



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

Summary report



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in partnership with:



Contents

Forewords	3
Introduction to the review	6
How the review was carried out	9
Review findings and discussion	10
 1. What people and families want from independent advocacy support	11
 2. Arranging independent advocacy	15
1. Commissioning Independent Advocacy	16
2. Legislation, guidance, and best practice	17
3. Funding	18
4. Very little support for self, group, and peer advocacy providers	19
 3. Providing independent advocacy	20
1. Independence	21
2. Hospitals commissioning their own advocacy services	21
3. Hypernormalisation	21
4. Advocates becoming part of the system	22
5. Physical Presence	22
6. Advocates' skills and knowledge	23
7. Advocates and families	24
 4. Accessing advocacy	25
1. Advocacy is misunderstood	25
2. Accessing advocacy	26
3. Long(er) Term, holistic advocacy	27
4. Family members need to access advocacy for themselves	28
 5. Supporting effective advocacy	29
1. Hospital approach, culture and values	29
2. Family members aren't taken seriously enough	30
3. The impact of the wider mental health system	30
 6. Examples of effective advocacy	31
Recommendations for creating change	36
Conclusions	47

Forewords

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 Independent Care (Education) Treatment Reviews 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

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.

Introduction to the review

Independent Advocacy^[1] 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.^[2] For more information about the different types of advocacy and who it is for, [please click here](#).

Independent advocates are exclusively focussed on ensuring people are 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](#), Care Quality Commission'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'^[3] 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.

NDTi, alongside partner organisations, [Bringing us Together](#), the [Challenging Behaviour Foundation](#), [People First Independent Advocacy](#) and [Speakup Self Advocacy](#), have undertaken a review of 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 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 includes what is working and not working in the commissioning and delivery of independent advocacy to people with a learning disability and autistic people who are inpatients in mental health settings. We wanted to understand this from the perspectives of lots of different groups of people to make sure we understood the full picture, including families' experiences of advocating for their relatives.

1. 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

2. [See NHS Digital information on learning disability services statistics](#).

3. See the [Safeguarding Adults Review on Whorlton Hall Executive Summary 2023](#)



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.

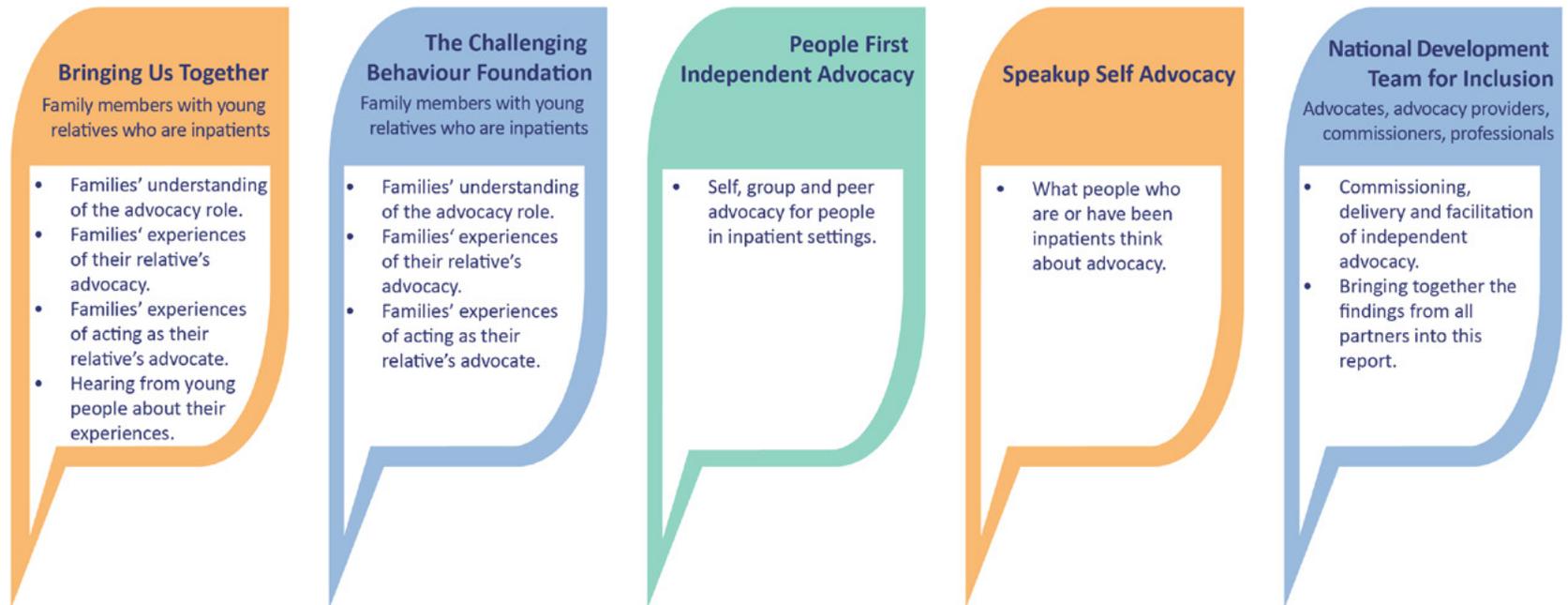
Much of the review focuses on statutory Independent Mental Health Advocacy (IMHA)^[4] provision as this is the main form of advocacy that people are entitled to if they are detained under the Mental Health Act. This focus does not diminish the value and importance of other types of advocacy.

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.

⁴ [Read more about the different types of advocacy and who it is for.](#)

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:



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 which affect independent advocacy delivery and prevent it 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.

We hope this report shines a light on the value of independent advocacy, its impact on those who draw on it and that its findings will lead to real change, so people get access to the advocacy support they want, need, and are entitled to.

