
Detention under the Mental Health Act	Yes, the person has support from friends or family	IMHA	For ‘issues’ concerned with mental health care or treatment or rights under the Mental Health Act
		NHS Complaints Advocacy	To make a complaint about NHS funded services
		Care Act Advocacy (if the person has substantial difficulty)	When assessment or planning may mean the person moves to NHS funded provision Care and support assessment, planning or review where there is a disagreement between the local authority and friends or family
	There are no family friends available (or appropriate) to support the person	IMHA	For ‘issues’ concerned with mental health care or treatment or rights under the Mental Health Act
		NHS Complaints Advocacy	To make a complaint about NHS funded services
		Care Act Advocacy (if the person has substantial difficulty)	If the person is affected by a safeguarding enquiry (or review). Care and support assessment, planning or review When assessment or planning may mean the person moves to NHS funded provision
		IMCA (if the person lacks capacity)	For decisions about Serious Medical Treatment or a decision about where the person will live when no longer detained under the Mental Health Act
	DoLS authorisation (if the person lacks capacity)	Yes – the person has a family or friend acting the RPR role	39d IMCA
Care Act Advocacy (if the person has substantial difficulty)			When assessment or planning may mean the person moves to NHS funded provision Care and support assessment, planning or review where there is a disagreement between the local authority and friends or family
No - the person does not have any family or friend available to support them with the DoLS process or to be RPR		39a IMCA	To support and represent the person through the DoLS assessment
		Paid RPR	Once the DoLS has been authorised an advocate may be appointed to undertake the paid RPR role
		IMCA (if the person lacks capacity)	For decisions about Serious Medical Treatment or a decision about where they live when no longer detained under the MHA
		Care Act Advocacy (if the person has substantial difficulty)	If the person is affected by a safeguarding enquiry (or review). Care and support assessment, planning or review When assessment or planning may mean the person moves to NHS funded provision
Yes or No		NHS Complaints Advocacy	To make complaint about NHS service(s)

Voluntary patient (also known as informal)	Yes	NHS Complaints Advocacy	To make a complaint about NHS funded services
		Care Act Advocacy (if the person has substantial difficulty)	When assessment or planning may mean the person moves to NHS funded provision Care and support assessment, planning or review where there is a disagreement between the local authority and friends or family
	No	Care Act Advocacy (if the person has substantial difficulty)	If the person is affected by a safeguarding enquiry (or review). Care and support assessment, planning or review When assessment or planning may mean the person moves to NHS funded provision
NHS Complaints Advocacy		To make complaint about NHS service(s)	

The many types of statutory advocacy and differing eligibility requirements causes confusion when working out what advocacy support someone might be entitled to at any given time and in any given place. This complexity makes it harder for people to understand, navigate, and ultimately access independent advocacy.

### 2.4.3 The impact of different legislation and guidance on advocacy in practice.

The primary legislation and associated codes of practice clearly set out a need for joined up advocacy provision, and reviewers heard that people want clarity and consistency in their advocacy support. However, the manner in which statutory advocacy has been introduced over a long period of time, in specific situations, has had the unintended consequence of introducing piece meal entitlements which are complex and hard to navigate. This has serious and real life consequences for people, disproportionately impacting people who are in hospital a long way from their home.

The current landscape of having a plethora of advocacy entitlements based on legal status and decision-making processes has resulted in a number of problems:

#### People are sometimes not able to access advocacy for the issues they want and need support with, when they need it most

- Professionals are confused and do not fully understand which advocacy is available when.
- People and their families are not provided with clear information nor being referred to the most relevant service.
- Advocacy providers incorrectly interpreted eligibility which resulted in referrals being declined, and/or passed to alternative providers.
- Advocacy providers may not have been commissioned to deliver all types of advocacy to all people and so need to pass on referrals to alternative providers which can cause confusion and introduce delays.
- Commissioners were unclear about their responsibilities and/or chose not to follow the legislative guidance.

### Advocacy not being person led or not meeting people's needs

- People want their advocate to follow them in and out of hospital, however current legislation does not support this directly.
- Current requirements, clearly outlined within legislation and guidance, that advocacy is joined up and specifically meets the need of people with a learning disability and autistic people, is rarely adhered to.
- Legislative frameworks do not recognise the use of non-instructed advocacy as a fundamental and successful approach in supporting and representing people who lack capacity in relation to the decisions being made, to instruct their advocate, or consent to advocacy support.

### Inequity in accessing rights

- Different routes to challenge detention and appeal decisions often relies on the 'system' working and people being able to access advocacy in a timely fashion. Those detained under the Mental Health Act, are able to appeal their section via a Mental Health Tribunal and/or a Hospital Managers Hearing. Those in hospital under a DoLS authorisation should have an RPR who can request a section 8 review or raise a section 21a challenge with the Court of Protection. Not being able to access advocacy easily means people lose out on these fundamental human rights.
- People placed 'out of area' are more likely to be affected by the lack of joined up working needed to make all of the different types of advocacy available. Reviewers heard different local authorities make different arrangements for people placed out of area which could be based on specifically commissioned services, spot purchasing or relying on more informal reciprocal arrangements. This inevitably introduces different levels, or unequal levels, of access.

### Families' rights to advocacy and involvement

Legislation does not currently recognise the important advocacy role many family members undertake. This was acutely felt by families who's loved one lacked capacity to instruct the advocate or make care and treatment decisions. It was also apparent when a young person turned 18; families reported being suddenly excluded from decision making overnight.

Once a person with a learning disability and or autistic person is over the age of 16, family members rights as parents with parental responsibility changes as per the Mental Capacity Act. Family members can no longer consent to actions, care, or treatment on behalf of their relative unless they have court appointed deputyship or an LPA is in place.

Family members of relatives who are inpatients have very few rights to advocacy for themselves. Currently this is limited:

- carers may be entitled to Care Act Advocacy if they are deemed to have 'substantial difficulty' as set out above. However, this is unlikely to be triggered whilst their loved one is in hospital, as it is limited to when the carer is going through their own assessment or support planning process.
- family members undertaking the RPR role when their relative is under a DoLS. Unpaid RPR's, can access the support of an IMCA 39d.



If the person lacks the mental capacity to make particular decisions, families should be being consulted as a part of Best Interest decision making processes under the Mental Capacity Act, where the decision maker deems them appropriate to consult.

If the person is detained under the Mental Health Act a family member is likely to be the person's 'Nearest Relative'<sup>37</sup> and will have associated rights. The code of practice also refers to 'consulting with' family members in decision making processes.

We heard that family members are not always supported in their role of 'Nearest Relative' or 'Unpaid RPR'

### Challenges in accessing advocacy when in hospital 'out of area'

Reviewers found that there are challenges in delivering person led advocacy as a direct consequence of how eligibility to different types of advocacies is set out in law.

Care Act Advocacy and RPR are the main challenges here: Care Act because your ordinary residence local authority needs to arrange your advocacy and Paid RPR because different local authorities make different arrangement for 'out of area' provision for Paid RPR.

There may be very real decisions about whether to engage an advocate from the person's ordinary residence authority who may know the person well, but doesn't know the new area or the hospital the person is currently in. Is it better to have an advocate geographically close who may get to see you more, or someone far away who may know you better and understand you and life at home and your connections and relationships?

The reality is that people are not able to make that decision without potentially needing to commission or spot purchase different advocacy arrangements.

Guidance tells us that people with a learning disability and or autistic people should be being supported as close to home as possible, so in theory this legislative challenge shouldn't pose much of an issue, but in reality, it means spot purchasing and 'wonky' advocacy arrangements.

Reviewers heard from advocacy providers about the challenges of providing joined up, 'seamless' advocacy when people were placed out of area and away from their local authority of ordinary residence:

*"We can provide IMHA and IMCA support to people in our patch, but technically we shouldn't be supporting people with Care Act advocacy if they're not from our area without getting a spot purchase arrangement in place. We do our best to be as flexible as we can be and our commissioner is very supportive, but there's a barrier there in the legislation." Advocacy Provider*

### Accessing advocacy to challenge or protest a stay in hospital

The table above alludes to the complexities of ensuring people have adequate rights and access to advocacy depending on how they are hospitalised. The right to challenge or appeal a detention, or deprivation of liberty is based on the status of their stay.

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<sup>37</sup> As set out in the Mental Health Act and Code of Practice

## Care (Education) and Treatment Reviews

The 2023 Dynamic support register and Care (Education) and Treatment Review policy and guide<sup>38</sup> highlights the importance of advocacy and sets out when people should be able to access advocacy support.

It reminds professionals to consider an individual's need for advocacy, such as when the person is identified on the dynamic support register.

It places responsibilities on the panel chair for the C(E)TR to ensure that the person's chosen advocate is invited to the C(E)TR and given adequate time to plan and prepare.

It also provides guidance about how C(E)TRs should respond if the person has not been able to access advocacy.

Whilst the policy document is clear about best practice, it does not introduce a right to advocacy at C(E)TR and reviewers heard many stories of people being unable to access support for these crucial reviews. IMHA providers often said it did not fall within their remit, or that they did not have capacity to support people in such long meetings.

## Duties to support advocacy involvement

The codes of practice and guidance for all forms of statutory advocacy include responsibilities to refer to and support the involvement of advocates. In Care Act and IMCA, it is unlawful not to arrange advocacy where people are entitled to it. Duties extend to informing people about their rights to advocacy and enabling the advocate to fulfil their role.

## Legislative changes

The Mental Capacity Act has recently been amended and at the time of writing, the implementation of the new Code of Practice has been paused. In addition, the revised Draft Mental Health Bill was published in 2022. There are significant changes in rights to access advocacy within both of these pieces of legislation, however it's unclear on how, if or when these changes will be implemented. The changes would provide opportunities to ensure issues that impact on people's ability to access advocacy are addressed at a fundamental level within the legislation.

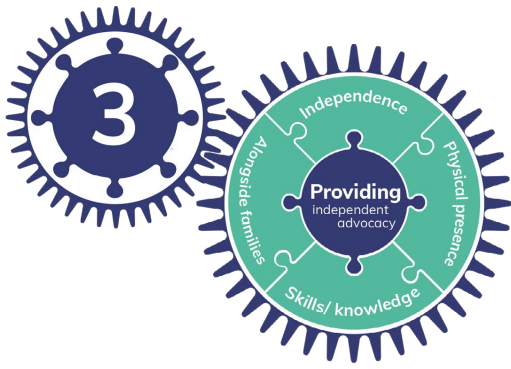
## Non-instructed Advocacy

As set out earlier, non-instructed advocacy happens when a person is unable to instruct their advocate and potentially when people have been deemed to lack the mental capacity to decide about having an advocate or to make the decision at hand. In England, we do not currently have any up-to-date guidance for advocates to support their delivery of non-instructed advocacy. For people with a learning disability and autistic people who are inpatients, the most recent guidance was developed by Action for Advocacy in 2011, 'Non-Instructed Advocacy and the IMHA role'. Whilst there are a number of helpful elements to this guidance, our understanding of best practice in non-instructed advocacy delivery has continued to develop and the guidance can be helpfully updated.

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<sup>38</sup> <https://www.england.nhs.uk/publication/dynamic-support-register-and-care-education-and-treatment-review-policy-and-guide/#heading-1>

We also need to ensure that the language we use to describe non-instructed advocacy delivery is nuanced enough to support advocates to understand when their advocacy may be partially instructed, semi-instructed etc. so that they are in turn clearly able to communicate this to others.



# Providing independent advocacy

## Key Messages

This section is about how advocacy is provided and what is getting in the way of effective delivery.

The review heard very real threats to the independent nature of advocacy: both in how advocacy is arranged and funded, and also in the way advocates behave. There was evidence that not all advocates are raising issues and protecting rights in the way that is needed.

Advocates are not always physically present on the wards and frequently do not have the time needed to build effective relationships.

The lack of resource also means that advocates are not always developing skills in understanding autism and learning disability and in using non-instructed advocacy. Lastly, improvements are needed in how advocates approach working with families.

The subheadings are:

3.1 Independence

3.2 Physical Presence

3.3 Advocates' Skills and Knowledge

3.4 Advocates and Families

## 3.1 Independence

A founding underpinning principle across advocacy is that of independence. For an advocate to be able to offer effective advocacy support they must be 'free from influence and conflict of interest so that they can represent the person for whom they advocate'.<sup>24</sup> Reviewers heard universal agreement that this principle must be protected and preserved; however, there are very real and significant threats to independence that must be addressed.

### 3.1.1 Hospitals commissioning their own advocacy service

Reviewers saw a well-established practice of most independent hospitals commissioning their own advocacy services. We heard of some specialist NHS settings which also commissioned their own advocacy, but not in the routine way that we heard about with independent providers.

Reviewers found that in some areas this was in addition to the statutory local authority commissioned IMHA service, which created problems due to the complexity of multiple providers being on site. In other areas this was in lieu of the statutory IMHA service, which meant people missed out on statutory entitlements.

The specific reasoning behind this is unclear but it is possible that this has developed over time due to:

- Legacy practice pre–Mental Health Act 2007. Independent hospitals were frequently asked during CQC visits about their advocacy provision which meant they sourced advocacy services. When statutory advocacy was introduced in the 2007 Act, the independent hospitals simply continued with these arrangements.
- Misunderstandings of who should commission advocacy and a lack of joined up approach
- Being more able to influence, restrict, or control the advocacy service.
- Perceived expectations from NHS England within service specifications that independent hospitals should commission advocacy.

The following requirement outlined in the service specification for Low Secure Services could lead an independent hospital to understand it is their responsibility to commission advocacy:

*“An independent Advocacy service including IMHA must be provided for patients in the service and commissioned independently to ensure patients’ rights are safeguarded.”<sup>39</sup>*

Throughout the review, there was almost universal agreement that it is not appropriate or effective for any hospital to commission their own advocacy service. Put simply, hospitals paying for advocacy, whilst well-intentioned, absolutely compromised the independence of advocates.

*“How can the advocate be independent, when the hospital is paying them?” Family carer*

*“If you’re providing advocacy but commissioned by the provider you are marking your own homework”. Professional stakeholder*

*“It is important advocates are independent and not funded by the local authority or hospital so not in their pocket” Person who uses advocacy*

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<sup>39</sup> <https://www.england.nhs.uk/publication/service-specification-low-secure-mental-health-services-adult/>

*‘Really good support can only be offered by well-informed/qualified individuals who are independent of the responsible agencies’ Family carer*

*“Advocates don’t operate fully independently when we commission the service” Hospital Director*

The potential cost of this, is that people feel they cannot trust the advocates.

*“I’ve seen patient lack of trust of advocacy – this is where the person feels that the advocates are in the pocket of the hospital. Lots of people have started with advocacy but then disengaged. This happens sometimes because they see the advocate just as another member of staff.” Professional stakeholder*

In addition to concerns that it was inappropriate, and that independence had been compromised, reviewers worryingly uncovered examples of the hospital controlling (or trying to control) how the advocacy service behaved.

This happened in subtle ways, often from good intentions. Reviewers heard from a number of hospital commissioners who appeared far too close in their relationship with the advocacy provider:

*“One of our advocates was sick – so we picked that up” Hospital Commissioner*

Management and involvement in the daily running of the advocacy service was undoubtedly coming from a ‘helpful’ place whereby the commissioner was being supportive. However, this level of ‘interference’ in the day-to-day running of the service can threaten the independence of advocacy, for example when you have a commissioner referring to advocates as ‘our’ advocates and seeing the advocate as part of the hospital team.

Another worrying example was how one hospital responded when the advocacy service raised safeguarding concerns about people’s experience in hospital. The response from the independent hospital was to withdraw or limit advocacy available to people:

*“We raised a safeguarding concern and were then told that that they would be removing the advocacy from the ward. We then took this to the CQC to raise further.” Advocate*

Advocates provided further examples of not being ‘allowed’ onto the wards, only being able to access certain parts of the hospital such as the family room or being allowed on site by appointment only.

*“In two of the private wards, when we have raised safeguarding concerns say because of lack of staff and the risks, they have now decided we are not allowed onto the wards. We have to meet patients in the family room”.*  
*Advocate*

*“I’m not allowed on the ward – I have to make an appointment to see a specific person” Advocate*

One independent hospital tried to direct how the advocacy service would report safeguarding concerns, which the advocate felt was indicative of how the hospital did not ‘want any trouble’:

*“The hospital wanted the advocacy provider in their pocket, they didn’t want us to be independent. It was blatant. They wouldn’t let us report safeguarding externally – they didn’t want us to, we could only report it internally”*

*Advocate*

Reviewers also saw evidence of some independent hospitals closely managing advocacy delivery, getting involved in discussions and decisions about staffing levels, deciding how many hours could be spent on a particular ward, dealing with staff absence or sickness. There was even an example with one independent hospital influencing recruitment decisions.

*“One hospital said they wouldn’t allow one of our advocates in because they didn’t like his attitude so they said we couldn’t give him a contract. They didn’t like his level of informality and the way he communicated. But he passed his probation. We couldn’t give him an advocate role because the hospital wouldn’t let him in. They controlled our staffing”. Advocacy manager*

Such interference into who the advocacy service employs is a clear and obvious threat to the independent nature of advocacy.

