

Insights



Independent advocacy in restricted settings for people with a learning disability and autistic people

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background & context

The current system of providing care and support to people with a learning disability and autistic people has come under increasing criticism. Despite repeated recommendations for people to be supported in the community, there remain over 2000 people detained in restricted settings, many whom do not need to be there and are forced to 'stay too long in these settings and are subject to unnecessary restrictive interventions'. ⁽¹⁾

Such is the failure to move people with a learning disability and autistic people into appropriate accommodation, the Equality and Human Rights Commission issued a legal challenge against the Secretary of State for Health and Social Care. ⁽²⁾ The Joint Committee on Human Rights concluded that young people's human rights were being abused; that they were detained unlawfully contrary to their right to liberty, subjected to solitary confinement, more prone to self-harm and abuse and deprived of their right to respect for private and family life. ⁽³⁾ The NHS Long Term Plan clearly aims to reduce the number of autistic people and people with a learning disability being admitted into inpatient mental health services.

Plainly hospitals are often not the best place for someone with a learning disability and or autism, and the current care and support system is not working, with far too many people unable to access support to live a happy life in their own home.

Advocacy

Everyone detained in a mental health hospital is legally entitled to access support from an Independent Mental Health Advocate (IMHA). The advocate is there to provide a safeguard for people who are subject to the Mental Health Act and will support a person to express and communicate their views, participate in decision-making and understand what is happening. The advocate is also there to safeguard a person's rights. ⁽⁴⁾

Advocacy is ideally placed to support people with a learning disability and autistic people in these settings and advocates make a difference in many people's lives, frequently questioning decisions, supporting people at meetings, accessing Tribunals and using safeguarding processes to protect individuals. Advocacy often takes place in quiet unseen spaces - indeed good advocacy frequently goes unnoticed. Feeling empowered, having a greater sense of self or confidence, understanding more about what is happening doesn't happen at one 'tah dah' moment.

There are however concerns about the availability and quality of advocacy which has been described as 'very variable'. ⁽⁵⁾ In response to this, in November 2020, a group of advocacy providers and advocates came together to explore what is affecting the quality of advocacy and preventing it from having the impact needed.

The group heard from experts who have experience of restrictive settings, family members whose loved ones have been detained and a number of professionals who support and represent people with a learning disability and autistic people who are (or who are at risk of) being detained in restrictive settings.

The findings in this paper are the result of those discussions.

A group of approximately 25 people representing 18 advocacy services met on a monthly basis between November 2020 and June 2021. During this period seven online remote focus groups were held. The initial meeting was an open discussion wherein participants identified key themes and issues affecting the delivery and impact of advocacy. The themes were collated into a high level list of discussion topics which informed subsequent sessions.

A number of expert speakers were invited to the monthly meetings. This was to ensure the topic discussions were informed by people who had used or worked alongside advocates. We would like to extend our sincere thanks to the following people who contributed to the discussions in that role:

- Alexis Quinn, autistic campaigner and author
- Julie Newcombe, mother, campaigner and founder of Rightful Lives
- Kirsty Stuart, solicitor, Irwin Mitchell,
- Lloyd, expert by experience
- Jim Blair, learning disability nurse and friend of Lloyd
- Jill Corbyn, NDTi associate

The following themes were identified as factors having significant impact on the quality of advocacy.

#1 Inconsistent and poor commissioning

Put simply, independent advocacy is not resourced and funded to the level it needs. There is little evidence of commissioners agreeing funding and contracts in response to local demand but lots of evidence of advocacy services being asked to increasingly do more with less money available. The consequences of this are obvious: advocates are not equipped with the resources to consistently and effectively advocate to the standard required.

There are also concerns that commissioning does not allow enough time and space for advocates to deliver impactful advocacy. For instance, some people with a learning disability and some autistic people detained in these settings may lack capacity to instruct their advocate. This means the advocate will adopt an approach called 'non instructed advocacy' to inform their work. This approach takes much longer to use as the non instructed advocate has to spend significant time to establish what the person's likely views are and understand what the person would want to express.

A common complaint from advocates is that they are not given enough time to do this.