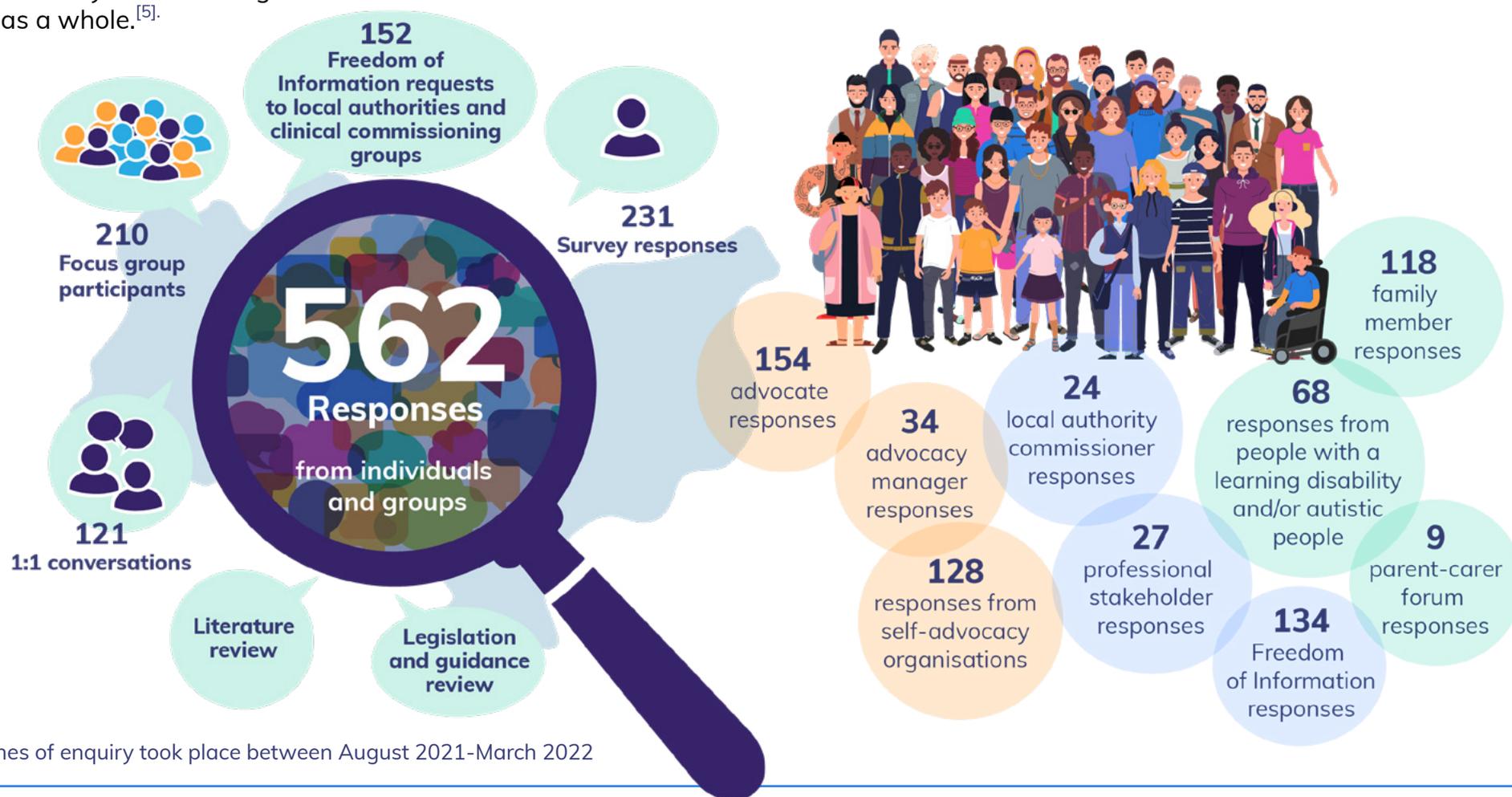
How the review was carried out

Review partners each led on their own lines of enquiry. In total there were 562 responses from individuals and groups, directly providing evidence for the review.

The graphic shows the consolidated information about the work undertaken by the reviewing team as a whole.^[5]

The team at NDTi then 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 ideas for creating change.



⁵. All lines of enquiry took place between August 2021-March 2022

Review findings and discussion

We identified factors which impact on the quality and availability of independent 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 better understood families' experiences of advocating for their relatives.

We have set out our findings, which we have grouped into six chapters:

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



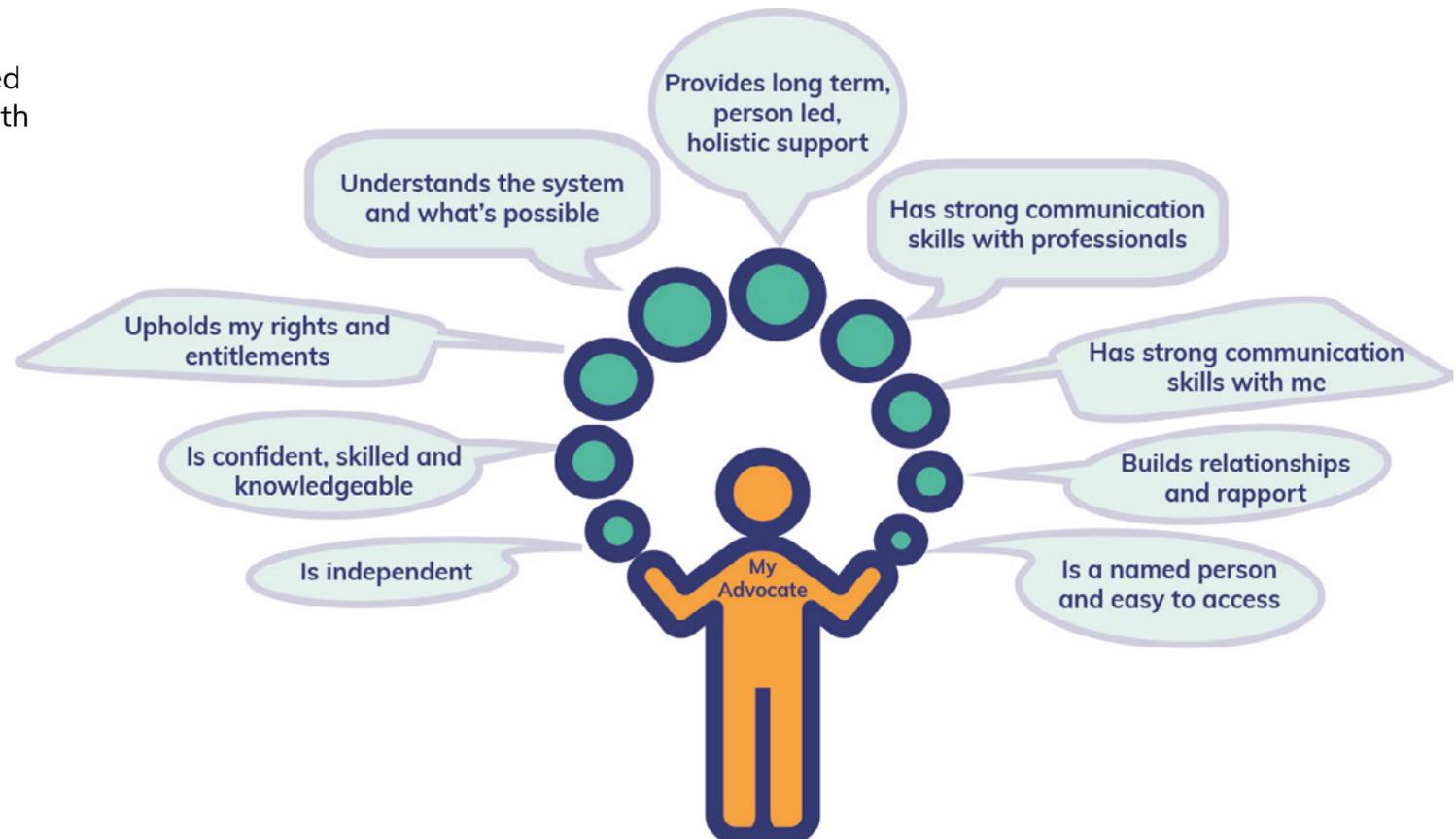
To review all the evidence, quotes and the full findings please see [the full report](#).