### **3.1.2 How advocacy is delivered (the behaviour of the advocate)**

A common thread throughout the review, was the importance of advocates not just being seen as independent but behaving in ways that protected their independent nature. Many advocacy services were sensitive to this and were able to identify potential threats and take appropriate action:

*“The hospital did talk to us about co-location so having an advocate based on the hospital all the time. I’ve been a bit wary as it can compromise our independence. I worry that the staff then see us as part of their organisation and team.” Advocacy manager*

*“The biggest way to show independence is by being prepared to challenge. Respectfully of course. But you have to challenge when things aren’t right. If you can’t challenge then there isn’t much point to you as an advocate is there?”*

However, reviewers also heard concerns that advocates acted on behalf of the hospital and were more likely to align with professionals:

*“They [the advocates] work on certain agendas. If they think what you are raising is irrelevant, they don’t listen to you.” Family carer*

*“[The advocates] spoke to the nurses but never spent any time with my sibling or trying to get to know them. I was shocked – I thought their role was to help my sibling’s voice be heard! They didn’t show any interest in doing so.” Family carer*

*“The advocate goes to my daughter’s ward rounds and CTRs. I have no idea why as she knows nothing about daughter, and she never sees her from one week to the next. I find it so wrong. Family member.*

*“I’ve been worried about the skills and attitude of some colleagues that don’t deliver a person-centred service partly as they align with professionals on the wards and work alone on the units ‘their wards’ with the same patients and professionals referring” Advocate*

Reviewers found evidence of this and heard examples of advocates behaving in ways that threaten their independence, such as this advocate who had become desensitised to restrictive practices and inhumane/undignified care:

*“One person had been in seclusion for weeks and was required to pass their poo out through a hatch, as well as be subject to other indignities. A strong advocate would have been “all over this” but the advocate appeared to have accepted it as the norm, justified by the pressures on the staff team and other issues”. Professional stakeholder*

Constant focus and attention is required from senior leadership within advocacy to support advocates to actively promote and protect their independence from service providers.

### 3.1.3 Hypernormalisation

Hypernormalisation describes what happens when systems are flawed, and recognised as flawed by all working in them, but because credible alternatives are difficult to achieve, people become resigned to accepting and working within these limits and stop acknowledging the flawed system. Over time, this becomes a self-fulfilling prophecy. An effect termed hypernormalisation<sup>40</sup>.

In the context of this review, it is entirely possible that because of the challenges to the system, in supporting people with a learning disability or autistic people to move on from inpatient settings, the advocate does not think there are other ways forward, and their creativity is stifled. Crisis, closed cultures, restrictive practices, parent, and patient blaming can become accepted parts of the culture, leaving advocates feeling impotent in the face of the system.

An example of this is how the practical challenges of supporting people to leave hospital and live in the community, such as a lack of suitable homes and support in community settings, has contributed to a rhetoric that people have very ‘complex’ needs and are ‘difficult to place’, whereas factors to do with market shaping, recruitment and availability of services in the community, that have little to do with the person can be at play. The false belief that people with a learning disability and autistic people in some way cannot cope in the

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<sup>40</sup> The phrase was first coined by Yurchak in his book *Everything Was Forever, Until It Was No More: The Last Soviet Generation* (2006) and later explored in the seminal Adam Curtis BBC Documentary ‘Hypernormalisation’ (2016)



community and need institutional settings in order to be 'safe' becomes normalised and over time becomes harder for the advocate to see the need to challenge.

### 3.1.4 Advocates becoming part of 'the system' and Isomorphism

Advocates are unique in their role, in that they have to be outside of the system in order to challenge it, but they have to be inside the system to know how it works. Similar tensions are present in developing working relationships with mental health professionals: advocates need to have effective communication and understanding of different roles, but they cannot be too 'close' or familiar with staff.

*"The advocate sits in a strange space. They are not part of the hospital staff; they aren't family and they aren't people using the service so it's not obvious where they sit. I think sometimes this means it's easier for them to be aligned with the staff" Commissioner*

Whilst some advocates were fiercely protective of their independence, the reviewers heard from stakeholders who had witnessed advocates seemingly becoming part of the system - having NHS email addresses, NHS ID, or hospital lanyards, and holding keys, for example. All things that will have come about for good or practical reasons and not necessarily with negative intentions, but none the less they are factors which indicate system led over person led advocacy delivery.

A more subtle finding was the high number of advocates who used 'service land' language. Not all, but most advocates reviewers spoke to, referred to people as clients, service users, patients, beneficiaries who had placements, issues, challenging behaviour. In some more rare instances, advocates saw their work in terms of 'referrals' or 'cases' to close. For some, there was a default position to use medical model 'thinking'. This could be indicative that some advocates find it easier to see their work through professional language rather than the person or the 'patient's' experience.

It is understandable how these things come to be; it is easier and quicker to get around the hospital if the advocate has an NHS ID and a pass or keys. Advocates also described that if they used 'professionals' language' they felt they were more likely to be respected and responded to.

However, the consequence of this, is that some advocates appear overly tolerant and understanding of the challenges faced by the hospital staff, instead of questioning and pushing back when they should in order to ensure the rights and interests of the person are being upheld.

*"When you go on the ward, the staff are really busy. They are running around like headless chickens and I'm sensitive to that. There are genuine resource issues that mean they don't have time for advocacy". Advocate*

Reviewers also heard evidence that some advocates may have become accustomed to accepting and at times justifying restrictive practices focusing on risk rather than patient experience and rights.

*“We went to an IC(E)TR for an autistic man who also had a learning disability. The IC(E)TR was so concerned the care was so poor that the person’s human rights were being breached. The advocate had endorsed the hospital’s position. The advocate had bought into the hospital’s perspective, everything was about risk and managing risk, which justified the person’s segregation”. IC(E)TR clinical reviewer*

One advocate described:

*“There’s a high level of aggression and violence of the ward, but over time everyone has just got used to it.” Advocate*

Part of the challenge in guarding against ‘becoming part of the system’ is the isolated nature of advocacy - a feature that is becoming increasingly common since Covid. Advocates are often working on their own, in hospital settings making it difficult for the advocate to remain outside of the system.

*“You would be in the same hospital for all your hours on your own. Isolation was a big problem”. Advocate*

Reviewers also heard from advocates who were self-employed and contracted by an advocacy provider to provide support in particular wards and settings. We also heard from advocates who had been on the same ward or unit for 10 years and more.

It is very difficult for advocates in this position, and unless advocacy services actively guard against this, there is a risk that advocacy becomes subsumed as part of the hospital culture rather than being distinctly independent and able to hold services to account.

It is also important that contracts and commissioning arrangements are supportive of advocacy providers in proactively managing their independence and service delivery.

Isomorphism<sup>41</sup> describes what happens when the culture of a dominant service starts to take over the culture of another. Advocacy services are particularly at risk of this as their smaller, independent culture can become subsumed into the larger dominant culture of the hospital. This is particularly seen when advocacy services are based in one site, have a static advocacy team or are a small, isolated team.

One Advocacy Manager said:

*“We are mindful of trying to prevent ‘closed culture advocacy’ developing and existing within the closed cultures that many of these restricted settings are”*

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<sup>41</sup> The development of theories of isomorphism in sociology was primarily the work of Paul DiMaggio and Walter Powell.

DiMaggio, P.J., & Powell, W.W. (1983). The Iron Cage Revisited: Institutional Isomorphism and Collective Rationality in Organizational Fields. "American Sociological Review

Isomorphism starts in subtle and small places, in the culture of the service, in the unspoken rules of what is expected by advocates from their colleagues and managers. The reviewers saw evidence that some advocates were at risk of becoming more aligned with staff teams rather than people who draw on advocacy, possibly because the advocates are known as 'staff' themselves and/or have an office on site. The reviewers also heard concerns that advocates might spend too long within one setting and become desensitised to the person's experience of being a patient in hospital.

*"Some people who looked like they did really well in the advocacy role - well we were worried about their boundaries and understanding of the role. They got sucked into the culture of the hospital and I don't think they were truly independent. The good advocates who were great and got advocacy were the ones who left, got ill, or became stressed". Advocacy manager*

Unless the advocacy service and hospital setting they are working in is aware of this phenomenon and takes active steps to guard against it, the advocacy can become part of the system it was designed to challenge.

## 3.2 Physical presence

**Good advocacy is being present, visible, and available. Not having a regular presence on the wards severely limits the effectiveness of advocacy.**

The reviewers heard that advocates routinely face restrictions in seeing people in person or remotely. This has been exacerbated by Coronavirus restrictions but was a trend before Covid and is continuing post-lockdown even as restrictions are lifted.

Findings from the surveys show:

- 57% of advocates reported being able to have free access to people in mental health settings.
- 58% of advocacy providers said they have a regular presence on mental health wards.
- 30% of advocates could only visit people if they had a pre-arranged appointment<sup>42</sup>

This suggests that over 4 in every 10 advocates/advocacy providers do not regularly visit the hospital wards in person. Given the previous findings about problems with accessing advocacy, getting to know people, and taking a holistic approach (rather than being issue based) this is concerning.

Having a regular presence on the wards is universally accepted as an essential component of delivering effective advocacy. This not only allows the advocates to take the advocacy directly to the person rather than wait for a referral, but it importantly provides opportunity to *'have a poke around', 'see, smell, hear things with my own eyes'*. *Advocates in focus groups*

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<sup>42</sup> Data taken from advocate and advocacy provider survey

Reviewers found many instances where advocates are not consistently having a regular presence on the ward:

*“Wards limited the [advocates] time on each ward, some clients will be missed due to this, and these are usually the less vocal”. Advocacy manager*

*“Somebody turning up once a month to say Hi isn’t really the thought out committed advocacy the person needs” Professional stakeholder*

*“We get a phone call and go over; we don't have a presence at all. There is a generic advocacy service on site, but they aren't IMHA. This is ridiculous for the patients and confusing”. Advocate*

People with a learning disability and autistic people also told reviewers that advocates weren’t not always there to speak to when they need them.

Unless advocates are able to have better access to the mental health settings where people stay, they will continue to face difficulty in making advocacy accessible, building relationships, and challenging closed cultures.

We heard from some professional stakeholders that they felt IMHA’s should have powers of entry:

*“They [the advocates] need a power to be able to go onto a ward. Advocates should have a power of entry – because providers can say no and then want to do they need. It’s just so important” Stakeholder from CQC*

### **3.2.1 Making the advocacy offer**

Independent advocates are the best people to explain their role and what they can (and cannot) do. Whilst this can be achieved with written information for some people, reviewers heard that for the majority of people with a learning disability and autistic people, many of whom use non-verbal communication, experience significant sensory overload, and may have difficulty in accepting a new person into their life, the offer and explanation of advocacy needs to be in person and on more than one occasion.

*“We need to be able to get in there. In the units we are in, the advocates go in very often, sometimes 4 out of 5 days a week so they are very visible... We sometimes get referrals but most of the time it’s the advocate picking up a referral”. Advocacy manager*

*“Drop in is so important - having a presence reminds professionals to refer especially for people who cannot instruct. But I can just work with someone who is eligible (i.e. don't NEED the professionals to refer)”. Advocate*

Where this does not happen, people who are in most need of an advocate are most likely to not get one:

*“The advocate might come in once a week and chat to the people who are the most chatty but the people who are quiet or non-verbal get missed. When I’m*

*on the wards I see this. They just saw the easy people". Professional stakeholder*

The reviewers also heard criticisms of some advocacy organisations who operated central helplines or referral lines. These were used as way to support and manage contact and communication but instead of helping they were often experienced in terms of blocking and introducing delay. They are no substitutes for being physical present in order to respond to advocacy need:

*"If you have a problem and you'd like to speak to advocacy, I want to speak to them. They say sorry, call tomorrow. It goes to the advocacy control centre - it's their policy" Self-advocate*

Some people with a learning disability and autistic people said that they did not know how to access advocacy or just didn't think they had or needed an advocate.

The reviewers heard that advocates are sometimes limited to when they can come onto the ward. When access to advocacy is restricted to appointment only, or having set times on a ward, this can be very problematic to a person who might struggle with concepts of time and future planning.

*"[The] advocate [is] available only 1 hour and on one day a week. My son is unable to see the advocate when he needs, unaware of the time or how to access them" Parent*

This is not a suitable way of making contact with people; people with a learning disability and autistic people who are staying in mental health hospitals shouldn't have to fit in with schedules that suit advocates and the ward, advocates need to be around with frequency and regularity so that people have more options and chances to speak to the advocate – at a time that suits the person.

### **3.2.2 Building relationships**

An essential component of advocacy is building relationships.

*"Cost cannot be the number one factor – it's got to be about the relationships. I know there are different principles, but we need to enshrine it in the relationship". Professional stakeholder*

*"We need advocates who can build a relationship with the person and not just be there for the individual meetings or moment in time – they need to be there throughout not just at those one-off moments. We need to make it easy for people to feel safe with their advocate". Professional stakeholder*

*"You need a relationship with your advocate – you need to feel like someone is looking after your interests. So much is happening around you that you don't want, that you need to have a relationship with your advocacy. It's the most important thing. It cannot be transactional. It needs to be more meaningful". Professional stakeholder*

*“The advocate is very visible, approachable, and developed really good relationships with people. I see how he engages with people, putting in the effort to get to know people and build trust. They are very person centred – it shines through” Professional Stakeholder*

Throughout the review, self, peer, and statutory advocates all highlighted the importance of seeing people in person and agreed it is impossible to develop strong relationships with every person who wants an advocate via a telephone or screen. Having a physical presence on the wards helps the advocate, to get to know a person, it helps the person to get used to the advocate, and it helps the advocate to learn how best to communicate with the person and what is important to them.

*“It removes the uncertainty and anxiety from the person visiting. It gives them reassurance, and those who care for them. All parties can see how each other are reacting to the situation, questions etc.” Peer advocate*

It also helped the advocate to ‘sit side by side’ with the person which:

- better reinforced the independent nature of the role
- allowed the advocate to pick up on non-verbal communication
- supported the person better to plan ahead of meetings/tribunals/hearings
- enabled more self-advocacy support
- enabled drop ins and group advocacy
- encouraged the advocate to respond to issues there and then

*“Drop in is so important... I've sorted out clothes for someone who had been admitted and didn't have any clothes or family to bring them in”. Advocate*

Without the ability to spend time on the wards to get to know people, it is more likely that advocacy becomes more about fixing and responding to single issues, rather than about an empowering relationship. We also heard that when the advocate was more present, people who hadn't yet engaged with them were more able to ‘see’ the advocacy in action with the advocate and other peers and consequently better able to understand the role and benefits of advocacy.

For anyone who is unable to instruct their advocate, the advocate being physically on the ward, or wherever the person is, will be even more important. In order to be able to represent people robustly, much of the work of the non-instructed advocate is getting to know the person, building up a picture of their views, wishes and preferences – understanding what is important to, and for someone, what makes a good day and a bad day etc.

Advocates need to build up this picture in a variety of ways:

- Getting the person's views directly from them if they can
- Observing the person in different settings and with different people
- Learning what someone's non-verbal communication is telling us about what is important to them, what they do and don't like and how they prefer to be supported
- Learning from other people who know the person well; family, friends and paid support network
- Understanding the person's needs, care, and treatment from their records

These actions require the advocate to actually be around, and around for more than 1 hour a week.

### 3.2.3 If you want to improve closed cultures you have to be present

Understanding 'closed cultures', their causes and their impact gained increased significance, due to the identification of closed cultures in institutional settings such as Whorlton Hall, Winterbourne View and Mid Staffordshire Hospital that witnessed the horrific abuse of people with a learning disability and autistic people.

The Care Quality Commission explain that 'by a closed culture we mean a poor culture that can lead to harm, which can include human rights breaches such as abuse. Any service that delivers care can have a closed culture, and features of a closed culture include:

- staff and/or management no longer seeing people using the service as people
- very few people being able to speak up for themselves. This could be because of a lack of communication skills, a lack of support to speak up, or fear of abuse.
- this may mean that people who use the service are more likely to be at risk of harm
- this harm can be deliberate or unintentional. It can include abuse, human rights breaches, or clinical harm"<sup>43</sup>

One of four risk factors identified by this guidance is the lack of external oversight which could be indicated by a lack of monitoring by outside agencies; limited interaction with outside agencies; or having few visitors. Having regular visits from independent advocates could really improve instances where there is a lack of external oversight.

The reviewers heard from some advocacy services who have developed approaches to delivering advocacy which included having regular visits and the ability to drop into services on an ad hoc basis. This allowed the advocates to be mindful of closed cultures and get some small sense of what it is like to be on the ward.

*"We have a strong presence; we have our advocates on the wards. If you only pop in you don't pick up on culture... but with us being on the ward so much we can observe so much more - see, smell hear what's going on". Advocate*

*"[remote] is also not as good as being with the person in the Hospital. When you are in the hospital you can get a feel for how it is for the person, what the place is like, they can speak more easily to you. When online people might not feel comfortable speaking on the camera, or they might have staff with them or other patients. We have also found it better in person to be able to see how the persons health is, to see if their health is getting worse" Advocate*

The reviewers heard from advocates who were mindful that visiting wards at limited times or only being allowed to visit in specific places meant they only caught a glimpse at the culture of the ward – that attending at a specific time meant that they may be seeing the

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<sup>43</sup> [Identifying and responding to closed cultures: Guidance for CQC staff](#)

ward 'at its best'. This reflected the idea that staff modify and moderate their behaviour in front of external visitors:

*"If you only pop in you don't pick up on culture - staff are on their best behaviour" Advocate*

*"I've had staff tell me 'I'd better be on my best behaviour – do things the right way' as if it's a joke. I find it really concerning they would joke about behaving properly just because I am there" Advocate*

*"We get a phone call and go over; we don't have a presence at all. The staff are always on their best behaviour when I'm there" Advocate*

*"Whenever I visit the young people's ward, they always ask me who am I there to see. I'm not there to see anyone specifically – just a drop in. They then accompany me wherever I go". Advocate*

For some advocacy services, they were mindful that not being allowed back in after the Covid restrictions had been lifted, could be indicative of closed cultures and made the advocate more determined to access the ward.