"Every year we get a reduction in funding"

Where contracts are in place, there is huge variability across the country in what is commissioned: there are contracts which limit the number of hours the advocate can work, hours can be 'capped' after which the advocate needs permission to continue to offer support. Other contracts restrict the type of 'issue' an advocate can offer support with: if a person needs support with a complaint, in some areas the IMHA can take this up, in others this should be referred to a specialist NHS complaints advocate – who may or may not have any experience of mental health settings.

There are however some pockets of strong practice. We saw instances where commissioners had considered the need to offer flexibility and extended advocacy to informal patients, people using mental health services in the community and even family members where this promotes voice and better planning.

This variability in what is commissioned obviously contributes to the wide fluctuation in what can be offered – leading to the inconsistencies in people's experiences around what support they can access.

Who commissions?

Although the Code of Practice which accompanies the Mental Health Act is clear that commissioning IMHA rests with the Local Authority where the hospital is located, advocacy is currently commissioned by a range of bodies including the local authority, the CCG and also by private hospital providers themselves.

This is problematic in many respects. Firstly, it can lead to multiple providers being commissioned by different bodies. It is not unusual for there to be a choice of 3 or even 4 providers within a hospital. This in turn introduces confusion for patients, families and advocates as to who is the named IMHA (with the associated rights and duties conferred on the role through the Mental Health Act). This also leads to multiple advocates 'dipping in and out' of a person's life, rather than one advocate providing robust support throughout the person's journey in hospital.



“Private hospitals commissioning advocacy is problematic. It threatens our independence and is massively confusing”

Secondly a lack of clarity of who commissions (or multiple commissioners) can obfuscate monitoring data: there is confusion of who is monitoring uptake and outcomes, which in reality means that no-one does. There is also a general concern that it is not in the interests of the hospital to publish monitoring data about concerns the advocacy service has raised so this is something that is not routinely completed.

"The commissioner doesn't care if we support 10 or 100 people"

Thirdly, having multiple commissioning bodies can threaten the independence of the advocacy service, especially when commissioning is by a private hospital provider. It gives the impression that advocacy is part of the hospital and their ability to challenge is compromised. Considering how crucial it is that advocacy is independent, any threats to this - perceived or real - must be addressed.

#2 Limited skillset of advocates

There are many expert and gifted advocates who have developed skills in providing advocacy and are able to use these skills to deliver effective advocacy. However the group identified three main gaps where advocates need to develop robust skills:

Understanding autism

There is a lack of co-produced training available to advocates on understanding autism and learning disabilities. This is creating very low levels of confidence as advocates are uncertain of how to communicate, support and understand people. This can create a culture where the advocate is so occupied on not making mistakes re 'understanding autism' that they forget to focus on the person and what autism means for them. This is a fundamental requirement and must be urgently addressed.

"The advocate didn't know how to communicate with him. He said he didn't want to see her so she left. She never came back. He had no idea what he was saying. He needed an advocate who knew that"

Understanding the broader context

Advocating with people with a learning disability and autistic people requires the advocate to understand the broader context of what is happening. Many advocates are not aware of the national context of the Transforming Care programme, reviews into restrictive practice, concerns of the use of segregation, CQC work into closed cultures and the wider policy drive to get people out of hospital. For advocates to be effective there needs to be greater awareness of these themes and a general upskill in knowledge.

Core advocacy skills

Advocates must have skills to constructively challenge decisions, processes and environments where human rights are threatened. This means advocates need to nurture and value basic advocacy competencies of professional curiosity, willingness to ask questions, person driven approaches, how to use non instructed advocacy and a keen understanding of the law. There also needs to be more confident use of reasonable adjustments and disability rights.

"There is a nervousness in getting it 'wrong' which stops advocates from trying things and taking risks"

#3 Reticence to work with families

Most advocates do not routinely work closely alongside family members. This undoubtedly arises from the tradition of advocacy being 'person led' and solely

"advocates need to work with families a lot more. They should ask parents how their child communicates. We know them best and the advocate could learn a lot from us"

focusing on what the individual wants to express. There is a strong culture and history within advocacy that is based on individual rights. However, this can fail to see people in the context of community and families.

Advocates have traditionally resisted being influenced by family members who may need advocacy themselves to amplify their own

voice. Advocates must focus on the individual's voice and choice – not family views – and have historically been wary of family views 'overtaking' those of the individual.