What people and families want from independent advocacy

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.

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

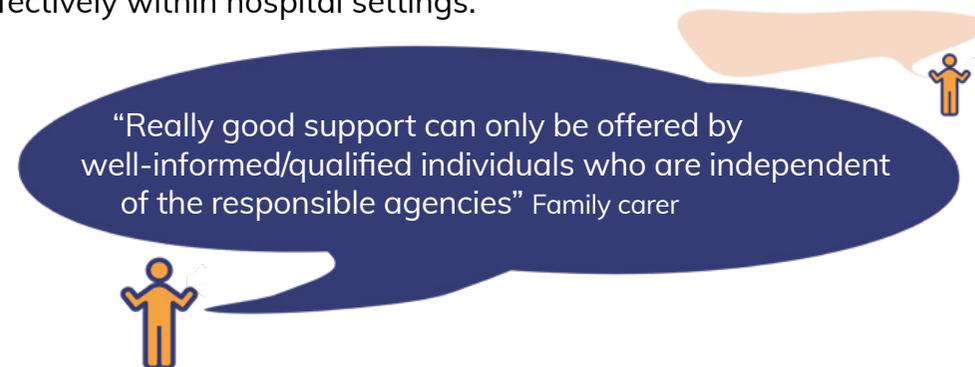
2. A range of longer term, person led, holistic and proactive advocacy support

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.

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 said they want advocates to 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.



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 who will stand up for them and not judge them based on other people they have supported or what the advocates feel the person is able to do”.

Self advocate



5. Relationship and rapport

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.

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. This means advocates needing to know how to communicate with people and having 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. 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 is 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^[6].

⁶ See [NHS information on Care \(Education\) and Treatment Reviews](#)

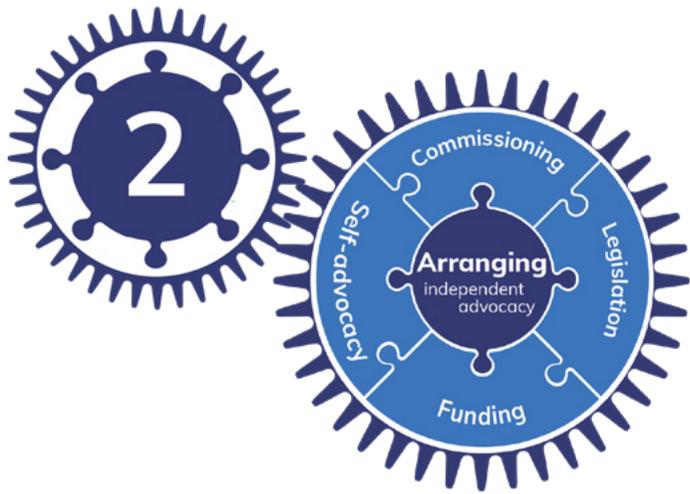


“Knowledge of the law and rights for advocates is a problem. The advocates in the hospital might be mental health advocates and not know much about the Care Act. To get a successful discharge, this is really important!” Self-advocate

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 they are acting in an advocacy role for their relative, family members want health and social care professionals to include them proactively 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. Legislation, guidance and best practice
3. Funding
4. Support for self and peer advocacy



1. Commissioning Independent Advocacy

In England, local authorities have a legal duty to commission and arrange statutory independent advocacy; Independent Mental Health Advocacy (IMHA), Independent Mental Capacity Advocacy (IMCA), advocacy under the Care Act 2014 and advocacy to support with making complaints about NHS funded care and treatment and advocacy for children. There is no legal requirement to commission and provide access to family, peer or self-advocacy.

We found that there is no standard model or approach to how advocacy is commissioned, monitored, delivered, and costed, across the country and from local authority to local authority. This inconsistency has created gaps in people's ability to access advocacy including peer and self-advocacy support as well as introducing significant confusion as to who an individual's advocacy provider should be. This is ultimately resulting in inequity of access for people who draw on advocacy services.

This inconsistency in commissioning approaches was evident throughout the review:

- Some commissioners incorrectly interpreted who should commission advocacy. This has led to gaps in provision, especially for children and young people. This can also lead to a duplication in advocacy being commissioned (two services being commissioned by different commissioners) which causes confusion as to who the advocacy provider is.
- Different commissioning models (one provider, hub, or multiple providers) can also lead to confusion and a lack of clarity about where to go for different types of advocacy support.

- Disjointed commissioning arrangements between children and adult settings can make it more difficult to get an advocate. For example in some areas the commissioned advocacy service did not offer support to under 18s.
- There is no standard length of contract for advocacy providers which makes it very difficult for advocacy leaders to plan and secure longevity. The reviewers heard how short-term contracts for independent advocacy particularly impact the quality and availability of advocacy.
- Non-statutory self, peer and community advocacy is not consistently commissioned meaning that there are gaps in this type of provision in many areas.



Reviewers also heard concerns from all agencies and families that there are no 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 quality of the advocacy provided, or the impact of the advocacy provided. This is significant because it means there is no understanding or intelligence about the national impact or state of advocacy. Nor is there any central understanding or evidence of how or if advocacy is being resourced properly.

Without this, there is a lack of accountability, poor practices remain unchallenged, problems unresolved and we move away from, not towards, consistent high-quality advocacy.

2. Legislation, guidance, and best practice

At the time of writing, there is a range of statutory entitlements to advocacy^[7]. However, the reviewers found this can fall short of what people with a learning disability and autistic people, and their families want and often need. Current entitlements provide advocacy to help in a particular setting or with an 'issue', but the reviewers heard from individuals that what is needed is "person led advocacy for as long as it takes."

This is further complicated as eligibility to access advocacy under different pieces of legislation don't align with each other which can

lead to people experiencing episodic and short-term advocacy. It can also mean that people may need to access different types of advocacy from different advocates or different advocacy providers. For example, you might have one advocate for a ward round, a different one for a safeguarding process and a different one again for adult social care processes.