*"We weren't given access remotely during Covid, when trying to go back they want us to stay remote. More important now than ever that we're in. Why are they trying to keep us out?" Advocate manager*

Having arrangements that encourage advocates to be present in informal ways (as well as formally such as attending ward rounds) increases the safety of people as it increases opportunities for advocates to observe cultural norms, staff behaviour, and how people are treated behind closed doors.

### 3.2.4 The legacy of Covid-19

Advocacy is not unique in having to rethink how it delivers support to people since the Covid pandemic first hit in 2020. During the height of lockdown, the majority of independent advocacy services could not physically visit people in mental health settings, as steps were taken to isolate people and stop the spread of Covid-19. It is worth noting that a variety of responses were observed ranging from hospitals continuing to allow advocates on site as essential visitors - to other hospitals who introduced blanket bans.

The Valuing Voices report<sup>44</sup> helps to understand this:

*"Most people in mental health hospitals have a right to advocacy. An advocate's presence on the ward is vital to make people aware of that right. Unlike under the Care Act or Mental Capacity Act where there is an obligation that an advocate is provided, in England under the Mental Health Act this is an opt-in right, meaning people are not provided advocacy by default. Because advocates were prevented from spending time on mental health*

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<sup>44</sup> [https://www.ndti.org.uk/assets/files/Valuing\\_voices\\_-\\_Protection\\_rights\\_through\\_the\\_pandemic\\_and\\_beyond\\_Oct\\_2020.pdf](https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf)



*wards as they normally would, people were not able to see advocates working and were not prompted to ask about advocacy for themselves. This is particularly problematic where the person lacks capacity to request an advocate and results in advocacy being less available for this group who arguably need it the most.”*

Reviewers confirmed that this is having a detrimental impact on the advocacy service’s ability to deliver its support:

*“When we visit, we generally visit a specific person – and we might informally or accidentally bump into people who are interested in advocacy. But during Covid we haven’t had that presence for 2 years, so we haven’t had that informal chat with new people” Advocate*

*“Advocates not going in during Covid is not good. It’s so hard to get to know the person over the phone – I don’t think you can do this.” Professional stakeholder*

Two years later, reviewers found that differences remain in how hospitals have enabled independent advocacy to get back onto the wards.<sup>45</sup> The following comments were taken in January and February 2022 – at a time when no national lockdowns restricted movement.

*“We are operating both remote and virtual still - very changeable due to different restrictions in place depending on the Covid status on the wards – we try where possible to do face to face visits, but sometimes [we are] not able to access the patients” Advocacy manager*

*“Going on the wards, when we have to” Advocacy manager*

*“All work has been remote, but now they are back on the Wards - only using remote if it suits client needs (remote meaning, phone, and video call)” Advocacy manager*

*“[we are] operating at pre covid levels i.e. face to face, all the time - unless an outbreak in the wards - remote is not the norm” Advocacy manager*

*“Working in person (aside from initial lockdown and a bit over last Christmas) unless there has been an outbreak on a ward. Believe that remote working is a very poor substitute for face to face - proving a challenge in [x area] as they have a large number of private hospitals as well as NHS provision - the [advocate] has been asking the providers to let them know in advance if people have a diagnosis of autism so they can offer more timely and appropriate support” Advocacy manager*

*“Mixed approach – approximately 50/50” Advocacy manager*

*“60% ward, 40% remote” Advocacy manager*

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<sup>45</sup> This section is very time specific and reflects experiences up to February 2022

*“Throughout the pandemic we have maintained at all times to do face to face visits unless we haven’t been able (but only where this has been on behalf of the Ward) - tribunals are still done remotely” Advocacy manager*

This reflects a variety of attitudes and arrangements to seeing people in person in the mental health hospital.

In light of these restrictions, advocacy services like many other services have had to embrace technology as an aid to meet and communicate with people. The reviewers have heard a variety of experiences:

For some, opportunities to meet remotely via online platforms such as Zoom or Teams, has yielded positive results.

*“The big meetings have got better – and decision making has got better. People have been discharged in the pandemic because virtual meetings have become better and more efficient. People have been better involved (family etc). So, the use of technology has suddenly become better and more efficient” Advocacy Manager*

*“Teams meetings – I’m not at hospital with them [the other staff] – it can make me more independent”. Advocate*

*“I’ve been surprised by how well remote technology works for some people. I’ve had a number of autistic people prefer online meetings – its more focussed, there’s less chit chat, it almost feels safer” Advocate*

However, the reviewers also learnt about instances where remote technology just is not appropriate and can operate as a stressful experience that prevents effective communication and relationship building:

*“How am I meant to build a relationship with someone who is non-verbal over Teams?” Advocate*

*“Remote working just ain’t appropriate sometimes. It’s very difficult to explain your role to someone who lacks capacity, I can’t tell if they have understood what I’ve said. Whereas when I’m in the room, I’m picking up on all the subtle non-verbal cues” Advocate*

*“Virtual meetings stop me from speaking up” Person with a learning disability*

There are also challenges with using the equipment needed for remote communication and advocates rely on staff to offer this support. Reviewers heard mixed experience in the hospitals’ ability and willingness to support:

*“We have found that people using technology to connect to their advocate has been difficult. Sometimes staff will say at the last minute that people cannot use the ward laptop and stops them from speaking to us” Peer advocate*

Whilst it is reassuring to learn that remote and digital methods of communication are preferred by some people and are, in fact, improving the accessibility and experience of

advocacy, remote working is not something that should be relied upon or used as the default approach due to the particular requirements of the role.

*"It's not an acceptable substitute for face-to-face support. You need feet on the ground" Professional stakeholder*

### 3.3 Advocates' skills and knowledge

**The skillset, knowledge and aptitude of advocates is not always as strong and developed as it needs to be.**

People with a learning disability and autistic people may express themselves and what they want in different ways that advocates need to learn and understand.

Advocates need to find the right ways to explain information or the options available to the person in a given situation. For people with a learning disability and autistic people who are admitted to mental health hospitals, it is vital that they are supported in their preferred ways of communicating and understanding, so that the advocate can understand what they want to do and what they are able to do in their current situation.

The reviewers heard from advocates who had developed excellent understanding and skills in communicating and supporting people with a learning disability and autism:

*"One lady liked things explained in a particular way and needed information in a particular way. She liked to pronounce depot<sup>46</sup> – "dee – pot". So, when she moved to the community and the staff offered her a 'depot', she got very angry. All they need to do was to pronounce it differently, in a way she understood. I advocated for this and had to explain the significance of how it was pronounced". Advocate*

*"One consultant was really difficult about one person who wouldn't wash his hair himself – I said it might be sensory issue. The consultant was very blasé about it – he didn't seem to know about autism. He dismissed it – saying 'of course he can wash his hair'. But I could see it was a sensory issue so kept raising it and asked for OT support". Advocate*

*"One client was becoming very aggressive when she was woken in the morning. I was able to see this through the lens of autism and asked questions about how this should happen – what should the routine look like? What type of alarm? Should she have a weighted blanket? What should happen with the lights? Once they looked at it through sensory perception and not mental health things got better" Advocate*

However, the reviewers also heard evidence that this does not consistently happen, and too often advocates are not confident in supporting a person with a learning disability or an autistic person. Only one third of family carers described the advocate supporting their loved one as 'skilled and experienced.'

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<sup>46</sup> An injection where medication is released slowly

*“I’ve spoken to 100s of advocates and none of them (or hardly any) have specialist training. Understanding the nuance of the person’s behaviours is critical” Professional stakeholder*

During the review, advocates were asked if there was anything that could increase their confidence, skills, and abilities in effectively advocating for people with a learning disability and autistic people. Training was the overwhelming answer. The following topics were specifically identified:

- Training on learning disability and autism,
- involving experts-by-experience,
- communication
- the law/legislation with this group of in-patients
- Non instructed advocacy
- Hearing stories about what works and what doesn’t work
- Acting independently
- Knowing how and when to challenge

In addition, the literature review<sup>47</sup> identified that there appears to be three main deficits in advocates skill sets:

1. a lack of basic understanding of autism and learning disabilities.
2. a lack of practical communication skills, particularly when working with a person who uses non-verbal or augmented communication.
3. there is evidence that IMHAs lack confidence in using non-instructed advocacy.

### 3.3.1 Understanding autism and learning disabilities

The reviewers heard universal agreement across all participant groups that advocates **must** be trained and have skills in advocating with people with a learning disability and autistic people. This would include, as a minimum, understanding autism, understanding learning disability and understanding the impact on communication, sensory experience, and individual need.

*“I think the role definitely requires a level of training or experience/understanding of autism and learning disabilities to be able to provide effective advocacy as not everybody has a clear understanding of this or a knowledge of different approaches” Advocate*

Without this training, advocates are not fully equipped to provide effective support. The consequences of not developing these skills means that advocates do not understand non-verbal methods of communication – and therefore are unskilled in using a range of communication techniques (such as PECs, [Talking Mats](#), [Makaton](#), total communication, objects of reference, [intensive interaction](#), [social stories](#), easy read, etc).

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<sup>47</sup> [NDTi literature review](#)

Without training, the advocate is less likely to understand the importance of the person's individual communication method and, therefore, less confident in meeting the person's communication needs. Without training, the advocate may fail to understand behaviour as communication – and therefore be less likely to challenge restrictive practices and push for trauma-informed care. Without training, the advocate will not appreciate the impact of environment and sensory experience on the individual and will therefore be unable to effectively improve things for the individual as they are less likely to get a handle on the person's 'world'.

Without training it is very difficult to effectively advocate.

*"We need more training for advocates in communication needs, access needs, autism, learning disabilities, not less" Advocate*

*"Advocates should be well versed in autism, sensory processing and draw upon experts if not". Family carer*

There was a split amongst participants whether an advocate for someone with a learning disability and autistic people should receive 'enhanced' training and be classed as a 'specialist' advocate or whether all advocates should be equipped to support people with a learning disability and autistic people. The former approach would ensure a highly specialist skillset of dedicated advocates who could offer 'advanced' support to a person with a learning disability or an autistic person. The latter alternative is for all advocates working in in-patient settings to be trained in autism and learning disabilities and be equipped to make the appropriate reasonable adjustments each person needs. The latter approach would make most sense in ensuring all advocates are equipped to meet the needs of a wide range of people.

### 3.3.2 Skills in communication

People with a learning disability and autistic people may communicate differently. They may express their wishes, preferences, or needs in a way which is not typically obvious, and which requires advocates to really tune in and understand, especially when they don't know people well. People who lack capacity, in particular, may not use words to communicate, use few signs or communication aids. Family carers expressed concern that even 'good advocates' would "undoubtedly struggle" to understand their loved one's wishes, feelings, and communication.

Whilst some advocacy services told reviewers "There are never any issues in accessing training" and there are some services who support advocates to access training, we did not find evidence of advocates receiving well designed and substantive training in communicating with people with a learning disability and autistic people.

*"I've never been given specific training – I have raised it. Never worked with people with learning disabilities before this job". Advocate*

*"I'm a Makaton tutor and give autism training – but the knowledge I have learnt is from outside of advocacy". Advocate*

*"No, I haven't had any training - advocacy services rely on transferable skills".  
Advocate*

*"Training – how many advocates are PECS trained? I've spoken to 100s of advocates and none of them (or hardly any) have specialist training. Understanding the nuance of the person's behaviours is critical. At the very least they need to understand PECS, talking mats, social stories" professional stakeholder.*

We did hear a couple of examples of advocates having received training in previous roles or seeking out training and doing this under their own steam.

People with a learning disability and autistic people highlighted the need for advocates to be skilled in communication:

*"Speak to me in a way I understand"*

*"Be clear, use picture cards and take things step by step"*

The review also heard the advocates were not routinely engaging with people's families, who may be best placed to help the advocate understand their relative's non-verbal communication.

### **3.3.3 Skill in using non-instructed advocacy**

The reviewers witnessed a huge variety in the use of non-instructed advocacy by advocates working in inpatient settings: some services were skilfully competent, others less so, others appeared not to use it at all. Given that significant numbers of people with a learning disability and autistic people will lack the capacity to decide whether they want an advocate or be able to clearly instruct an advocate on what they want to happen, this is most concerning.

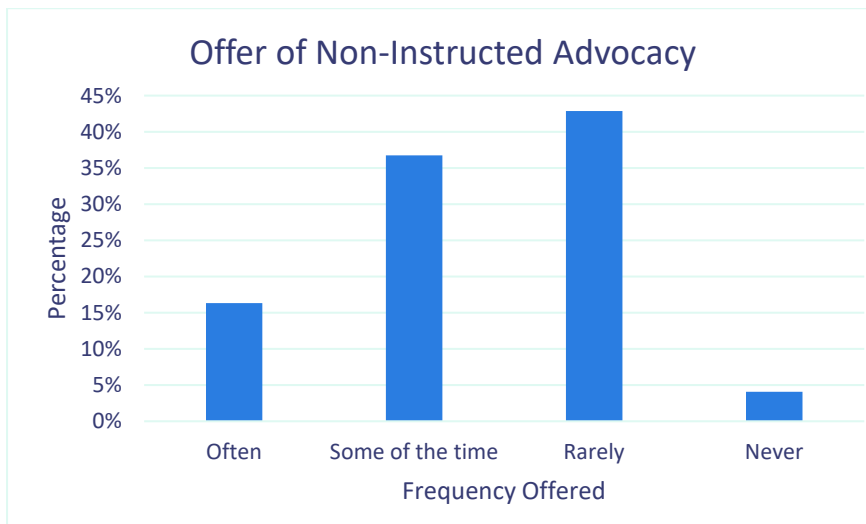
Some services had developed a sophisticated understanding of non-instructed advocacy:

*"Our advocates have the presence and drip, drip - build relationship - being visible – they may shift to instructed, semi instructed, non-instructed, more involved, whatever is needed" Advocacy manager*

However, nearly half of the advocates who took part in the survey, told reviewers that they rarely or never use non-instructed advocacy (see figure below with people with a learning disability or autistic people. One advocate said:

*"I use non-instructed advocacy for a small percentage of my work with this group - which worries me as I know we are not seeing everyone. The barriers of using non instructed advocacy is difficult. I went to see one person on segregation and was kept waiting 90 minutes. Staff wouldn't let me see the notes or anything. They kept putting in barriers.*

*I did raise this as a concern and pushed but I often feel like I haven't done as much as I should have done or could have done. There are definitely people who aren't getting IMHA".*



This could reflect low confidence and an absence of training in non-instructed advocacy; particularly for IMHAs who tend to focus their knowledge development on the Mental Health Act sometimes at the expense of the Mental Capacity Act. There needs to be more of a readiness within IMHA services to recognise that some people detained under the Mental Health Act will also lack capacity.

Within services that did identify regular use of non-instructed advocacy, there was some evidence to suggest that advocates are not using non-instructed advocacy to its full potential. Reviewers frequently heard that non instructed advocacy is about protecting rights and using the legal framework, but less about advocates using this approach to find out what is important to a person.

*“As an IMHA I use [NIA] all the time. I supported an older man with autism. He will not instruct me. The hospital wanted him to have independent support. I use law and legislation in that case”. Advocate*

This is an example of missed opportunity: the person may have an advocate in their life, and the advocate might be doing some good work in protecting their rights, but if non-instructed advocacy was used to its full potential, its likely advocates could have an even bigger impact as they would now what was important to and for the person and not just what their rights are.

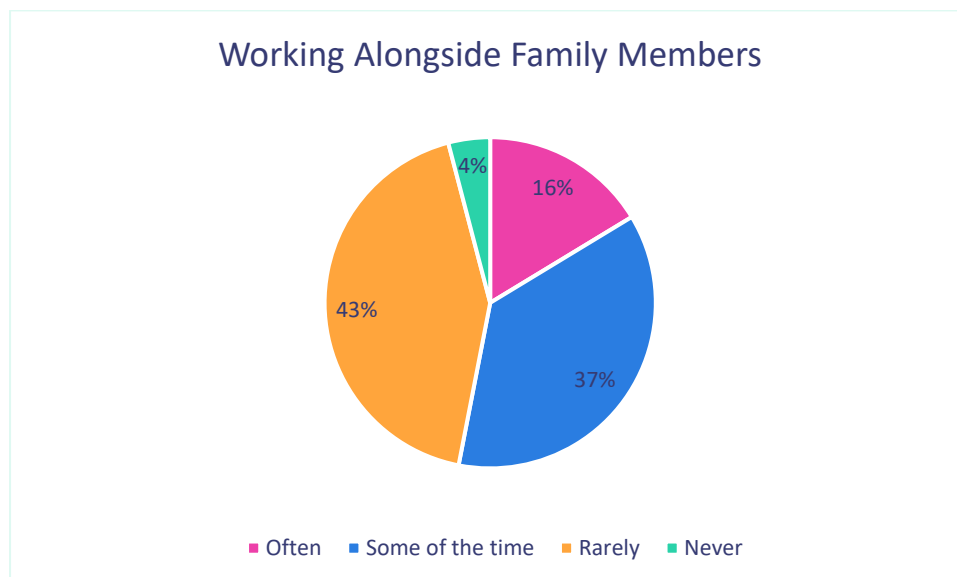
As referenced earlier, non-instructed advocacy guidance for advocates is out of date and the ways that we talk about non-instructed advocacy may also impact on how advocates use it in practice. The reality is that advocacy is often a mix of instructed, semi-instructed and non-instructed, but current guidance describes practice in a much more binary way. Updating guidance could support practice improvements.