Legal entitlements to advocacy do not reflect that some people who are inpatients are detained under the Mental Health Act, some are under Deprivation of Liberty Safeguards (DoLS) authorisations, and some people are in hospital voluntarily. People's status as patients has a significant impact on the advocacy that they can access and can leave informal patients with no access to advocacy at all.

There is a lack of guidance and clarity regarding the use of non-instructed advocacy^[8]. The reviewers are concerned that overall, advocates' ability and confidence in using non-instructed advocacy is very poor in many instances. This results in advocates being uncertain what to do and ultimately not doing what needs to be done.

Too often, family members and carers report being ignored, excluded, and blamed when it comes to discussing arrangements for care and support of their loved one. They can face barriers in being heard and respected by the 'system'. At the time of writing there is no current legislative entitlement for a family member or carer to access advocacy for themselves. This is something that can support family members and carers to understand what is happening, influence decisions and be involved.

7. [View information about the types of advocacy available to people in different circumstances.](#)

8. Non-instructed advocacy (NIA) is an approach that advocates use when the person lacks the capacity to consent to the advocates involvement and is unable to clearly instruct the advocacy about what they want to happen.

3. Funding

The reviewers heard from participants that independent advocacy is routinely underfunded and that the level of available resource is not enough to support effective advocacy for people with a learning disability and autistic people.



“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



“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



The reviewers saw evidence that:

- Local authorities are often limited in the resources they can invest in advocacy.
- There is often a lack of strategic approach to funding and commissioning advocacy.
- The lack of resource inevitably limits the advocacy support that is available to people and this disproportionately affects people with a learning disability and autistic people who may want or need to spend more time with their advocate in order to receive effective support. This is compounded further for people in secure settings and those in long-term segregation.
- Limited resources mean that often, only statutory advocacy is funded, leading to a lack of much needed self-advocacy groups, peer advocacy and general or community advocacy.
- Statutory advocacy is also often underfunded resulting in some services having to operate waiting lists or limit the support they offer.
- Commissioning processes appear to prioritise the cost of the advocacy service above indicators for quality and the impact of competitive tendering processes can lead to a 'race to the bottom.'

4. Very little support for self, group, and peer advocacy providers

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 evidence that very little self, group, or peer advocacy is delivered in inpatient settings.

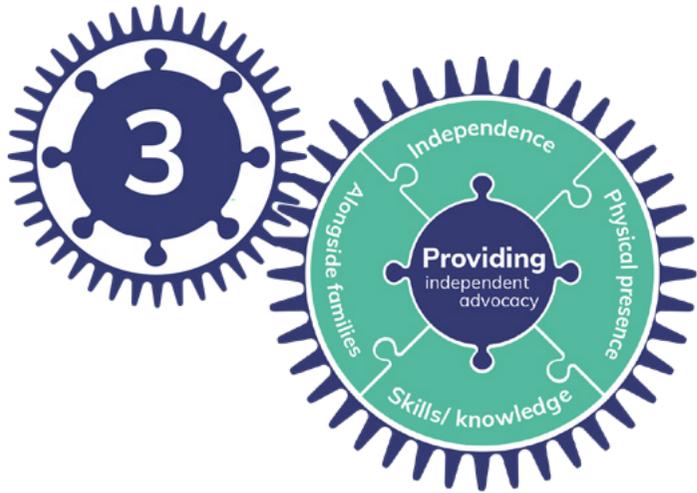
Reviewers heard that people with a learning disability and autistic people are clear that they value and want to access advocacy support from people who have been in the same situation as them. This is not instead of statutory advocacy, but as well as. This type of advocacy which supported people to talk together about their own experiences with other people who have had the same or similar experience was seen as crucial.

Where self-advocacy groups are commissioned, they reported experiencing exceptionally short-term funding, often just for months or for a specific project, impacting on the sustainability of groups.^[9]

There is also an absence of joined up peer advocacy support for family members and carers. Many family carers expressed the need for this and sought support through national charities and carer led groups – although these organisations receive very little funding to provide this help.



⁹ [Read The Open University and Learning Disability England's report on finding for self-advocacy groups. 2022](#)



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.



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

1. Independence

Independence from all other statutory and non-statutory service provision is a fundamental requirement of independent advocacy. 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'.^[10] 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.

2. Hospitals commissioning their own advocacy services

This was seen to be problematic by nearly everyone who contributed to the review including the hospitals who commissioned services and most of the advocacy providers we spoke with who deliver directly commissioned services.

In many instances the hospital commissioning the service did so out of good intentions; to extend the access to advocacy. However, reviewers heard that:

- People and families did not always trust the advocate and said they were not independent.

- Some hospitals limited the access to independent advocacy, limited where in the hospitals the advocate could go and meet with people and/or micro-managed the advocacy service.
- Advocacy providers didn't always raise issues or represent people fully for fear of 'rocking the boat' or because the hospital wouldn't let them, e.g., by not letting advocates raise safeguarding concerns externally to the local authority.
- Private space for people to meet with the advocate was often not made available.

3. Hypernormalisation

Hypernormalisation^[11] 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. There was evidence that some advocates are starting to accept the hospitalisation of people with a learning disability and autistic people as 'normal' or expected. There was also evidence of some developing the false belief that people are 'difficult to place' or cannot cope in the community. Over time this impacts on the advocates' approaches, and it can become harder for advocates to see the need to raise challenges.

¹⁰. See the [Advocacy Charter, NDTi](#)

¹¹. 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)

4. Advocates becoming part of the system

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 and effectively support people within it. Similar tensions are present in developing working relationships with mental health professionals: advocates need to have effective communication and relationships with professionals and understanding of different roles, but they cannot be too 'close' or familiar with staff. Reviewers heard evidence that some advocates were adopting practices that limited their actual or perceived independence:

- Wearing NHS ID or hospital issued lanyards
- Using email addresses from the hospital or NHS (for example @nhs.net)
- Holding keys and passes
- Use of 'service speak' e.g., 'patients, placements, referrals, beneficiaries, cases'
- Accepting restrictive practice and becoming sympathetic to staffing shortages
- Becoming aligned with staff teams in their identity and allegiance

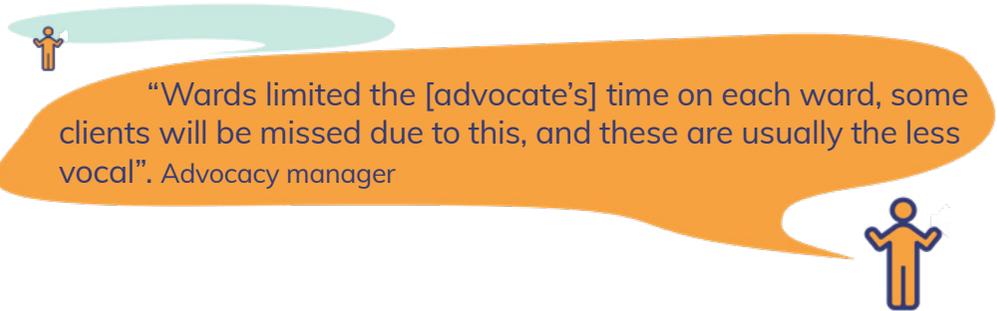
Reviewers concluded that advocacy services must actively guard against the risk that advocates become subsumed as part of the hospital culture rather than being distinctly independent and able to hold services to account.