### 3.4 Advocates and families

**Advocates are not working alongside family carers, often to the detriment of the advocacy support and the individual.**

**3.4.1 Advocates not working alongside family carers** There was very little evidence of advocates developing a thoughtful approach to working alongside families.

Reviewers heard a mixture of experiences and approaches in working with, and alongside families; however, overwhelmingly reviewers heard a general reticence from advocates to speak, engage with or work alongside families. Over 50% of families involved in the review said they had not met or spoken to the advocate. This was reflected in the survey to advocates. Advocates were asked how often they worked alongside family members and 43% said rarely and 37% said some of the time (see figure below). For the IMHA only group 48% said rarely and 34% said some of the time.



We heard many reasons for this:

For some people who use advocacy, the idea of the advocate working with families just isn't appropriate or safe:

*"Some people I work with have complicated relationships with family members - estranged, complex and difficult. Some don't have family".  
Advocate*

Some felt that some families did not welcome advocacy:

*"Sometimes family members don't want an advocate because they feel like the advocate is usurping them. Or in some way, they feel that the fact that the person needs an advocate means that the parents have been a 'bad' advocate" Professional stakeholder*

Others reported family members not being clear on the advocacy role and this causing difficulties and ill feeling:

*"They also get frustrated that I haven't done everything they want... they might expect me to do a, b, or c but I'm working to the person. For instance,*



*the sister wants her brother to have 24/7 hours care, but he doesn't want that" Advocate*

Some advocates felt that it would be a threat to their independence and person led status:

*"Yes, I often work with families, but only if the person asked me to or gave me permission" Advocate*

*"It's very difficult to speak to the families. You have confidentiality issues that you have to consider. I have one client whose mum is brilliant – she wants to know the ins and outs of his life, but he doesn't want her to know everything. She has brilliant insight into what he is doing and what's going on. But I have to respect his confidentiality" Advocate*

There is also an unspoken unintended consequence of advocacy being person led. Focusing solely on the person's wishes, feelings, and outcomes can result in the advocate seeing the person in the context of their individual lives rather than in the context of family, friends, social network, and their broader community.

Reviewers believe there are times when it would be essential to work alongside families in order to ensure effective advocacy support is accessed by the person, for example when the person is unable to instruct the advocate, or where people's families are involved and the person is happy for the advocate to connect.

Advocacy needs to get better at appreciating the important role of families and how the advocate can contribute to successful family plans – especially for people who lack capacity to instruct their advocate.

It is clearly not always appropriate for the advocate to work alongside the family carer: whenever the person has capacity to instruct the advocate, the decision about if and what the advocate shared with the family would be at the full instruction of the person – i.e., the advocate would only speak to the family when the person told them to or consented to this.

There are times, however, particularly when the person cannot instruct the advocate and the advocate is using non-instructed advocacy, when it is not only appropriate to speak and work closely with family carers, but imperative to.

*"I knew a family whose son was ready for discharge. The plan was for him to go back to his home area and live close to his family. His parents are going to be heavily involved in his day to day care. His relationship with his mum, dad and brother are quite possibly the most important relationships in his life. He is non-verbal and has really complex communication. I assumed that his advocate would be speaking to mum and dad every week – but they never did. It was like they avoided them. In meetings the advocate would turn up – but never speak to mum and dad. I never understood this. What a missed opportunity" Professional stakeholder*

If advocates are to respond to the whole person and think long-term about what the person needs to live a happy, independent life, outside of the hospital setting, then it is incumbent on the advocate to speak to the family member, unless there are compelling reasons not to.

Fortunately, we did hear about occasions where the advocate is confident in bridging this gap and able to work closely with the family:

*“The independent advocate, not connected to the hospital, worked for a voluntary organisation. She stood with me [family member] at every appointment, the endless meetings, CPA, CETR's, tribunals. Ensured we knew our rights via the law centre we had training on the care act and regarding direct payments, supported me to research providers and introduced us to our amazing local small not for profit provider who was instrumental in the safe discharge and successful ongoing support we now have at home and in our local community.” Family carer*

*“She [the advocate] supported me to support my daughter” Family carer*

People with a learning disability and autistic people deserve more of this joined up work.

### 3.4.2 Advocates are not respecting or valuing family carers

Whilst the independent advocate has to be clear that they work for the person with a learning disability or autistic person, we heard concerns from family carers that they are not involved when they should be – and their views when they are offered, are not respected, or valued by the advocate.

Family carers shared experiences where they felt the advocate:

- would be ‘nodding and smiling’ but not appearing to act on what the carer said, or factoring what the carer said into decision-making
- did not seem to respect the carer
- did not trust that the carer was authentically relaying the person’s wishes
- was suspicious of the carer and family members (linked to a wider culture of parent-blaming and suspicion).

Family carers generally felt that advocates were not on the side of their relative, and instead a “voice for the system”<sup>48</sup>. Several carers believed that advocates often had an agenda that they were reluctant to deviate from and were more likely to seek the opinions of professionals than family carer advocates.

*“An IMHA was reported to have ignored evidence that a family’s relative could live safely and happily within the community, and out of hospital. The person had visited home safely over 400 times, but the IMHA didn’t say this.” Family carer*

Reviewers observed, on a number of occasions, that advocates were likely to seek out and accept the opinion of professionals but be less likely to welcome or seek input from families.

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<sup>48</sup> Challenging Behaviour Foundation survey

*“Advocates won’t think twice about speaking to professionals about what is important to a person, or what’s going on in their life, or how they communicate. They don’t seem as willing to do this with family members. I don’t know why. Families know their loved one a lot more – yet advocates aren’t asking them” Professional stakeholder*

*“[Advocates] work on certain agendas. If they think what you are raising is irrelevant, they don’t listen to you.” Family carer*

These experiences leave family carers feeling as though they cannot speak to the advocate on alternative issues.



# Accessing advocacy

## Key Messages

This section presents key findings which capture the experience of people who access advocacy. Reviewers found evidence of broad misunderstandings of advocacy across all groups, largely caused by a systemic lack of clarity in the advocacy role and its boundaries.

Information is frequently not given and when it is provided to people and family carers, it is often confusing and sometimes inaccurate.

Accessing an advocate is too difficult for too many people: multiple providers, unclear arrangements, underfunding and poor access to people are some factors contributing to a system where when you do get an advocate, the support is often episodic, issue-based, short-term and not joined up. What is needed is long-term, relational, holistic advocacy based on the person's needs, not legal status.

The subheadings are:

- 4.1 Advocacy is Misunderstood
- 4.2 Accessing Advocacy
- 4.3 Long(er) Term, holistic , effective advocacy
- 4.4 Family Members need access to advocacy themselves

## 4.1 Advocacy is misunderstood

Independent Advocacy and the legislation, frameworks, and process around it are complex and difficult to navigate and it is important that this context is understood when reviewing the findings.

Throughout the review, participants shared concerns that people at all levels of the system, from those working in senior roles in statutory services, to front line staff, families, and people who draw on advocacy services, misunderstood what advocacy is, including the role that advocates play, what advocates can and cannot do etc. There was evidence of a systemic lack of clarity in the advocacy role and its boundaries.

The names of different types of advocacy and the sheer number of these was also found to be extremely confusing; terms such as formal, natural, peer, family, IMHA, IMCA, non-instructed, voluntary, or statutory often accompany the word 'advocacy' and for many, are causing more confusion than clarity.

This lack of clarity makes it difficult to really understanding what the different kinds of advocacy are, or when a person has a right to a certain type of advocacy and is leading to many self-advocates, people who draw on advocacy, family members, carers, professionals, and policy makers being understandably confused.

Family members described that if they had known that advocacy had existed that it would have been a useful service and support to draw upon. Families also didn't always recognise the advocacy role they play for their relative.

Finally, family members often didn't recognise the advocacy role they were undertaking naturally with their family members.

The confusion and misunderstandings at times, indicate misinterpretations or differing interpretations of the law and codes of practice, meaning that sometimes people are not able to access advocacy they are entitled to. Different advocacy providers and commissioners interpret the legislation differently and so advocacy will vary in its delivery across the country.

#### **4.1.1 The term 'Speaking up' is preferred by many to the word 'advocacy'.**

People with a learning disability and/or autistic people often described finding the words 'advocate' and 'advocacy' problematic. Some review participants explained that it is a strange word that overcomplicates something that is actually quite simple.

*"For people who are non-disabled, if they don't like something say in a restaurant, they complain, they don't 'self-advocate'. So why do we use words like 'advocacy' and 'self-advocacy'" Self-advocate*

*"Professionals and non-disabled people have 'professionalised' self-advocacy and it's really just 'speaking up'. It's the same as 'person centred planning' – it's a label, what it really means is what I want to do in my life" Self-advocate*

People understand what 'speaking up' is and see this as a very natural activity that most people are able to do much of the time. People also felt that often, the problem isn't that people cannot speak up, it's that people are not listened to or understood and that's why another person, who is recognised as an advocate is needed.

Self-Advocates suggestion is that phrases like 'speaking up' should be used more often in place of the term advocacy or when describing the advocacy role.

The reviewers also heard concern about the term 'speaking up', particularly from family members whose relatives do not use spoken or written words to communicate their views, wishes and preferences.

These differing views all indicate that 'advocacy', both the word and the concept, can be hard to describe and to understand. This can present a significant barrier to participation, and it is important that advocates are able to explain the concept in ways the person can understand.

## 4.1.2 Family carers are not supported to understand advocacy

As well as placing a clear duty to inform patients about their right to an IMHA, the Mental Health Act also places a duty onto hospital managers, the local authority and the person's responsible clinician to inform the family member about their loved ones' rights to an IMHA:

*"The relevant person must also take whatever steps are practicable to give a copy of the written information [about IMHA services] to the patients' nearest relative, unless the patient requests otherwise" 6.18 MHA Code of Practice*

Given that IMHAs 'must also comply with any reasonable request to visit and interview a qualifying patient, if the request is made by the patient's nearest relative',<sup>49</sup> this information should include details about who the advocacy provider is, the advocacy role and how to make a referral.

Reviewers frequently heard that this is not happening:

- 1 in 4 family members had received information from the hospital about advocacy.
- 1 in 4 family members said they did not know about statutory advocacy nor their loved one's entitlement to an IMHA.
- Only half knew about different types of advocacy.
- Just 1 in 8 family members knew that advocates might use non instructed advocacy.<sup>50</sup>

*"I never knew there was such a thing, we have been left floundering." Family member*

*"I didn't know about Advocacy, so haven't used the service." Family member*

This appears to be even worse for parents of young autistic people and young people with a learning disability. In the parent carer survey<sup>51</sup>, 70% of people did not access statutory advocacy for their child or young person during their child or young person's admission.

*"Never heard of advocacy before nor been offered it". Parent of 14yr old*

As previously motioned, reviewers learnt that commissioning arrangements for children and young people's IMHA provision was not always clear and it may be that a lack of provision has impacted on access to advocacy and families knowing that it is a support that is available to their relative.

People with a learning disability and autistic people who are in hospital settings, often rely on family carers to secure appropriate support and services. If family members are not informed and supported to understand what advocacy is, what advocacy is available locally,

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<sup>49</sup> see 6.22 of the Mental Health Act Code of Practice

<sup>50</sup> Statistics taken from survey completed by Challenging Behaviour Foundation as part of this review. 35 family members participated

<sup>51</sup> Survey conducted by Bringing Us Together, 47 families members responded

and what the advocate can do for their relative, this is not only a significant missed opportunity to get an advocate but also results in a limited awareness of what advocacy their relative is entitled to, how this advocacy is designed to benefit their relative and the role advocates are supposed to fulfil.

### 4.1.3 Professionals do not always understand advocacy

Professionals working within mental health hospitals frequently misunderstand the advocacy role and do not always realise when a person must be offered advocacy. This leads to misinformation being supplied to family members, as well as people with a learning disability and autistic people. This appears to also be linked with poor understanding of the Mental Capacity Act and how to support a person who lacks capacity.

*“The hospital said that because my relative had capacity, they can’t have an advocate.” Family carer*

*“A CPA co-ordinator said I can’t work there as the lads don’t have capacity. I explained non instructed advocacy and the watching brief”. Advocate*

*“The hospital stated that an advocate was not needed as there was no conflict of interest between the hospital’s care/treatment decisions and the patient’s needs” Family carer.*

### 4.1.4 Advocacy providers do not always understand advocacy

Concerningly, we also heard about instances where advocacy providers also seemed to provide incorrect information about advocacy that people were entitled to:

*“We discovered that over three quarters of the people in the Hospital did not access the statutory IMHA advocacy. We tried to find out the reasons for this and thought that COVID could be an issue because a lot of meetings were held online, and people found that difficult. But we also heard that the advocates only saw the people who asked to see them.*

*We asked the Advocates about this and were told that because of the law, IMHA advocacy could only be provided to the person and only if they had capacity and asked to speak to them. This confused us so we looked to see if this was in law.” Self-Advocacy Organisation*

This is quite plainly incorrect. As set out previously, people are entitled to IMHA support if they are detained under the Mental Health Act:

*6.8 Patients are eligible for support from an IMHA, irrespective of their age, if they are:*

- *detained under the Act*
- *liable to be detained under the Act, even if not actually detained, including those who are currently on leave of absence from hospital or absent without leave, or those for whom an application or court order for admission has been completed (but not those listed in paragraph 6.9 below)*

- *conditionally discharged restricted patients*
- *subject to guardianship, or*
- *patients subject to community treatment orders (CTOs).*<sup>52</sup>

One family member shared their experience where the IMHA explained they would only provide advocacy if the person directly approached them to ask for support on their weekly visit to the unit. The advocate explained staff would bring over anyone who had asked to see the IMHA on the weekly visit. Outside of that, the person would have to phone for support.

The family member tried to explain to the advocate that their relative had a learning disability and was not able to understand the advocacy role and likely wouldn't remember to ask. The provider told them they had misunderstood the IMHA role and that IMHA's only support with specific issues under the Mental Health Act and once the issues are resolved, the IMHA will end their work. They were told that the IMHA does not routinely check on the welfare of someone unless it is about a specific issue that the person had asked for help with.

This example illustrates where the advocacy service didn't respond to the request of the nearest relative, did not make appropriate reasonable adjustments to service delivery, has a very narrow and potentially incorrect interpretation of the IMHA role and a lack of understanding of how and when to deliver non-instructed advocacy.

## 4.2 Accessing advocacy

**Accessing an Independent Advocate is far too difficult for far too many people. This is caused by a lack of information, lack of awareness, and unclear arrangements caused by multiple advocacy providers being commissioned.**

There is no reliable data currently maintained at a national level on how many people with a learning disability or autistic people receive advocacy support, for how long and what for. Best estimates suggest that half of the over 2000 people with a learning disability or autistic people currently detained in hospital have support from an Independent Mental Health Advocate.<sup>53</sup> Assuring Transformation data for June 2022 indicates that 75% of the 2005 people in hospital had an IMHA.

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<sup>52</sup> Mental Health Act Code of Practice

<sup>53</sup> Figure taken from <https://www.local.gov.uk/parliament/briefings-and-responses/reforming-mental-health-act-white-paper-2021#advocacy> accessed 17.03.22



The Assuring Transformation data set<sup>54</sup> does ask about access to advocacy, but the questions asked, indicate a potential misunderstanding of the different types of advocacy provided and what advocacy a person might be able to access. Also, the Assuring Transformation data does not collect information on frequency or duration of advocacy, quality, number, or types of issues raised. We could also assume that the complex picture of commissioning arrangements must impact on the collection of some information. Consequently, the data would appear not to support an accurate picture of access to advocacy.

Advocacy is a type of support that people may draw on at specific times in their lives, or they may use for longer periods. Some people will not choose to use an independent advocate as they are able to and want to self-advocate. Others will prefer to be supported by family members and friends to act as their advocate. Not everyone who is entitled to independent advocacy will access advocacy.

However, many will, and we heard concerns that people with a learning disability and autistic people who are in a mental health hospital are missing out on their legal entitlement to be supported by an independent advocate. This could be because:

- they are not informed of advocacy,
- haven't received inaccurate information about what an advocate can do
- not be able to ask for advocacy themselves and not referred by staff
- or there may not be an advocate available when the person

However, there are additional barriers that people with a learning disability and autistic people face that are well known. For people who do not use words to communicate, requesting and working with an advocate is not straightforward. It may not be possible to understand the advocacy role, understand written information, access a phone, email, or have direct contact with an advocate to self-refer.

Advocates must make all reasonable adjustments to support people to understand and access advocacy.

In addition to these factors, the reviewers learnt about the following systemic issues that are increasing this inequity of access.

#### 4.2.1 Lack of information

The reviewers found evidence of a general lack of appropriate, quality information that helped inform people and their families about advocacy.

*“On the unit I was on, advocacy was not something that was talked about. Just some posters dotted about. We weren't informed about it properly, just some random posters.” Young person*

A lack of quality information was not just an issues within hospital settings but also online:

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<sup>54</sup> <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/assuring-transformation/reports-from-assuring-transformation-collection>

*“When we visited the council website as parent carers looking for advocacy, we found the Local Offer... [this] should have all the information for parent carers in their area. But when we then searched the Local Offer for advocacy, there was no mention of [the advocacy provider]. We also searched the main website... but it still did not come up. We then did a search for parent carer support in [the geographical area] but nothing” Family Carer*

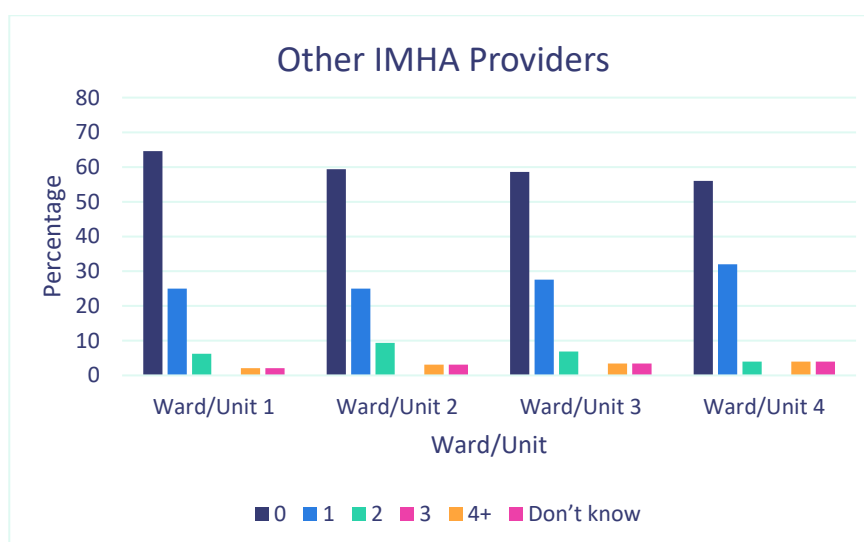
This is simply not good enough. People with a learning disability and autistic people, like many people who are experiencing mental ill-health, have specific needs to have information provided in a timely and appropriate way – using forms of communication that are known and recognisable.

*“For someone who doesn’t use words, who is incredibly distressed at being in hospital, is surrounded by people they don’t know. Well, the idea that you can shove a leaflet at them or just ask ‘do you want an advocate’ is ridiculous. This isn’t giving them information” Professional stakeholder*

Unless information about the advocacy role and people’s rights to advocacy is given in ways that are appropriate and meaningful to that individual person, and repeatedly given at different points as the person remains in hospital, they will be denied a critical opportunity to understand and therefore access advocacy.

#### 4.2.2 Having multiple advocacy providers introduces confusion and difficulty in getting an advocate

Reviewers learnt that approximately 40% of mental health hospitals have more than one advocacy provider, sometimes as many as four at any given time. The chart below shows survey responses from advocates about how many other IMHA providers were present in up to 4 wards that the advocate worked on.



Focus group and individual discussions with advocates suggested that this was higher within independent hospital settings, although it is also prevalent in NHS hospitals, especially in particular parts of the country.

These arrangements essentially mean that staff and people on the ward might work alongside and refer to advocates from one service or with advocates from multiple services,

depending on the borough of origin of the person and or the different types of advocacy provided by different providers.

*“It was confusing for people. There were some who had three advocates: all from different services” Advocate*

*“There were also advocates who just appeared – I think some families independently commissioned advocacy. I never got to the bottom of this – but it was very confusing”. Advocacy manager*

*“In one hospital I think there may have been four advocacy providers. The IMHA [that I had commissioned] were then told [by the hospital commissioned service] back off you can’t work as the advocate. These people need really quality advocacy - they didn’t need a bidding war from four different providers” Commissioner*

Where there are multiple providers, the opportunity for confusion to arise is persistent and at times seemingly arbitrary:

*“In one hospital they [the independent hospital provider] commissioned the IMHA. The local authority boundary ran through the hospital. On one side the local authority commissioner said that the local authority commissioned IMHA and they had to see each person who was eligible. But the local authority on the other side weren’t bothered at all. It made it impossible to know who should see who” Advocate*

*“I’ve been on wards where there are three different advocates depending on which geographical location you were from. There were three posters – none of them easy read – explaining advocacy. When an advocate comes on the ward, the first question they ask the person is ‘where do you live? Oh no I can’t support you’. That’s awful advocacy.” Professional stakeholder*

Multiple providers also affect a person’s ability to use advocacy that is triggered for different decisions: a person in hospital will nearly always be entitled to IMHA – but they may also receive IMCA support if they lack capacity to make certain decisions. Similarly, at the point someone is being discharged from hospital and there are decisions about s117 aftercare are being made, the person may receive advocacy under the Care Act.

*“It’s so confusing when you go into a setting and there are different providers. I work with someone, and they might have an IMCA from a different service. It’s very confusing”. Advocate*

*“People just need one advocate; it doesn't matter what hat they have on. Just one advocate who will stay with them for how long is necessary. IMCA? IMHA? Who cares?” Professional stakeholder*

Only 13% of advocates from the survey said it was clear which advocacy service would respond in a given situation. This lack of clarity was also experienced by hospital staff who didn’t always know who to refer to and when:

*“It meant that staff were very confused about who to go to”. Advocate*

*“As an organisation we hear that if the person has an IMCA they don’t need an IMHA. That comes from [hospital] staff” Advocate*

Where multiple providers exist, this inevitably included both statutory and non-statutory provision. Reviewers heard many examples of this introducing an extra layer of complexity with IMHAs being confused as to how much they should engage in independent hospitals as the hospital had commissioned an advocacy service<sup>55</sup>. Although there was broad understanding with the correct assertion that the local authority commissioned advocacy service should be offering IMHA support, the IMHAs felt they were not always encouraged to go into independent hospital settings.

*“One local authority commissioner said that about once a month we should remind the private hospital that we’re there, but don’t go in unless they ask. I don’t think the commissioner wants us in there. Their viewpoint is very much leave it to the private hospital commissioned service” Advocate*

Commissioners were not clear about what was available locally and shared frustrations of not being involved in commissioning arrangements undertaken by others:

*“I was surprised to find there was another advocacy provider operating in my area which was supporting in a level 4 CAMHS unit. The CAMHS unit was arranged on a regional basis by the NHS. It wasn't connected to the local provision it seemed there was no accountability” Commissioner*

It was noticeable that we did not hear one example where having multiple providers was an effective way to make advocacy available to people. Instead, advocates, professionals, local authority and hospital commissioners and people who draw on advocacy, all agreed: having multiple providers introduces confusion and undermines people’s ability to get an advocate.

Reviewers established that the reasons for having multiple providers in one setting were:

- Not following the commissioning expectations set out in the Mental Health Act Code of Practice
- Hospitals commissioning their own advocacy to improve availability or because they had been requested to by CQC
- The NHSE service specifications for low, medium, and high secure mental health services contain ambiguous references to arranging advocacy. We heard from two hospital directors that their contracts from NHSE required them to commission independent advocacy.

### 4.2.3 Opt out

‘Opt out’ is a specific model designed to increase the availability and accessibility of IMHAs. It requires the hospital to automatically refer the person to the advocacy service unless the person ‘opts out’. If the person lacks the capacity to make this decision, the

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<sup>55</sup> Please see previous sections re hospitals commissioning their own advocacy

Mental Capacity Act must be followed, and a decision made to ascertain whether making a referral to the IMHA service is in the person's best interests. It would likely be a fairly rare occurrence for it not to be in someone's best interest to have independent representation whilst subject to the restrictions of being in hospital and the Mental Health Act .

Opt out was first discussed in the 2012 research report 'A Right to Be Heard'<sup>56</sup> which recommended that "consideration should be given to establishing an opt-out rather than an opt-in system to promote access to IMHA services". This was in response to inequity of access experienced by different groups of people – including people with a learning disability.

More recently, [The Draft Mental Health Bill 2022](#) has been published and this legislates for 'opt-out' advocacy, so people automatically get support from an advocate when they are admitted to hospital, although this is limited to people who are detained under the Act.

Reviewers asked advocacy providers if they currently operated an opt-out system: data collected from the surveys<sup>57</sup> suggest between 20% and 35% of hospitals use an opt out model. The providers who did operate opt out rated the system highly and positively:

*"On most of the hospitals we have an opt out system – which monitors people. We use this to find out if the person lacks capacity in which case we will always go out and see them. It's very easy to say do you want an advocate, but sometimes it very hard to find out do they understand the advocacy." Advocacy manager*

*"Advocacy must be an opt out service. People need professionals to actively support them to access advocacy. Advocates then go in and explain their role... Once we have a foot in the door, we can kick it wider". Advocate*

Other providers who did not use opt-out referral systems expressed a strong preference to operate such a system as they felt this would improve accessibility.

*"There is a degree of relying on ward staff to refer suitable patients as we don't have the resource to offer opt-out" Advocacy provider*

*"We are totally reliant on continually promoting patients' rights for referral to mental health staff. Our presence on wards all the time is the only way we get referrals, this has been a challenge during Covid. The current referral model does not work as it is not compulsory and again reliant on staff to make referrals." Advocate*

*"Mandatory opt out would make a difference" Advocate*

Although there is a lack of research and national data into how much opt-out increases the accessibility of advocacy, the experience of people and advocacy providers using opt-out points to this being a sensible and easily implementable approach to making advocacy accessible.

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<sup>56</sup> The Right to Be Heard Review of the Quality of Independent Mental Health Advocate (IMHA) Services in England Uclan 2012

<sup>57</sup> Commissioner, advocacy provider and advocates

#### 4.2.4 Responding when the person says ‘no thanks’ to advocacy (& non-instructed advocacy)

One of the founding and most important principles underpinning advocacy is that advocates are person-led and would never take action that conflicts with what a person instructs and would want to happen (with the notable exclusion of responding to safeguarding concerns). In practice this means respecting a person’s choice, whatever that choice is, including whether they would like to use advocacy or not, where people have capacity to make that decision.

The reviewers heard uncertainty about how advocates respond to a person who declines advocacy when this decision may be a result of unknown communication styles, or a lack of capacity in understanding what advocacy is.

*“When a person says no. We have a lot of people who decline us, we have a lot of people who say no, who don’t understand what we do. I have to look at it and ask would this person really like us to get involved, would me being involved really distress them, would it really upset them. I might then be looking at if there are big decisions about to be made and how can I contribute to that without upsetting the person” Advocate*

*“We also take no really easily. If they say no that’s fine case closed. But if we are doing it properly, we would be going back, being around, have a presence and pick up the referrals. And with this group this is critical because the trust isn’t there and we need trust to begin the advocacy. We just take the no and move on.” Advocate*

The reviewers heard from family members who were concerned that their loved one found it difficult in accepting a ‘new’ person into their life and would say ‘no’ to the offer of an advocate. This was not based on any meaningful choice, but simply reflected that they did not want someone ‘new’. Family members were concerned that advocates, who did not understand this, would too readily accept the person’s rejection and leave.

*“My son won’t take to anyone new. It takes ages before he’ll accept you. When the advocate came and introduced himself, the advocate asked if he would like an advocate and [my son] said no, like he says to anyone he doesn’t know. I couldn’t believe it when the advocate just left. He didn’t speak to me about his communication or ask if he might need an advocate. He just left”. Family member*

The reviewers saw a range of skills and approaches from advocates. Some advocates appeared to follow the description above and demonstrated a very simplistic understanding, accepting communication at face value and not making any reasonable adjustments:

*“If we have a referral and we go and see the person and they make it clear they don’t want to see us, then we need to respect that. It makes it very difficult to keep seeing them when they have said they don’t want us” Advocate.*

*“If someone says no, they don’t want to see me, I really need to respect that choice. You cannot force advocacy onto someone” Advocate*

Other advocates, however, appreciated that saying yes or no is not always straight forward and that investing in relationships and getting to know a person is important when making the advocacy offer.

*“You have to be very sympathetic and sensitive when working with an autistic person. Change and new people can be very scary and uncomfortable, so you have to be mindful of that.” Advocate*

*“You have to persevere. You don’t force yourself, but you persevere. For instance, one young autistic boy calmly takes me to the door. But I keep going back and it’s taking longer and longer each time between when I arrive and when he shows me the door.” Advocate*

*“I find just talking about the person’s hobby [special interests] really helps to get rapport – sometimes I don’t talk about the advocacy, just try and get to the person. It took 6 months to get to know this person. We stayed involved because of the level of violence and segregation. He was selective in who he would talk to. He wouldn’t speak to the advocate. We worked with the staff to try and understand this and Speech and language therapy. We just keep visiting and persevering. Another guy was clear he didn’t want an advocate and told us why he didn’t want an advocate. Nothing in his care or situation meant that we were really worried. So, it made sense to accept this and move on. But the first guy, because things were not going ‘right’ (i.e., on seclusion and the level of violence) we wanted to hang around more” Advocate*

*“Being in a communal area really helps because people get to see you and get used to you.” Advocate*

Advocates were often unclear about when they should be providing non-instructed advocacy and weren’t alert to the need to be mindful of an individual’s capacity to make the decision about whether or not to access advocacy. There needs to be an increase in advocates' skills and understanding of knowing how to communicate and interpret communication if they are to be effective in truly making advocacy accessible.

## 4.3 Long(er) term, holistic , effective advocacy

**People need holistic advocacy; however, they are being offered short term, issue-based advocacy.**

The current experiences of people who draw on advocacy tends to be having an advocate or different advocates for short periods of time, typically at certain points in their journey through their stay in hospital.

The reviewers heard little evidence that advocates are enabled to develop longer-term relationships. Self and peer advocates were more likely to have a remit of responding to a broader range of support issues, but statutory advocates were less likely to stay with the person for long periods and had limits on what 'issues' they could respond to. Reviewers also heard that advocates were limited in the time they had available to support people. This doesn't allow time to get to know the person and understand how they communicate their preferences or to address other inter-related issues.

25% of advocates who responded to the survey said they were referral based: i.e., they would support for one 'issue' only, and then close their work. When we followed this up in focus groups, 'issues' were mostly described as being one 'thing', e.g., one meeting, one ward round, raising one concern about leave. This points to process led rather than person led advocacy being provided.

Half of the advocacy providers described their delivery as 'one issue per referral'. This creates a 'stop start' type of relationship with an advocate (sometimes) being involved in key decisions, but rarely continuing with the relationship outside of this.

The reviewers research search indicates that most people want and need access to longer term, holistic and person led advocacy which this current approach is not supporting.

### 4.3.1 One person: one advocate: for as long as it takes

The reviewers heard that people want to draw support from the same advocate for as long as they need. People expressed frustration at receiving support from different advocates.

*"Stop changing advocates! If you get to know one advocate, then he goes"*  
*Self-advocate*

Part of the problem of being offered different advocates is that people have to start from the beginning in their relationships. This has a particularly adverse effect on people with a learning disability and autistic people, many of whom may find it difficult to accept and work alongside new people. It may take weeks and months for an advocate to finally be accepted by a person, and for the advocate to start to really get to know them and be trusted enough to effectively advocate.



*“It’s not good having an advocate disappear, then another new one comes in. They will have to repeat things again and again with new advocates about what kind of support they might need. This could make them feel upset and angry. You’ve made a relationship with one advocate, then a new one comes in and he’s probably thinking how long he will last before I’ve got to start again.” Self-advocate*

*“When the person moves, the advocate should go with them. As part of that change, they have to build another relationship with another advocate. It would be useful to have the same advocate to stay with the person as they move”. Professional stakeholder*

Families told reviewers there was no sense of consistency in the advocacy system. IMHAs were found to change frequently, so it was thought unlikely that they would come to understand the person and their wishes, since this requires spending time. Family carers also attributed advocates’ failure to follow up on case developments with parents, or feedback from meetings regarding the relative, to this inconsistency.

In addition to obvious causes such as advocates leaving their role and staff movement, we also heard that people may be offered different advocates for the following reasons:

- The person moves ward – and the advocate doesn’t ‘work’ on the new ward
- The person moves hospital – and the advocate (or advocacy service) doesn’t deliver support in the new area
- The person is eligible for different types of advocacy – which their advocate doesn’t offer
- There is a number of advocacy providers – all offering advocacy
- The person wants advocacy support on an issue which is outside of the commissioned role of their advocate

These ‘problems’ are created by the framework of advocacy commissioning and delivery. If these are addressed, people could reasonably expect to be supported for the duration of their stay in hospital by one advocate.

Reviewers also learnt about the need to provide advocacy support **before** the person is admitted and when the person leaves hospital. Whilst this review exclusively explores inpatient advocacy, advocates can contribute to reducing the risk of admission into mental health hospitals by giving the person dedicated support to work out what they want, how they could be supported, as well as protecting their rights. This was particularly crucial for young people and worked well.

*“The last 2-3 years has seen an increase in young people presenting with mental health needs, self-harming or developing eating disorders. There can be a lack of crisis intervention, which means that things can escalate quickly and result in young people being placed in specialist provision. We now aim to further develop our self-advocacy groups by forming links with local colleges, specialist schools and mainstream schools”. Self-advocacy provider*

Self-advocacy groups further identified that having strong connections between different types of advocacy was important for ensuring that people are supported in the community once they leave hospital.

*“It was felt that advocacy within inpatient settings was important for making connections between people and self-advocacy groups for when they leave hospital.” Self-advocate*

*“Advocacy is really important. It’s not as good as it has been in the past with the consistency of some advocates. This advocate is leaving - he’s very good - really engaging” Self-advocate*

If advocates are to be successful at establishing rapport and building relationships, they need to be enabled to remain with the person for as long as it takes to do so.

### 4.3.2 Advocates must listen to people

People with a learning disability and autistic people told reviewers that advocacy is vitally important in enabling them to have a voice and be heard.

Worryingly they also shared examples where they felt their advocate hadn’t listened to them. People with a learning disability and autistic people told us:

*“Advocates not coming to my meetings stops me from having a voice” Self-Advocate*

*“If I do speak to my advocate about a problem I am having, things don’t seem to change”*

*“Sometimes it feels like my voice just isn’t heard and I get pushed back down again”*

*“Well why would I want an advocate, they don’t do anything?”*

Even though the person has a right to an advocate and even if they have one, people felt it might not make a difference to their voice being heard. If advocacy isn’t getting people’s voice heard, then advocacy isn’t working as it should be. The impact could be that then people might ‘give up’ and not engage in any advocacy support in the future because they don’t think it helps them to get their voice heard.