5. Physical Presence

There was universal agreement throughout the review that not having a regular presence on the wards severely limits the effectiveness of the advocate. 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 and is continuing post-lockdown even as restrictions are lifted.

Restrictions limit advocates' ability to offer and explain advocacy to people, they make it harder for the advocate to get to know people and staff (and vice versa), and they prevent the advocate from having a clear understanding about how people are being supported. This all leads to a reduction in the advocate's ability to challenge closed cultures and recognise and address potential poor practice or safeguarding concerns where they exist.

For anyone who is unable to instruct their advocate, the advocate being physically on the ward, or wherever the person is, is 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. This cannot be done remotely and requires the advocate to be physically present.



6. Advocates' skills and knowledge

People with a learning disability and autistic people may express themselves and what they want in individual ways that advocates need to learn and understand. It can also be harder for advocates to find the right ways to explain some information or the options available to the person in a given situation, and what they can and cannot do. 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.



"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



"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



Whilst we heard about some excellent advocacy from highly skilled and knowledgeable advocates, we also heard that some advocates lacked confidence or skill to support people with a learning disability and autistic people effectively. Advocates identified that they needed access to additional training and support in the following areas:

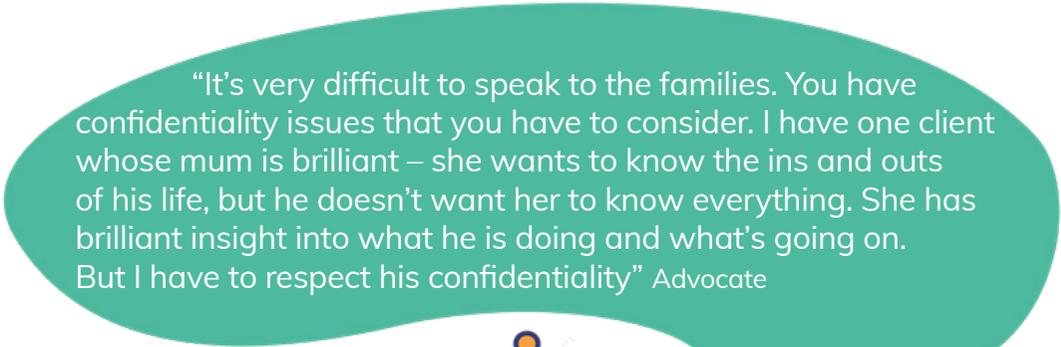
- Training on learning disability and autism
- Involving experts by experience
- Communicating with autistic people and people with a learning disability
- The law/legislation with this group of people
- Non-instructed advocacy
- Hearing stories about what works and what doesn't work
- Acting independently
- Knowing how and when to challenge

7. Advocates and families

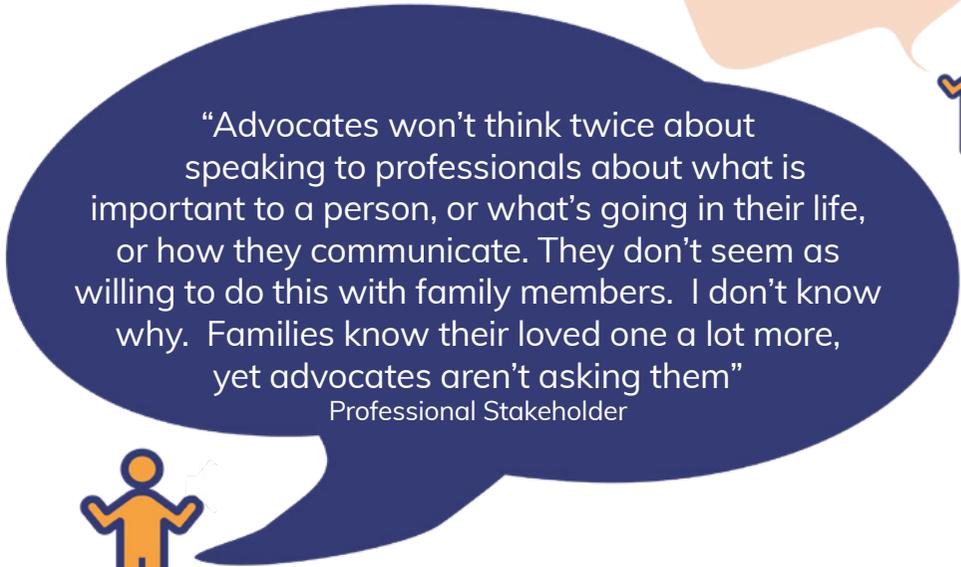
We also heard that advocates are not routinely working alongside family members, to the detriment of the advocacy support and the individual. Some advocates appeared to lack confidence in how to maintain the independent advocacy relationship with the person at the same time as connecting with their family.

The reviewers saw evidence that there are many times, 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 do so. People close to the person who is receiving advocacy support have critically important insights into how the person communicates, what they love and hate, what is important to them and what they might need. However, when advocates were asked if they worked with families the most common answer was 'not really'.

Advocates told the reviewers 'It's not appropriate', 'families don't welcome advocacy' or that it would threaten their independence. Reviewers believe that this is an ill-thought through advocacy approach and that advocates need to work more closely with family members more often if they are to effectively advocate with and on behalf of their advocacy partner. It is entirely possible to maintain advocacy boundaries, whilst working effectively alongside an individual's family.



"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



"Advocates won't think twice about speaking to professionals about what is important to a person, or what's going 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





Accessing independent 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 hospital said that because my relative had capacity, they can't have an advocate.” Family carer



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.