A mental health professional we spoke with shared this view:

*“It’s hit and miss with engagement with the advocates. People with a learning disability all have different levels of skills and abilities and communication styles. The advocate needs to know who to engage and interact. If they don’t it impacts on how people want to interact with the advocate. If they’re not getting it right, then people don’t want to engage. It’s really important advocates take the time to build relationships and really listen to people.”*

### 4.3.3 Process led, issue-based advocacy

The reviewers witnessed a worrying trend that saw advocacy as a menu of options of support to be delivered; a view that advocacy is there to raise or fix single issues and then the advocate 'closes the case'.

*"We do not provide ongoing advocacy – its issue based and then we close the case. People can re-refer but have to wait on a short waiting list again"*  
Advocacy manager

This move towards short-term, issue-based advocacy, has evolved over time but many people point to the introduction of statutory entitlement to advocacy as the moment where advocacy became 'professionalised' and shifted from being a movement (where citizens came together) to a service (where one 'helper' responds to a 'client').

The reviewers heard about restrictions on what types of 'issues' the advocate could help with: over 1/3 of IMHAs (37%) who responded to the survey were not able to help with some issues and a lack of time to focus on developing relationships meant they had even less time and flexibility to get involved in long-term life decisions.

*"Most of our advocacy is short term, rights based - like telling people what their rights are and Tribunals. We don't really get involved in the broader care and treatment plans or longer decisions"* Advocate

Advocates also reflected on how advocacy has become fixated on single issues at the expense of building relationships and improving services.

*"The whole sector has become so far removed from peer advocacy it feels like I'm working for McDonalds, we are just providing a service. We don't get any feedback from our partners, no focus groups with people about what they want, it's all commissioner led. Surely the people we are working with should be the focus."* Advocate

*"The mental health advocate slips in and out, it is not helpful."* Family carer

This pressure appears to come from a variety of sources including inadequate resources, commissioning approaches, and management of services:

*"I remember one local authority who were not happy with the number of issues that we had worked on, so they brought in an 'expert' who then went through case by case, line by line, and said 'this isn't IMHA' 'this isn't eligible'. This included group work. They wanted it [the advocacy] to focus on CPA, ward round, medication, and that's it. We couldn't do anything outside of this".* Advocacy manager

*"[Because] funds are not specified or ring fenced, some people who need a long time to establish relationships, recognise body language as communication and create a meaningful way forward, are offered just 2 hours contact"* Professional stakeholder.

*"There is just not enough funding to be able to employ enough advocates to support people long term while in the setting".* Advocate

Independent advocates need to have the flexibility and freedom to be able to offer personalised support which is not limited to mental health care and treatment but extends to broader issues such as day-to-day life, where they live, friendships, employment, contribution, and involvement in society.

Where independent advocacy is purely issue-based, and time limited, it is perceived as being process-driven rather than led according to individual need and does not address the person's long-term wellbeing. This must change.

#### 4.3.4 Interplay between different types of advocacy

A theme throughout the review is that offering different types of advocacy, from different advocates or services, is often not helpful. When a person is entitled to receive multiple types of advocacy (IMHA for inpatient issues: Care Act Advocacy for s117 aftercare decision: IMCA for decisions under the Mental Capacity Act), all stakeholders agreed that it is usually nonsensical for 3 advocates to all offer support to 1 individual.

*"I don't think there should be a distinction between the different [advocacy] roles. The person doesn't care what type of advocate of you are. But I've seen advocates say 'no, that's IMHA and they come every third Tuesday every month'. They trip over the mechanics of it – which isn't in the spirit of the law which is about protecting people's rights" Professional stakeholder*

What people need is ongoing support from a knowledgeable and skilled advocate – someone who knows the law, knows the person well, knows what is important to them and understands what needs to happen to support their future plans.

*"Knowledge of the law and rights for advocates is a problem. The advocates in the hospital might be mental health advocates and not know much about the Care Act. To get a successful discharge, this is really important!" Self-advocate*

It is well documented<sup>58</sup> that people with a learning disability and autistic people face serious delays in discharge to suitable homes, with suitable support in the community. This results in people having to be detained in restrictive settings, sometimes for years despite having no need for care and treatment in hospital. Advocates could have a very real impact on this and should be offering much more support in getting people out of hospital. We heard examples of people being in hospital or even seclusion for long periods of time and advocates not seeing a role in supporting the person to achieve change.

Part of the problem could be that the focus on the IMHA tends to be treatment issues 'in' hospital whereas access to Care Act Advocates, who could have an impact on care and planning for community living, tends to be triggered once discharge planning is commencing or even not until the person leaves hospital. This creates a gap in who can and should

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<sup>58</sup> <https://www.gov.uk/government/publications/building-the-right-support-for-people-with-a-learning-disability-and-autistic-people>, <https://www.cqc.org.uk/publications/themed-work/rssreview>, <https://www.gov.uk/government/publications/independent-care-education-and-treatment-reviews>

support discharge planning whilst the person is in hospital. If discharge planning is being undertaken jointly, with the local authority then Care Act Advocacy can be available to people for discharge planning if they are eligible. We didn't hear many examples of Care Act advocates supporting discharge planning and it will be important that this right to advocacy is maximised as far as possible.

*“People often have a right to access advocacy under the Care Act however this is often disjointed from the mental health advocacy they receive”. Peer advocate*

#### **4.3.5 Commissioning specialist or add on advocacy support**

Throughout the review, we learnt about services that had been commissioned in addition to statutory advocacy. These services differed from community advocacy support or non-statutory advocacy insofar as they were specifically designed to support people who were already entitled to an IMHA.

Advocacy providers and commissioners we spoke with, who were delivering or commissioning services like these were seeking to ensure that there was an adequate level of service available to people as the local IMHA service didn't have capacity to respond and support people as needed.

Phrases like 'legally literate advocates', 'advocacy plus', 'specialist advocates' 'enhanced IMHA' are used to describe some of these services. There is a growing concern that framing advocacy in this way is unhelpful as it can actually undermine the statutory role. By describing one advocate as 'legally literate' or 'specialist' it implies that the others are not.

There are also concerns that this approach encourages limits to advocacy: by funding 'specialist' advocates who can do special activities, it perpetuates the myth that there are limits to the IMHA role which do not actually exist. Core activities and skills, such as learning how someone communicates, developing a rapport and working-relationship with someone, making reasonable adjustments to your advocacy delivery to ensure individuals can access it, are suddenly viewed as something 'special' or in addition to standard advocacy.

The drive for this specialist advocacy commissioning appears to have come in response to a lack of resources available for IMHAs to do their job. Advocacy providers, faced with restrictions in what they can get funding for, have looked to supplement core activity with 'new' projects and services – which in reality cannot or should not be meaningfully distinguished from existing IMHA provision.

*“The extra funding allows us to work with families in a much more holistic approach” Advocacy Provider*

Whilst well intentioned, the reviewers believe that is an unhelpful approach that could make it appear as if it's fine for IMHA to be commissioned and delivered to people with a learning disability and autistic people without the capacity for advocates to make the required reasonable adjustments to their delivery.

More improvements would be made if advocates were simply supported and enabled to undertake the full range of actions the advocacy role entails.

## 4.4 Family members need to access advocacy for themselves

**There is no legal duty to provide advocates to family members, but there is massive demand for family carers to receive advocacy in their own right.**

The reviewers found considerable evidence from families that they want and need their own independent advocate to support and help them to navigate the complex system of mental health.

*“We received appalling treatment from [x] CAMHS for six years. An independent advocate would have helped us to understand exactly what we were entitled to and it may have helped the catastrophic breakdown in communications between us as the family and CAMHS.” Family carer*

Parents who did not access advocacy support said that they would have found it helpful: almost all (28 of the 30 respondents) agreed that an independent advocate could have helped them:

*“There should be 2 advocates, one for the young person and one for parents separately’ Family carer*

*“As an autistic parent it’s exhausting, I need an advocate too” Family carer*

*“Strongly believe parents and young people should each have access to separate independent advocacy services. In my role I do sometimes signpost parents or provide info about advocacy but do not act as their advocates.” Advocate*

Most family carers recognised that they act as advocates for their relatives. Relatives recognised the emotional investments they were making and how this could influence them in their advocacy role. They expressed a need for an independent advocate to be there to help them to:

- Understand and navigate the mental health system which is *‘complicated and confusing’*
- Attend meetings – of which they are many: ward rounds, CPAs, MAG, CETR, Best Interest Meetings, Medication Review, Segregation Review, CQC Inspections, Tribunals.
- Understand their rights. The Code of Practice confers a number of important rights to Nearest Relatives and family members but there is a gap in family members being informed of these. An advocate could plug this gap
- Provide information
- Raising concerns and challenges

- Checking the lawfulness of decisions
- Discharge planning
- Understanding the professionals involved – there are a lot!
- With emotional burnout
- Access Peer support

Where family carers received informal advocacy and support, it came mostly from a family friend, or a parent carer support group. Where statutory advocacy was not available, some family carers had instructed voluntary advocates provided by charities. One parent said that when they had an advocate from a charity:

*“People started to listen, and a good residential placement was found”.*

Within the current Deprivation of Liberty Safeguards framework, every person subject to a DoLS authorisation has to have a named person who is there to represent them through decisions. This role is called a ‘Relevant Person’s Representative’. Family members often take on this role. The regulations allow an unpaid representative to have support from an advocate wherever the ‘person’s representative will benefit from the support of an advocate’. The type of advocate is called a 39d IMCA and the supervisory body must arrange a 39d IMCA whenever the person’s representative asks for support from an advocate. Within the DoLS framework, the 39d IMCA can support the person and/or their representative through the process. This involves understanding the DoLS process, attending meetings, raising concerns, requesting a review, or even applying to the Court of Protection.

The reviewers believe that family carers, especially Nearest Relatives, would benefit from access to a version of a mental health ‘39D IMCA’.



# Supporting advocacy and facilitating access

## Key Messages

Advocacy operates within the broader health and social care system and the culture of these systems can either help advocates in their role, or seriously undermine them. The reviewers found that in settings where advocacy was welcomed and supported, the advocates were better able to provide their support and develop relationships. But in others, advocates (including family members) were not taken seriously, or felt excluded, and ignored.

Subheading are:

5.1 Hospital Approach, Culture and Values

5.2 Family members are not taken seriously when advocating for their relative

5.3 Impact of. The wider Menatl Health system

## 5.1 Hospital approach, culture and values

**Hospital behaviour, culture, and values can undermine or strengthen advocacy, dependent upon whether advocacy is genuinely welcomed and seen as an integral part of upholding rights and ensuring patient safety – or whether it is judged with suspicion and mistrust.**

The review heard a variety of experiences from advocacy providers where hospital staff appropriately supported independent advocacy. This included staff being proactive in informing the advocate when someone had been admitted to the ward or needed advocacy, letting advocates know when decisions were being made, sharing relevant information, ensuring the advocate was aware of meeting dates and times, rescheduling meetings so the advocate could support people at them.

Advocates valued this.

*“Developing a relationship with the multi-disciplinary team is [part of effective advocacy] – I get fuller picture of the needs of person” Advocate*

*“Some units are better than others. Some... are very proactive and tell us about safeguarding for instance” Advocacy manager*

Reviewers heard it is possible for advocates to build effective working relationships with staff whilst maintaining independence.



*“I can see that the advocate is accepted and respected by the team on the wards, they see him as a fellow professional, but understand and respect his role and that he’s there to help people speak up and share their views, represent people and to ask questions and sometimes raise challenges. They know they need to involve and include him” Mental Health Professional*

However, there were more instances of hospitals not supporting advocacy. This ranged from simple misunderstandings of advocacy, through to examples where the advocate felt there was contempt from the hospital towards the advocacy service. This played out in hospital staff not sharing information with the advocate or not inviting them to meetings, not allowing enough time within decision-making processes for the advocate to meet the person, understand the issues or effectively advocate.

The reviewers also heard about experiences where advocates were actively blocked from attending meetings or carrying out their role.

*“We have worked really hard with ward staff to try and explain what we do and encourage them to tell us about meetings. What works is getting in, once the staff see us working and see the benefits, they tend to understand it better.” Advocacy manager*

### **5.1.1 Culture where advocacy is not valued or wanted**

Reviewers heard from different stakeholders that the culture of the hospital has a tremendous impact on the efficacy and accessibility of advocacy. Where this culture did not value advocacy, advocates would face hurdles in getting into the wards and in carrying out their support.

*“The culture of the ward can have an impact. In one part of the Trust the advocates were having terrible problems with staff ignoring the advocates, not letting them in, the ward manager was obstructive, querying whether they should be looking at notes, making things difficult”. Professional stakeholder*

*“One manager never replied once to any of my communications, letters and concerns - well the only time she responded was about an invoice.” Advocacy manager*

*“I would describe the [hospital] culture as patriarchal, oppressive, gaslighting. I have seen dismissive attitudes towards advocates – because they are not qualified or ‘professional’”. Professional Stakeholder*

Advocates also described cultures that were dismissive, devaluing of people’s voice and the advocates involvement and responding in ways which obfuscated real issues. This meant issues the advocates raised were ignored, belittled, or resisted.

*“We would look at the systemic issues and we would try and raise these. We would write letters and be honest that we had not been instructed but we were raising this concern as we had become aware. It didn’t make any difference. The [hospital] response was very much this isn’t your role, stick to individual representation. They would then complain about our advocates ‘getting involved in issues they shouldn’t be’, and we would end up spending*

*time responding to their complaint rather than getting answers to the issues we were raising". Advocate*

We also heard examples of inflexibility that resulted in advocates being physically unable to offer advocacy support to people who wanted it, at a time they needed it.

*"If I was supporting two people and they both had meetings on the same day at the same time, I would ask the hospital to rearrange one, but the hospital would not budge and would never move one to allow the advocate to support two people. We had to then make the awful choice of who to support and who to not support" Advocate*

*"We have had refusals [to take in] laptops, pens, even lovely easy read versions but because they have staples in they aren't allowed on the ward. It's just a flat no." Advocate*

Advocates also shared instances where staff 'refused' to share information or allow access to records citing 'GDPR' or 'patient rights to confidentiality'. Whether this was due to poor understanding of what these frameworks allow, or an undermining of advocacy was unclear.

Peer advocates also shared examples where they felt the advocacy they provided wasn't valued adequately:

*"As a peer advocate, I don't get any travel expenses or get paid! I need support to be able to do my job properly."*

*"Statutory Advocates have access to patients and meetings. Peer and self-advocates need more power and strength. As a peer advocate, I do not have rights to access the patient and their records. I find it difficult to have private meetings with patients – I should be able to have the same rights as statutory advocates".*

There is a risk that Peer and Self Advocacy is seen as not as important as statutory advocacy, despite people with a learning disability and autistic people valuing this type of advocacy highly.

### **5.1.2 Sharing information in a timely way with the advocate**

Whenever an advocate is supporting a person who lacks the capacity to instruct them on what they want, the advocate will spend time finding out what is important to the person and what is happening in their life. They will then use this to influence what actions they, the advocate will take. This approach is referred to as non-instructed advocacy.

In these instances, the advocate will support and represent the person at decision-making points or where the advocate feels there are issues that need raising on behalf of the person. In instructed advocacy, the person will let the advocate know what decisions or meetings they would like support with; however, in non-instructed advocacy, the advocate needs to be informed of these decisions in advance by hospital staff.

Advocates told reviewers, that not being invited or kept up to date was a key threat to effective advocacy:

*“One person had a safeguarding issue but the advocate wasn’t told. They only found out because they happened to attend a ward round. Similarly, when someone is put into segregation or seclusion we are not told.” Advocate*

*“I was invited to my meeting, but my advocate wasn't invited”. Self-advocate*

*“We don’t get invited to CTRs. It’s very frustrating, very inconsistent. It’s almost like they think we are not important; we are just a passenger. I’ve had staff who were completely averse to advocacy. I don’t think its personal... but instead I’m a pest and a professional mitherer”. Advocate*

*“My biggest bugbear is not being told there was a safeguarding raised”. Advocate*

*“Professionals often say to me ‘We missed you at the last meeting, we thought you were going to be there’ and I’m like ‘what meeting?’. It’s very frustrating to not be invited. Or they invite the wrong advocate” Advocate*

This creates obvious problems for the advocate and the person they support, in that they are literally excluded from the room when key decisions are being made; the concern is that there may not be anyone else in that meeting who is there to represent the views and goals of the person.

As well as needing to receive the information that a decision will be discussed, or meeting is about to be held, the advocate needs to receive this information in advance so they have enough time to meet with the person and agree with them what they want to happen, or in non-instructed advocacy, form a view about what they would want to happen. This is more so, when the person lacks capacity, or uses non-verbal ways to communicate. Effective advocacy will take longer.

Throughout the review, advocates expressed concern at the short notice they routinely receive for meetings.

*“I'm involved in CTRs – the last time I got the referral two days before the meeting. I spoke to the lady for 15 minutes. I mean what do you with that? I went, and she said she was grateful for me attending but did I do a great job? Probably not. I would want to meet her physically and have an hour, get to know her, understand what she wants, her goals over the next year. How much does she want me to do?” Advocate*

Unless the advocate has enough time to work with the person, advocacy will become tokenistic or non-existent.

## 5.2 Family members are not taken seriously when advocating for their relative

Family members often advocate for their loved one, but within the review families reported feeling frequently ignored and excluded from decision-making processes and routinely portrayed as 'difficult'.

*"We are alone and vulnerable, we talk passionately, then we are not heard and not seen as professional." Family carer*

Reviewers consistently heard that many people want family members to act as their advocate and families wanted to take on this role.