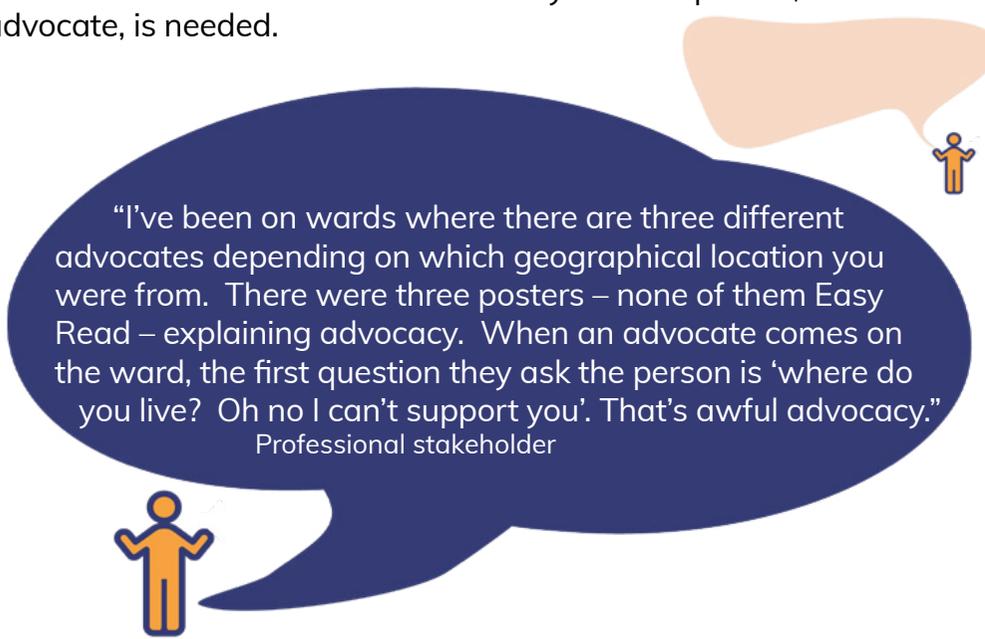
Throughout the review, participants shared concerns that people at all levels of the system, from those working in senior roles in statutory services, to front line staff, families, and people who draw on advocacy services, misunderstood what advocacy is, including the different roles that advocates play, what advocates can and can't do etc. There was evidence of a systemic lack of clarity in the advocacy role and its boundaries, and where information was provided to people it was often poor quality. This lack of clarity leads to confusion and negatively impacts people's ability to access advocacy.

Reviewers saw that this confusion extended to what different types of advocacy people were able to access at different times. The confusion and misunderstandings indicated 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, hospitals and commissioners interpreted

the legislation differently and so advocacy varied in its delivery, quality and coverage across the country.

Reviewers also heard some instances of advocacy providers having misunderstood people's rights to advocacy, e.g. incorrectly suggesting that "IMHA is only available to people who can instruct" or "advocates only work with adults". There were instances of advocacy providers giving incorrect information to people, families, and staff in mental health settings.

People with a learning disability and autistic people told reviewers that they preferred the term 'speaking up'. People understand what 'speaking up' is and see this as a very natural activity that lots of 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, an advocate, is needed.



"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

2. Accessing advocacy

The review showed that accessing an independent advocate is often far too difficult for many people. This is caused by a lack of information, lack of awareness, unclear arrangements, and a lack of monitoring. It is not known how many people with a learning disability or autistic people who are inpatients are actually accessing advocacy.

Reviewers heard that people are missing out on legal entitlements to be supported by an independent advocate and that there are a number of reasons for this:

- There is a lack of reliable and accessible information about advocacy and the different types of advocacy that can be accessed.
- Sometimes there are multiple advocacy providers working in one ward or hospital leading to confusion about which provider to go to.
- Different advocacy providers provide different types of advocacy, e.g. IMHA or Care Act, leading to confusion about which provider to go to.
- A lack of awareness about what advocacy services are available locally.
- Opt out referral systems not being implemented or implemented inconsistently.
- People needing to re-refer for advocacy support multiple times during their stay in hospital due to issue based approaches.

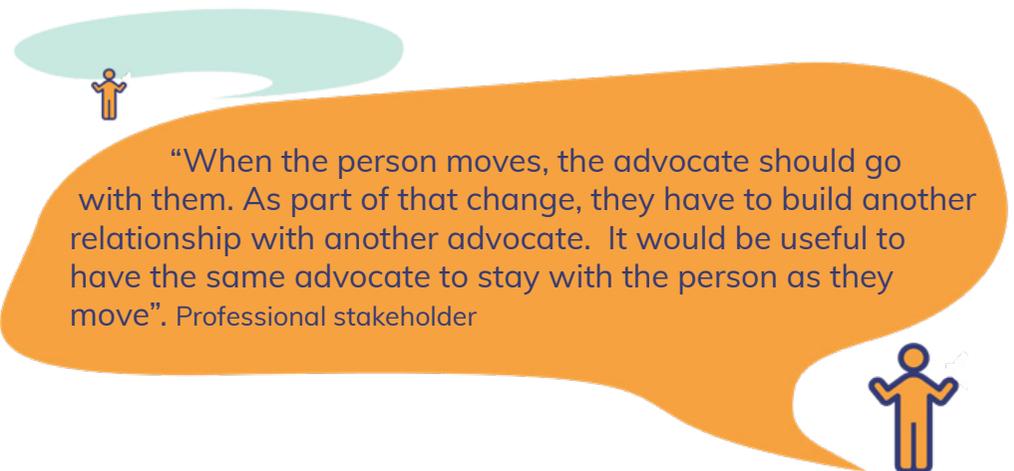
- Advocates not always taking a questioning approach when someone declines advocacy support.
- Advocates not re-making the advocacy offer.
- Advocates not taking the time to get to know people to build trust and a relationship in which the advocacy can take place.
- Advocates not knowing how to engage with people with a learning disability and autistic people.
- Advocates not listening to and responding to people.
- Advocates not being invited or informed of significant meetings and decision-making processes.

3. Long(er) Term, holistic advocacy

People with a learning disability and autistic people in hospital often need a more holistic approach to their advocacy as a reasonable adjustment; however, they are typically being offered short-term, issue-based advocacy. The current experiences of people who draw on advocacy tends to be having an advocate for short periods of time, typically at certain points through their stay in hospital. The reviewers heard little evidence that advocates are enabled to develop longer-term relationships with people. Self and peer advocates were more likely to have a remit of responding to a broader range of support issues, though the availability of this type of support was seen to be limited and inconsistent. Statutory advocates were seen to be less likely to stay with the person for long periods and, at times incorrectly, felt there were limits on what 'issues' they could respond to.

The reviewers heard that while choice is very important, most people want to draw support from the same advocate for as long as they need. People expressed frustration at receiving support from different advocates for seemingly irrelevant reasons, like moving to a different ward or there being a decision that triggered an IMCA. We also learnt that people want and need access to independent advocacy before they are admitted to hospital and statutory entitlements to advocacy don't always support this. Similarly, advocacy to support people with discharge planning can fall through the gaps of statutory entitlements.

Overall, 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 'case is closed'. This move towards short-term, issue-based advocacy, has evolved over time but many people pointed to the introduction of statutory entitlements to advocacy, commissioning arrangements and inadequate resources as the cause. Independent advocates need to have the flexibility and freedom to be able to offer



personalised support which is not limited to mental health but extends to broader issues such as day-to-day life, where people 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 often does not address the person's long-term wellbeing. There is an additional risk that this model of advocacy can potentially leave people more vulnerable to abuse as it creates an illusion of advocacy.^[12]

4. Family members need to access advocacy for themselves

There is no legal duty to provide advocates to family members, but 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 systems of mental health.



For example, 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.

Reviewers believe that family carers, especially nearest relatives, would benefit from their own version of a mental health '39d IMCA'.

12. See [Safeguarding Adults Review on Whorlton Hall Executive Summary 2023](#)



Supporting effective advocacy

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.



“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



1. Hospital approach, culture and values

The behaviour, culture, and values of the hospital can undermine or strengthen advocacy, dependent upon whether advocacy is genuinely welcomed and seen as an integral part of upholding rights, inclusion of the person and ensuring patient safety, or whether it is treated with suspicion, or not prioritised as a right to be supported. There was evidence of some hospital settings welcoming advocacy support and working hard to proactively facilitate people’s access to advocacy and other instances where hospitals created barriers to effective advocacy support being available to the person. For example, the reviewers heard of instances where, by not ensuring information was shared with the person in a timely way, people didn’t get the support they needed to prepare for and attend meetings about their care, treatment, or discharge. Reviewers heard many examples where advocacy was not welcomed or valued by the hospital. There is concern that this perpetuates the occurrence of closed cultures within institutional settings.

There was evidence however that advocacy worked well when there was a culture that valued the inclusion of people’s voices and championed person led approaches.

2. Family members aren't taken seriously enough

Family members often advocate for their loved one, including in the role of court appointed deputy, but many reported being frequently ignored, excluded from decision-making processes, and routinely portrayed as 'difficult'. This extended to not only being ignored, but proactively disempowered from influencing decision-making by different agencies.

Despite the Mental Health Act enshrining specific rights onto the Nearest Relative and also placing duties onto decision-makers to consult with family members and other relevant people, the experiences reported by family carers in the review suggests a system where family input is not always welcomed by professionals, making it difficult for relatives to provide the natural advocacy that many people want from their family members and carers.



"We are alone and vulnerable, we talk passionately, then we are not heard and not seen as professional."

Family carer



"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



3. The Impact of the wider mental health system

The ability for advocates to be effective is impacted 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 inpatient settings. Many advocates felt they were 'battling a broken system' and that no matter what they did, the problems facing people who are inpatients remained.



"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



Advocates felt they could only have a limited impact as there were limited choices available to people. For example, blockages in finding the right community services to support people made it much harder for the advocate to support people to get out of hospital in a timely way.



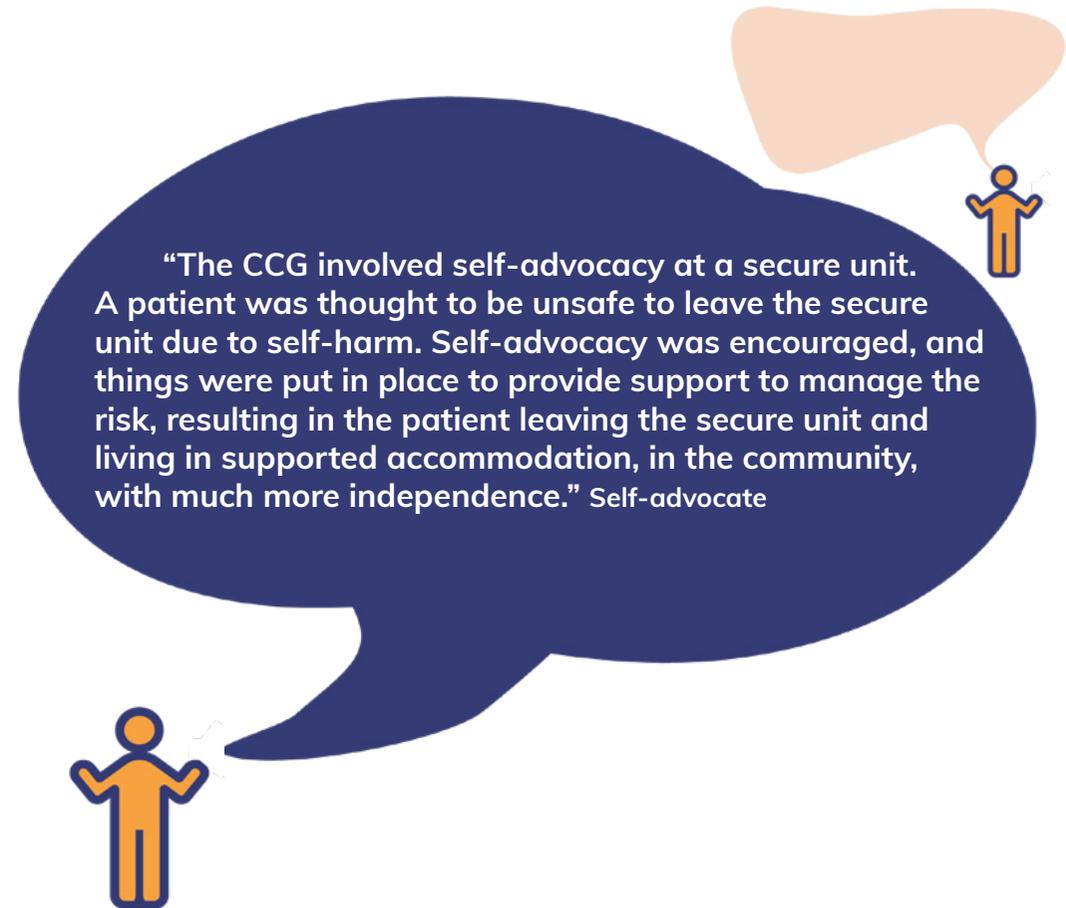
Examples of effective advocacy

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.

1. Commissioning self and peer advocacy

The reviewers heard from self and peer advocacy organisations who are able to make a difference in people's lives through their peer-led work in hospitals. Where they are commissioned, peer advocates are able to visit people in inpatient settings and offer support to enable self-advocacy. The reviewers felt this type of support is critical in understanding people's experience and helping people to feel like they are not alone.

For example, peer advocates were able to pick up on 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 the patient leaving the secure unit and living in supported accommodation, in the community, with much more independence." Self-advocate

2. 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, is restrictive, 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 people abuse takes place 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.

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.