*"My mum is brilliant. She understands me and communicates for me in those times. People underestimate parent's role in crisis and admission. My mum is my best advocate." Young person*

*"I was lucky my mum had the knowledge and time and was near enough to come and help me. Other young people were from much further away so didn't have parents there, so they had no one to advocate for them" Young person*

*"I think there is a lack of understanding of different needs about autism, about what can go wrong and what people might need afterwards. For example, my ADOS [Autism Diagnostic Observation Schedule] was too hard for me, I couldn't do it, but if my mum had been on the unit when me knowing she was there and that I could've been with her afterwards would have really helped. They don't follow it through that an advocate, for me that's my mum, needs to be there to help in many different ways." Young person*

*"My experience of advocacy really just involves my mum, and the way she has been my voice when I was unable to have one" Self-advocate*

However, people's experience was often that family members were consistently undermined and excluded from decision making.

*"My mum wasn't allowed to be in as many meetings as I wanted her to. She wasn't invited to most meetings. I don't think they saw her as my advocate. She essentially advocated down the phone. She wasn't supported to be involved and help me to speak up as my advocate. Having the option of another person for when mum wasn't invited or couldn't attend would've been helpful, especially if they had more knowledge about my rights." Young person*

*"We had no legal standing, they walked all over us." Family carer*

This extended to not only being ignored, but “proactively disempowered”, as they were often up against “aggressive’ behaviour from the NHS”<sup>59</sup>. Family members who raise concerns about the care and treatment of their loved one can be viewed as hostile and difficult.<sup>60</sup>

*“One carer was told by a nurse that they had a “a history of fighting against doctors” and came up against veiled threats from the advocate and hospital staff”. Family member*

*“Advocating for my daughter has been a “harrowing” experience”. Family carer*

*“I’ve felt so low, when advocating for my son” Family carer*

Despite the Mental Health Act enshrining specific rights onto the nearest relative but also placing duties onto decision-makers to consult with family members and other relevant people, the experience of many family carers suggests a system where family input is often not welcomed by professionals.

## 5.3 Impact of the wider mental health system

### **The ability for advocates to be effective is impacted on by the wider mental health system.**

The ability for advocates to be effective is impacted on by the wider mental health system. The majority of advocates interviewed as part of the focus groups expressed frustration and exasperation at the difficulties in providing advocacy within in-patient settings. Many advocates felt they were ‘battling a broken system’ and that no matter what they did, the problems facing people remained. Advocates felt they could only ever have a limited impact when there are limited choices available to people. For example, if there are no community services available to support people, then it will be much harder for the advocate to support people to get out of hospital in a timely way.

The majority of advocates interviewed as part of the focus groups expressed frustration and exasperation at the difficulties in providing advocacy within in-patient settings. Many advocates felt they were ‘battling a broken system’ and that no matter what they did, the problems facing people remained:

*“Unless there are homes for people to go to, what can the advocate ‘do’ to get people out”. Advocate*

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<sup>59</sup> Challenging Behaviour Foundation surveys

<sup>60</sup> For a fuller exploration of parent-blaming see Clements, L., Aiello, A.L. (2021) ‘Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children’s services departments’ Cerebra

*“My main issue is with the lack of understanding of staff. They aren’t trained in autism, they don’t understand sensory, they don’t know how to talk to the patients. It’s pointless trying to raise these issues because they just don’t understand” Advocate*

*“Until the culture within hospitals moves towards open cultures and social models [of disability], the advocate will not be able to embed a culture of human rights”. Advocate manager*

*I find it difficult when you get to a point with someone – say the CTR have said they shouldn’t be in hospital, there are 15 recommendations, all saying this is an unmet need. As an advocate I feel totally helpless as everyone is saying there is nothing, there are no services. Or there are services but they are miles away. Advocate*



# Good practice and examples of effective advocacy

So far, we have explored some of the issues which are seen as preventing advocacy from having the impact it needs. However, the reviewers also saw and heard many examples of advocacy working well and having an extremely positive impact in people's lives. This chapter provides examples of where advocacy is working well.

In this section we set out the factors which contribute to advocacy working effectively for people with a learning disability and autistic people who are inpatients in mental health settings.

## 6.1 Factors which support effective advocacy

Reviewers heard many examples of advocacy working well and having an extremely positive impact in people's lives by:

- Supporting and helping to resolve day to day issues connected to being in hospital
- Raising issues about the sensory environment and how this impacted people
- Proactively advocating for discharge planning
- Ensuring the person and their views, wishes and preferences were central to discharge planning
- Raising concerns when people's care and treatment wasn't meeting their needs or wasn't best practice
- Raising and addressing safeguarding issues

We heard from a number of highly skilled and committed advocates who were prepared to do whatever it takes to get improvements in people's care and lives.

We also heard about strong and well thought through commissioning practices where we saw:

- Well established and effective working relationships between the commissioner and the advocacy provider
- A robust understanding of each other's roles and of the different types of independent advocacy
- A wide range of advocacy support being commissioned
- Contracts that support independence as well as effective advocacy provision

- Open dialogue between mutually respected professionals
- The early raising of issues and concerns
- Action being taken to address individual or systemic issues when things weren't going well

We have set out more detail below:

## 6.2 Commissioning self and peer advocacy

The reviewers heard from self and peer advocacy organisations who are making a difference in people's lives. Where they are commissioned, peer advocates are able to visit people in in-patient settings and offer support to enable self-advocacy. This type of support is critical in understanding people's experience and helping people to feel like they are not alone.

*"Seeing all those patient's faces...it's not like they are just patients – its meeting new friends". Peer advocate*

Peer advocates were able to pick up important issues such as 'gate fever' - a stressful and anxiety inducing phenomenon that some people with a learning disability and autistic people can experience as they are about to leave hospital – as well as offer help in pushing for successful discharge.

*"The CCG involved self-advocacy at a secure unit. A patient was thought to be unsafe to leave the secure unit due to self-harm. Self-advocacy was encouraged, and things were put in place to provide support to manage the risk, resulting in patient leaving secure unit and living in supported accommodation, in the community, with much more independence." Self-advocate*

## 6.3 Having skilled advocates who are confident in raising concerns

An important part of an advocate's role is to raise issues and concerns. This could be because the person disagrees with a decision or process or because the advocate is worried that a decision is not in line with good practice, is unlawful, infringes a person's rights or contradicts what a person would want. Having advocates who can raise concerns is particularly critical for people who are in restricted settings – especially for people who are reliant on staff for all aspects of care. People who are unable to raise concerns individually because they lack capacity or don't use words to communicate, may well rely on advocates to raise concerns on their behalf. This is essential in guarding against closed cultures which are so often present when serious abuse takes place of people in restricted settings.

The reviewers saw examples of advocates who were confident in making challenges, able to raise concerns clearly, and repeatedly, until action was taken.

*"We worked on one ward and everything about it was wrong. As soon as you walked on you knew. People were miserable. We increased our presence [on the ward] and the moment we saw things we could raise, we did. This meant we had to work closely with CQC to raise concerns – the work we did led directly to them going in and doing an inspection" Advocacy manager*



*“I worked with one lady who was in segregation and being strip searched. I would constantly ask questions about this and insisted on her being treated in a more dignified manner”*  
Advocate

Without advocacy, people would have continued to have experienced these issues and there would have been a delay in changing how the service was delivered.

#### **6.4 Advocates understanding learning disability and autism**

Throughout the review, we met advocates who were skilled in understanding autism and learning disability. There was a clear commitment from many, to really get to know what was important to people, to understand how people communicated their preferences and individual needs as well as valuing and upholding the rights of people with a learning disability and autistic people. This led to advocates being better able to understand the world from their partners’ perspective and advocate from this space.

*“One day I was visiting a young person and the fire alarm was being tested. It went off 4 times. I could see the impact this was having on him, so I arranged to take him outside whilst the alarm was being tested.”* Advocate

We heard from some advocates who are trained in a broader range of communication techniques and where there has been investment in resources to develop their understanding and communication skills. Insights into how people’s non-verbal communication and behaviour is communication, resulted in one advocate raising a concern that the approaches to care planning were not right and failed to consider the person’s autism:

*“I challenged a Community Treatment Order using chapter 20 of the Mental Health Act (MHA) code of practice as the behaviour described was a form of communication rather than a mental health need and needed appropriate care planning rather than care and treatment under the MHA”.* Advocate

Similarly, we heard many examples where advocates would step outside of the box, get creative and use established approaches to communicate effectively with a person who didn’t use words to communicate. This includes *“a toolkit I have developed to go and use with people – it’s especially useful when working with someone who is non-verbal”*, talking mats, Makaton and sometimes simply committing to understanding the person’s personal communication methods.

*“One guy I supported had a really unique way of talking. When I met him, his language sounded really strange, I didn’t know if it was made up or a different language. After a while I realised, he was speaking backwards. After getting to know him I got a really strong sense that he was doing it to communicate on his own terms. He had been let down by so many people it was almost like he was saying ‘go on then, work it out, and only if you can bother to listen to me will I be bothered to talk to you’”* Advocate

#### **6.5 Influencing plans. Making things better**

While advocacy is about helping the persons to speak up for themselves, there are also times where the advocate needs to act. This is where professional curiosity, questioning and influencing is critical. Asking questions on behalf of the person, critiquing plans from

the perspective of the person and putting forward suggestions are all important actions that an advocate must take.

Reviewers heard numerous examples where advocates did so and achieved positive outcomes for the person they were advocating with.

*“I was supporting an autistic person who had a plan in place that he had to stop doing an action for a certain amount of time to demonstrate he was making progress. The first question I asked was ‘what is his concept of time?’. It turned out the person had no concept of time, so the plan was removed.” Advocate*

*“One person was moved to be closer to home but declined dramatically – let’s just say it was a less quality service. The Clinical Commissioning Group were worried about him and so commissioned an advocate to be their eyes and ears so they could see and understand the person better. She went to see him every week and spent time with him. She would look through his notes, talk to staff. Through this she picked up loads of stuff the care staff had missed. One example was physical health care had been missed, she managed to get a load of restrictions lifted. She was also fundamentally involved in the person’s life and getting him out.” Professional stakeholder*

## **6.6 Effective and thoughtful commissioning**

Reviewers found evidence of commissioners who are thoughtfully commissioning advocacy and thinking about the impact they want advocacy to have. This included commissioning and supporting a broad range of advocacy services which includes self, peer, community, and statutory advocacy. One commissioner reflected they had focused their work at developing a strong local ‘market’ of advocacy providers which included local and small providers as well as larger services. Stability was seen to be key in having a rich advocacy community and they emphasised ‘quality, partnership and collaboration’ between the providers that worked well.

*“Organising the communities – which includes providers, statutory organisations, charities, families, peer groups, community groups. Supporting the different actors and enabling and supporting the group – that community of equals – so that they have a proper dialogue. It’s important there is a proper way to ensure that they are supported to have their voice amplified – and that this results in something” Commissioner*

One commissioner, who described strong relationships with the advocacy provider spoke about the need to support smaller advocacy organisations:

*“We put in a lot of effort to help organisations to give a good account of themselves. We also tend to do this because we want to support the smaller organisations. The big players have resources and teams to do this, and we invite them to tender but they see us supporting smaller organisations, so they don’t bother” Commissioner*

## **6.7 Strong relationships which lead to improvements**

Reviewers also learnt of examples where a strong relationship exists between commissioner and advocacy provider which leads to better communication and improvements being sought. Part of the reason for this successful relationship was the commitment from both commissioner and provider to invest in positive relationships.

*“[The advocacy service] is an incredibly professional organisation. I can speak to their CEO very easily. He contacts me informally all the time. He’ll call me to say, ‘I’m about to send you an email and you might not like it!’ Then we go through it. They challenge when they need to. They give us a hard time when its needed. They really do advocate for people. The quality of provider makes a fantastic difference. They train and bring their advocates on – stability makes a really big difference.”*

These few examples capture that advocacy can and does work well, it can make a difference and it can have an impact. What is needed is more instances where this is happening every day. [Further quotes and examples from the Advocate Survey can be found here.](#)



# Recommendations for creating change

**The reviewing team identified the following areas to improve the availability and quality of advocacy for autistic people and people with a learning disability in mental health settings and their families.**

The reviewing team came together to coproduce the following recommendations for change. In the review we found that the issues impacting the quality and quantity of advocacy people can access are complex and multi-faceted and will require a multi-faceted approach to make things better. Our recommendations are grouped as follows:

- 1. Increase the availability of independent advocacy**
- 2. Ensure consistent commissioning of independent advocacy across England**
- 3. Advocacy should be longer term, person led and holistic**
- 4. Advocates to have a strong, regular, physical presence on wards**
- 5. Develop national standards for training, support, and supervision of advocates of people with a learning disability and autistic people**
- 6. Accurate and consistent information must be provided about advocacy for individuals, families, and professionals**
- 7. Strengthen oversight of the advocacy offer**
- 8. Advocates should work alongside family members**
- 9. People with a learning disability and autistic people should be employed in key valued roles**
- 10. A national advocacy strategy and task force to plan and action required changes**

## **1. Increase the availability of independent advocacy**

### **Gaps in rights and entitlements**

**We found:** The review identified gaps in people's rights and entitlements to independent advocacy due to existing legal frameworks. We also identified that understanding, implementation and delivery of different types of statutory and non-statutory advocacy are not consistent across the country.

Rights to independent advocacy have been introduced in separate pieces of legislation over time. Reviewers heard that current legislation and rights to advocacy don't always support commissioners and advocacy providers in the provision and delivery of person led, holistic, independent advocacy. Eligibility criteria for advocacy differs across different pieces of legislation and can mean that people often don't have a right to access advocacy when they most want and need support to have their voices heard and rights upheld.

This can contribute to people experiencing episodic, process-led advocacy rather than the holistic, person led joined up advocacy that people told us they needed.

We recommend systematic review of legislative framework: There should be a systemic review of the impact of the current legislative framework and exploring the possibility of new primary legislation which brings together people's rights to access independent advocacy.

**We recommend systematic review of legislative framework:** There should be a systemic review of the impact of the current legislative framework and exploring the possibility of new primary legislation which brings together people's rights to access independent advocacy.

**We recommend broadening the statutory advocacy role:** The new Mental Health Act and associated code of practice may give scope to considering how the IMHA role could include broader actions for people with a learning disability and autistic people (not just limited to rights under the MHA) e.g. preparing care and support plans in the community, developing friendships and networks, making advance decisions.

Professional meetings about the person (e.g. multi disciplinary team, ward round, care programme approach) which should include the person (Nothing about Us Without Us) need to protect the person's voice and right to advocacy. People organising those meetings should always assess the risk and impact on the person's voice and right to advocacy before changing meeting dates/times. They should make sure they do not remove the person's right to speak up by changing meeting dates/times etc. which then exclude an advocate from attending.

The draft Mental Health Bill proposes that Care (Education) and Treatment Reviews for detained patients become statutory and the recently updated DSR/C(E)TR policy includes guidance around advocacy within hospital and community C(E)TRs. Furthermore, it is vital that this is extended to people who are in hospital informally or accessing C(E)TRs in the community and have access to advocacy in the same way someone who is detained has.

**We recommend:** providing family members with advocacy.

The Mental Health Act recognises the critical role a Nearest Relative plays in a person's life (the draft Mental Health Bill will see this replaced with a Nominated Person). Reviewers heard that family members and those acting as Nearest Relative aren't always included and supported as they would like. Reviewers recommend developing an additional right to advocacy for people undertaking the Nearest Relative role for people with a learning disability and autistic people, to provide them with independent advocacy support to enable them to be effective advocates. This could be like the 39d IMCA DoLS role which has successfully supported many family members and friends who take on the RPR role AND the person who is subject to restrictions.

## **2. Ensure consistent commissioning of independent advocacy across England**

### **a. Exploration of commissioning models**

**We heard:** Reviewers heard about differing models of commissioning independent advocacy, with different advantages and disadvantages in each.

**We recommend:** That further work be undertaken to fully understand the implications of different commissioning models, where this responsibility should sit and the impact this might have on people's access to advocacy and ability to speak up, for example:

- Local authorities continuing to commission
- Centralised commissioning
- Regional commissioning
- The commissioner responsible for an individual's placement

**We heard:** The Joint Committee on the Draft Mental Health Bill has recommended 'The Government should examine the case for a Central Advocacy Service, to meet the needs of specific groups who may otherwise go unsupported in some areas'. The reviewers heard mixed views about this approach.

However, the review did identify a lack of consistency in current availability of advocacy from area to area as well as a range of different commissioning approaches being used.

**We recommend:** Reviewers believe that increased consistency in access to independent advocacy could be supported by the implementation of a national strategy to cost and fund advocacy services and feel that this warrants further exploration.

## **b. Investment in advocacy by hospitals**

**We heard:** Reviewers heard from all groups who took part in the review that it was problematic when independent and NHS hospitals commissioned their own advocacy; it compromised the independence and effectiveness of the advocacy service in many instances. Some hospitals told us they build in the cost of advocacy to the person's bed fees.

**We recommend:** Local and regional systems should work together to ensure that valuable resources are better utilised to improve independence of advocacy and meet the needs of people with a learning disability and autistic people without compromising the level of investment in independent advocacy.

## **c. Joined up approached between children and adults services**

**We heard:** Reviewers heard that there were often issues in relation to children's access to independent advocacy and many local authorities weren't clear on their responsibilities in this area.

**We recommend:** There needs to be a strengthening of arrangements between children's and adult commissioning to enable joined-up and clear access to an advocate and ensuring that children and young people's rights to advocacy are met.