"The advocate was excellent. I choose the Independent IMHA advocate. The advocate challenged the hospital on the Mental Health Act." Family Member

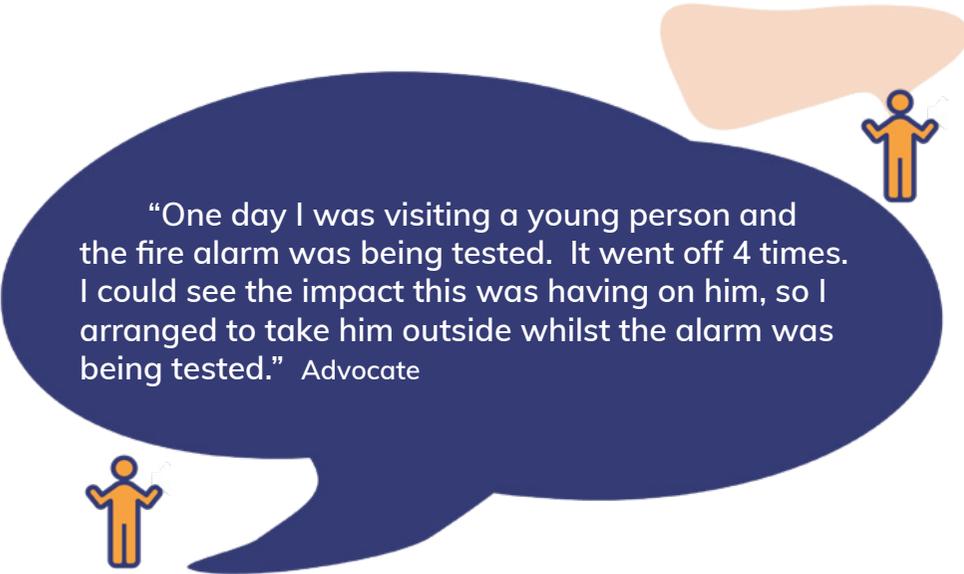


"We worked on one ward and everything about it was wrong. As soon as you walked on you knew. People were miserable. We increased our presence [on the ward] and the moment we saw things we could raise, we did. This meant we had to work closely with CQC to raise concerns – the work we did led directly to them going in and doing an inspection" Advocacy manager



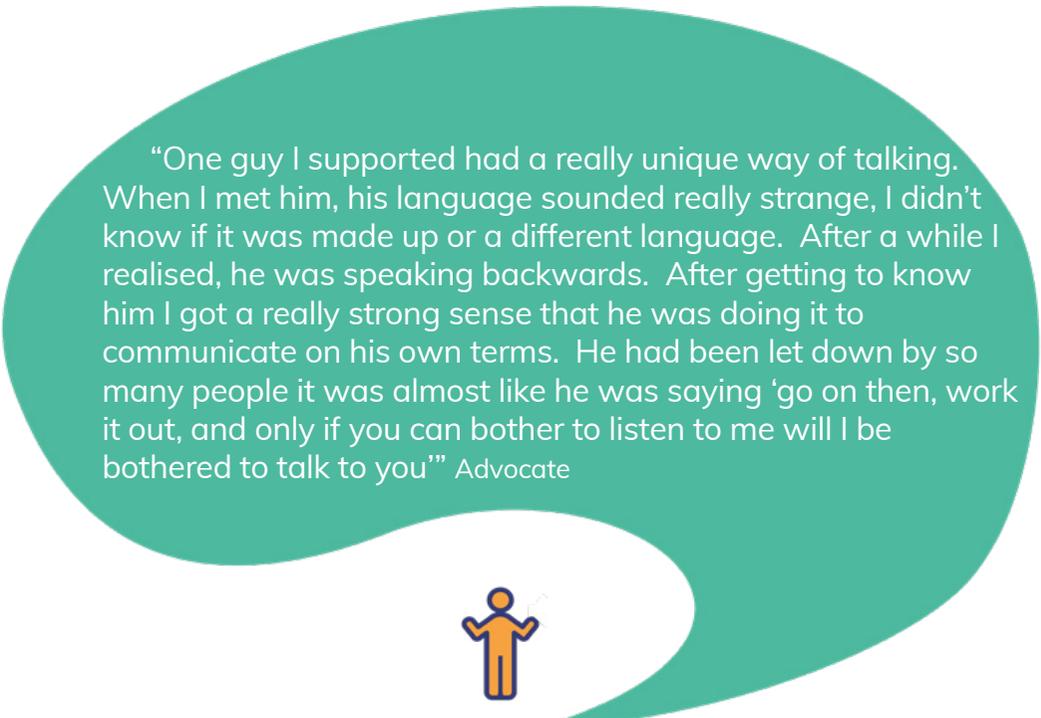
3. Advocates understanding learning disability and autism

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. Advocates understanding what people's non-verbal communication and behaviour was communicating, resulted in one advocate raising a concern that the approaches to care planning were not right and failed to consider the person's autism:



“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

4. Influencing plans and making things better

“I found out about [the patient’s] level of understanding” and “helped them to prepare what they wanted to say to services.”

Family member



While advocacy is about helping the person 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 questions and 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



5. 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 on 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.

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



We also heard from commissioners who had seen the benefits in commissioning providers for longer contracts, enabling investment in the advocates, the service and time for the service to become truly embedded within the community it serves.



“For a non-verbal person, long knowledge of the person is essential for any advocate” Family member



6. 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.

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 can be found in the Advocate Survey Analysis which can be [found here](#).



“[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.”



Advocacy commissioner

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, so 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 introducing automatic referrals: The opt out models of advocacy described in the Draft Mental Health Bill are welcomed and will help ensure people's rights to advocacy are better met, if enacted. Given the challenges identified in making and explaining the advocacy offer, opt out systems should be developed through coproduction and implemented so that people are given more than one opportunity to opt out, for example to enable advocacy services the opportunity to explain and make the advocacy offer at the point of admission, when a section is renewed or any significant decision-making process (such as C(E)TR, discharge planning, or medication review) is planned – not just upon admission.

The draft Bill introduces the opt out model to detained patients. We think that Opt Out should be extended to people with a learning disability and autistic people who are in hospital on an informal basis due to their additional needs as soon as possible.

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.

Current statutory entitlements fall short of ensuring people with a learning disability and autistic people have a right to access advocacy when at risk of admission to hospital. Whilst outside the immediate scope of this review, reviewers feel that people are at continued risk of a 'revolving door' approach to crisis and 'treatment' when their voices are not heard properly.

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 approaches between children and adult 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 focussed 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^[13].
- 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.

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.

¹³ [See more information about the Oliver McGowan mandatory training in learning disability and autism.](#)

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 to 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 highlighted that there is inconsistent access to advocacy 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

More information about the partner organisations involved in this report can be found on the [NDTi website here](#).



National Development Team for Inclusion