#### **d. A broader range of advocacy supports**

**We heard:** Reviewers also heard that there can be an over reliance on statutory advocacy. People with a learning disability and autistic people were clear that a broader range of advocacy services needed to be available including self, peer, group, and community advocacy.

**We recommend:** that a broader range of advocacy is coproduced and arranged for people with a learning disability and autistic people.

#### **e. Contracts that support effective advocacy**

**We heard:** Reviewers heard about the impact that shorter and longer contracts can have on an advocacy provider's ability to deliver effective advocacy. Longer term contracts were seen to be beneficial, especially when they include commissioning for different age groups and different types of advocacy.

**We recommend:** That commissioners should establish longer term contracts wherever possible.

#### **f. Guidance**

**We heard:** Reviewers noted that there is a gap in clear nationally recognised guidance to support best practice and accountability in the commissioning, delivery, and facilitation of independent advocacy for people with a learning disability and autistic people.

**We recommend:** The development of clear guidance for:

- Local authority commissioners
- Advocacy providers
- Mental health, learning disability and autism specialist hospitals

It was also identified that health commissioners could benefit from increased understanding in relation to commissioning arrangements for independent advocacy.

### **3. Advocacy should be longer term, person led and holistic**

**We heard:** Reviewers heard from people with a learning disability and their families that longer-term, holistic (rather than short-term, issue-based) independent advocacy is needed so that people can get to know their advocate and vice versa, and so that advocates are better placed to support people with their long-term health and wellbeing. This is especially needed when people are experiencing long lengths of stay and/or heightened levels of restriction such as long-term segregation which may require intensified advocacy support.

**We recommend:** With the right support and investment, local advocacy services can provide this, and commissioners should explore this further.

Reviewers think everyone with a learning disability or autistic people should have the option of continuity of advocacy support for as long as they are in hospital and once they leave hospital. If a change in advocate is unavoidable, then it is essential that a robust handover

takes place to ensure continuity of support. It is also important for people to be given a choice of an advocate.

We think people should also be routinely offered advocacy focused on discharge planning and post discharge in the community to prevent readmission.

#### 4. Advocates to have a strong, regular, physical presence on wards

**We heard:** Throughout the review there was universal agreement from contributors that effective advocacy starts with advocates having a regular physical presence on mental health wards. This means going onto wards, where people are, regularly throughout the week.

Having advocates who are visible and known to people and staff on the wards means that advocates are more likely to:

- Have time to get to know people and their families.
- Build effective working relationship with staff.
- See how people are being supported on a day to day basis.
- Respond to people when they need advocacy support.
- Be there at the right time to explain what advocacy is to people.
- Contribute to safe care and prevent closed cultures from developing.

The reviewers saw evidence that advocates are often unable to maintain this regular presence because they are not resourced fully to offer this, and hospital culture can sometimes prevent this from taking place (appointment-based visits or advocates only being allowed to visit certain areas).

**We recommend:** To mitigate against this, it is very important to find ways to ensure that advocates' regular access to the ward is expected and facilitated. This could include:

- Ensuring advocates have enough time to get to know people, their families, and staff.
- Legislation and guidance could be updated to ensure advocates have rights to access the areas of the hospital that patients use and to reinforce the importance of advocates being frequent professional visitors to the ward. This is currently limited.
- The use of advocacy on wards should be monitored by someone from outside of the hospital to ensure that hospitals are facilitating access, that advocates are visiting regularly and that the quality and independence of advocacy is maintained.



- There should be a named advocate for each ward to make it easier for everyone to know who to contact and liaise with to access advocacy and address other practical issues on wards.
- Reviewers heard that remote access with video and telephone calls didn't work for many people with a learning disability and autistic people. Consequently, video and telephone calls should only be used when the person prefers and requests this.

## 5. Develop national standards for training, support, and supervision of advocates of people with a learning disability and autistic people

**We heard:** Reviewers repeatedly heard about instances where advocates didn't have the adequate skills, knowledge, or expertise to effectively support people with a learning disability and autistic people in having their voices heard and rights upheld. Advocates weren't always making the reasonable adjustments they should be, particularly when people have additional communication needs or don't use words to communicate. Advocates also weren't always maintaining an appropriate level of independence.

### **We recommend:**

- Advocates should complete core training that equips them to meet the needs of people with a learning disability and autistic people in mental health settings.
- The development of a specific programme of continued professional development for advocates to ensure they have adequate training in understanding and supporting people with a learning disability and autistic people who are inpatients in mental health settings, including people who aren't always able to instruct their advocate.
- Developing a process for checking that advocates have the right training e.g. through registration and regulation of advocates.
- All independent advocates complete the Oliver McGowan mandatory training in learning disability and autism<sup>61</sup>
- IMHAs should complete the City and Guilds Level 4 qualification in Independent Advocacy Practice as a minimum.

We heard that parent carers and other family members, who want to and do act as advocates also wanted to access training to support them in this role. They give their time for free and we recommend that they have access to additional training and support to help them in their role, which then gives people assurances on the consistency of advocacy training and support for anyone acting in that role.

Reviewers also heard that self and peer advocacy groups (including ex-patients' groups) need more training for going into hospitals to support patients and other patient groups and again this training and support should be available.

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<sup>61</sup> [more information about the Oliver McGowan mandatory training in learning disability and autism.](#)

Beyond training and skills development, reviewers feel that robust ongoing support and supervision of advocates supporting people with a learning disability and autistic people is needed in order to ensure people are receiving high quality independent advocacy.

## 6. Accurate and consistent information must be provided about advocacy for individuals, families, and professionals

**We heard:** The review team heard that people are not supported to clearly understand what advocacy is and the role of the advocate. This leads to misunderstandings about advocacy from people who use it, family members, staff and others. Many people aren't always clear what advocacy is, or when people can access the different types of advocacy. Some people told the reviewers that they didn't know advocacy even existed. We also heard that some people were given incorrect information about their rights to advocacy.

### **We recommend:**

- Producing nationally consistent resources for people who use advocacy, their family members and staff that includes information about types of independent advocacy including family advocacy, group advocacy and peer advocacy, how to get an advocate and what an advocate does and doesn't do.
- Accessible information needs to be available to people when they first come to hospital and at key points like before professional meetings about the person (e.g. multi-disciplinary team meeting, care programme approach meeting, ward rounds), ensuring the latest national resources for these are used.
- Ensuring information for children who have a learning disability and autistic children is tailored to meet their needs and presented in appropriate and accessible ways. Equally, language that is used in information sources needs reflect different understanding. For some people the phrase 'speaking up' is preferred as 'advocate' and 'advocacy' are less well-known concepts. Not using the right language may disable people further.
- Hospital and other staff in someone's circle of support need to support people to understand information about advocacy and must facilitate advocacy within a person's life.

## 7. Strengthen oversight of the advocacy offer

**We heard:** There isn't a clear picture of what advocacy is available to people and where. We do not know what the local advocacy offer is in each area or how this differs from local authority to local authority.

Reviewers heard that there aren't any external audits of how well local systems support and facilitate independent advocacy within a given area and that there were often lots of problems for people in accessing advocacy.

## **We recommend:**

- Reviewers identified a need to increase national and local oversight and scrutiny of commissioning, delivery, and support of independent advocacy. This could include the development of a national and/or regional and local systems for monitoring and reporting on the commissioning and delivery of independent advocacy.
- In order to improve quality, reviewers recommend the development of coproduced systems involving people with lived experience, to audit how well hospitals, commissioners and other local systems are supporting and facilitating people's access to advocacy. For example, this could lead to the achievement of an 'Advocacy Aware Award' quality mark where it is evidenced that a local system or team has a strong understanding of independent advocacy and supports people to access advocacy. This could include the hospital's actions in supporting access to advocacy and also how advocates are included and responded to within decision-making processes.

## **8. Advocates should work alongside family members**

**We heard:** Advocates frequently did not work alongside family members in positive and constructive ways. In fact, many advocates described that they felt it was inappropriate to do so. We believe this needs addressing as there are many opportunities where it is beneficial for an advocate to work closely with the family or become an ally. This is particularly important within non-instructed advocacy when a person may lack the capacity to clearly instruct their advocate.

**We recommend:** Approaches and guidance in this area is developed to ensure that unless the person drawing on advocacy doesn't want the advocate to speak to or work with their family members, or there is clear documented evidence that it is not in the person's best interest (where the person lacks capacity), advocates should work together with and alongside family carers.

This guidance should recognise that families are often a vital resource to understanding a person's communication, and therefore their wishes, aspirations, and needs as well as being central in a person's support network and life. Any guidance that is developed should be coproduced with family carer groups.

## **9. People with a learning disability and autistic people should be employed in key valued roles**

**We heard:** Reviewers heard that people with a learning disability and autistic people weren't always given opportunities to have their voices heard and hospital cultures didn't always recognise people's skills, strengths and unique talents.

We also heard about the value of independent peer advocacy to people who are currently inpatients and feel it is important that this is further explored and made more widely available to people with a learning disability and autistic people.

### **We recommend:**

Hospitals, care providers, and advocacy services could consider specifically recruiting people with a learning disability and autistic people into a range of roles. This could include roles such as self-advocacy supporters, peer advocates, peer mentors, and former patients to support a person's discharge, specifically to support with the anxiety of moving on, called 'Gate Fever', to support the person make connections in the community and provide emotional/friendship support during and after discharge.

Other roles could include people with lived experience becoming independent advocates, quality checkers and trainers.

Organisations will need to ensure that people undertaking these roles have the right support.

## **10.A national advocacy strategy and task force to plan and action required changes**

**We heard:** Concerns relating to the commissioning and delivery of independent advocacy to people with a learning disability and autistic people in inpatient mental health settings were common and widespread, yet nothing significant had changed to improve things. This review brings together a clear understanding of the issues and challenges.

**We recommend:** A national advocacy strategy is developed to oversee and support delivery of the much-needed changes identified within this report. Reviewers believe there should be a multi-agency task force, which includes family members and people with a learning disability and autistic people to oversee development of such a strategy and to monitor its implementation.



# Conclusions

This review has shown the value of independent advocacy and the challenges experienced by people with a learning disability and autistic people in accessing the advocacy support they want, need and in many cases, are legally entitled to.

It has also highlighted that there is inconsistent access to independent advocacy for people with a learning disability and or autistic people who are inpatients in mental health, learning disability or autism specialist hospitals.

It is clear that the issues impacting on the commissioning, delivery and experience of independent advocacy are complex, multifaceted, and multi-causal and it will be essential that Government and agencies across health and social care, including providers of independent advocacy continue to work proactively to address the issues identified in this review.

We need to continue to develop our shared understanding of how best to arrange, provide and facilitate access to independent advocacy, as well as continue to support a broader range of advocacy services for people with a learning disability and autistic people.

When delivered at its best, independent advocacy can be transformative. It has the ability to enable people to change their lives, have their views, wishes, and preferences heard and responded to as well as ensure their rights are upheld. This is what people with a learning disability and autistic people deserve.

The findings and recommendations for creating change presented here will take time and commitment to address and there is an urgency in doing so.

The reviewers invite Government Departments and other agencies to consider both the findings in this report and the next steps that need to be taken to improve the advocacy offer for people and families in the future.

# Appendix 1 – About the partner organisations and reviewers

This report has been written by Kate Mercer, NDTi Advocacy Associate and Gail Petty, NDTi Advocacy Programme Lead with support and contributions from the individuals and organisations below.



## Bringing Us Together

**Bringing Us Together (BUT) is a user led organisation that brings together parent carers, family members and disabled people.**

For eight years BUT has:

- Supported families with lived experience of having a loved one who has been admitted as an inpatient in a mental health unit.
- Been part of national campaigns.
- Brought families together to amplify their voices.

BUT runs regular workshops with a focus on social care, wellbeing and avoiding crisis. Each includes speakers with experience of the complexities of our current services. BUT works in coproduction with families, commissioners and professionals and has carried out many rapid consultation focus groups.

### **Bringing Us Together team members**

The following team members were directly involved in the review team:

**Katie Clarke:** Cofounder of Bringing Us Together has worked for over 25 years in parent participation across the country. Parent carer and foster parent.

**Tony Bamforth:** Workshop and course designer, writer and facilitator, wellbeing oriented, worked with disabled people and families for over 20 years across the UK.

**Hazel Griffiths:** Retired nurse, mum of two, parent carer for an older autistic son. Peer advocate. Campaigner and advisor and involved in many pieces of work promoting the rights and needs of families with children and young people with a wide range of disabilities.

**Nicola Bartziz:** A parent carer whose autistic son with learning disabilities has been an inpatient in two ATUs. He is currently thriving in supported living and Nicola is working full time in statutory advocacy.

BUT would like to thank:

- All those who attended their focus groups.
- Their steering group: Hannah Otoo, Nikki Clarke, Anya Macdonald, Jayne Knight and Sam Sly.

## The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is the only UK charity specifically focusses on challenging behaviour associated with severe learning disabilities.

The team aims to make a real difference to the lives of children, young people, and adults with severe learning disabilities and those who care for and support them. Their overarching objective is to ensure children, young people and adults with severe learning disabilities, and their families have access to the right support in the right place at the right time to enable them to live a full, healthy, and active life. They do this by combining the direct lived experience of the families we support with strategic influencing work.

### Challenging Behaviour Foundation team members:

CEO Vivien Cooper (OBE) and Adult Policy Lead, Coral Histed are supported by interns Connie Mottram, Indigo Starkey, Celine Boreland and Liam Doherty. They worked in partnership with family carer Julie Thorpe to lead the review

of advocacy experiences of family carers whose adult relatives are in inpatient units. Grateful thanks go to all the family carers who contributed their experiences, knowledge and recommendations for change to this project.

In addition, we would like to thank the following advisory group members for their significant input and work throughout the project.

- Yvonne Newbold (Newbold Hope, family carer)
- Bella Travis (Mencap)
- Tim Nicholls (National Autistic Society)
- Lynn James-Jenkinson (NWTDT & CEX, family carer)
- Julie Thorpe (a2e Advocacy, family carer)
- Samantha Clarke (Learning Disability England)
- Xanten Brooker (Kent County Council)



**NDTi has worked with communities, government, health and social care professionals for 25 years to ensure that people with disabilities of all ages are given choice and control over their own lives.**

NDTi exists to make change happen by celebrating what's possible, supporting changemakers and building self-determination. Their work always focuses on wider life outcomes with the aim to enable disabled and older people to enjoy the same opportunities as everyone else – education, paid work, a place of their own, fulfilling personal relationships and a chance to contribute to their communities.

The team believes that all people should have choice and control over their own lives, that their human rights be respected and that they are valued as equals.

### **NDTi team members**

**Gail Petty:** Gail has led the Advocacy Programme and managed the Advocacy QPM at NDTi since 2015. She has

been involved in the advocacy community since 1993 and was an advocate for people with a learning disability and autistic people, including people who were inpatients.

**Dr. Karen McInnes:** Karen is the Evaluation Manager at NDTi. She is an experienced educator and researcher.

**Kate Mercer:** Kate supports advocates by delivering training, the advocacy qualification, learning events and an annual conference to the advocacy community. Kate has been an advocate for children and young people, adults and family members.

**Dr. Naomi Harflett:** Naomi is NDTi's Research Manager. She works on and manages a variety of research and evaluation projects across all of our work programmes.

**People First is an independent customer-led organisation that has worked in the North of England for over 30 years. They have a deep understanding of the region, its communities and the unique challenges.**

People First is the largest provider of advocacy in Cumbria, supporting thousands of people every year to have their voices heard and helping them to live their best lives. It's an independent organisation which dedicates itself to representing people's views.

In 2009 People First helped to set up a self-advocacy network across Cumbria which created a single voice in the form of People First.

### **People First team members**

**Lindsay Graham:** Lindsay is passionate about equality, respect, kindness and compassion. She is an experienced independent advocate and manages People First's advocacy offer.

**Rohss Chapman:** Rohss is an allie in the self-advocacy movement; committed to challenging inequality and upholding peoples' rights. She supports experts by lived experience.

**Mary Docton:** Mary is passionate about having equal opportunity and giving the best life for all disabled people so that they get treated equally. She is the sessional self-advocate expert by experience that is autistic.

**Maria Lord:** Maria works for People First on a sessional basis. She has collected information from self-advocacy organisations throughout the country and has been thoroughly inspired by their passion and dedication towards equal rights and respect for all.

**Lou Townson:** Lou has been part of People First for 30 years. She has a learning difficulty and is determined to ensure everybody's voices are heard in equal measure.

**Lucy Irid:** Lucy provides admin support at People First and has been involved in collecting and summarising information from Self Advocacy groups.



## Speakup Self Advocacy

**Speakup is a self-advocacy group run by and for people with learning disabilities and autistic people. The group helps people have a voice, employment opportunities and be valued and included in society.**

Speakup has been supporting, employing and training people with learning disabilities and autistic people to use their skills and abilities to help others and make a difference for over 30 years.

Speakup sees people and not labels and believe that everyone has the right to live a full and enjoyable life. It all started back in 1988 when a group of people with learning disabilities came together because they were unhappy that people were not listening to them.

### **Speak up Team Members**

**Amy Telford:** Amy is autistic, has been an inpatient herself for many years in the past, now lives independently and campaigns for the rights of autistic people.

**Marshall Wilson:** Marshall is autistic, has a lot of life experience as an inpatient and works as an expert by experience for Speakup.

**Vicky Farnsworth:** Vicky works for Speakup and has been an expert by experience on many Care and Treatment Review panels as she has a learning disability.

**Geoff:** Geoff supports the work of Amy, Marshall and Vicky to help deliver the project and organise the focus groups.