There is also a damaging perception that families are combative/difficult or that their involvement is not helpful in a person's recovery. This 'perception' is often portrayed by the hospital and is not always true. Advocates should be mindful of this and be careful to challenge these attitudes when carrying out their work, especially when this creates a culture where advocates unconsciously avoid connecting with families.

*"advocates often find it easier to talk and liaise with professionals than family. Advocates do not stop to consider whether its appropriate to consult with professionals – but we do all the time with the families.
WHAT IS THAT ABOUT?"*

The reality is that family members are often the person's best and most natural advocate. Independent advocates need to know when to work alongside and align their support to existing familial networks rather than working in parallel. This is not only true when understanding the person's communication and care needs, but especially when family are intrinsic to long term planning and getting the person out of hospital.

#4 Lack of support from mental health providers

"their [MH providers] understanding of advocacy is shockingly poor"

It is critically important for independent advocates to have positive relationships with mental health providers. However, many people reported difficulties in engaging with staff and developing relationships.

Obstacles included

- general resistance to advocacy,
- refusal to share information,
- questioning why advocates were there,
- not informing advocacy when people are admitted or moved,
- not inviting advocates to meetings.

"We are not told anything: not invited to meetings, not even told when someone leaves"

This has a massive and detrimental impact on how advocacy is accessed and used by people. Not being informed in a timely way of important decisions, means the advocate is denied the time needed to support the person and gather information on what is important to them. Blocks to advocacy (such as not being invited to meetings) results in the advocate not having a full or broad understanding of what is happening in the person's life.

One of the most effective strategies in developing relationships was having a regular physical presence on the ward where roles, boundaries and expectations were communicated frequently. Undoubtedly, more support is needed to educate and encourage mental health professionals to support advocacy.

#5 Isomorphism and independence

Isomorphism describes what happens when processes or structures of one organization begin to take over another. There are real concerns that advocacy services run the risk of becoming part of the very mental health system it is designed to question.

This was evident in the following instances:

- Advocates becoming more aligned with the staff team rather than people who draw on advocacy. This can happen simply because the advocates are known as 'staff' themselves and/or have an office onsite. But it can also be small indicators such as wearing ID lanyards of the same colour as the hospital or being a key holder.
- There is evidence of advocates adopting the medical model: language including words like 'patients', 'case loads', 'issue based advocacy' perpetuates the idea of people in need of fixing.
- Advocates spending too long within one setting and becoming desensitised to the person's experience of being a patient in hospital

"I know cultures can creep in where we [advocates] are just too pally with nursing staff – for instance being a key holder aligns us more with staff than people using advocacy"

All of these instances can create a culture wherein the advocacy service accepts, without question, information from the hospital - which can (and arguably should be) challenged. For example a person is labelled as 'difficult' or 'challenging' and subsequently given antipsychotic medication, when a deeper appreciation and understanding of what is causing the behaviour is needed.

"One advocate was terrified of me because of what the staff had told her about me. She couldn't wait to leave"

Advocates need to question the culture of the mental health institution but also the culture of the advocacy service.

When it works well....

Being independent allows advocacy to experience and approach services with a fresh, unfettered view. One advocacy service, commissioned by a local authority to provide advocacy in a specialist private hospital, held concerns that things were just not 'quite right'. This meant they increased their time spent on the wards and became aware of instances where people's rights were not being respected. This ranged from individuals not being included in decisions, being segregated from others, the overuse and inappropriate use of restraint and incidents which led to safeguarding referrals. The advocates documented their concerns, timelining incidents and raised these with the hospital directly. When matters were not addressed they continued to document their concerns and raised these with commissioners. At the same time, the advocacy service contacted CQC with evidence of concerns about patient safety and human rights abuses. This eventually led to CQC undertaking an unannounced inspection which led to enforceable action.

Strong, independent advocacy services are characterised by their ability to stand up and raise concerns where needed. This in turn, relies on strong advocates. Without this, advocates can too readily accept information that is presented by the hospital about people and behaviours. What is needed, is someone to question and check out the validity and truth about information, and advocates must do this starting from the perspective of the person they are supporting.

"We need confident advocates questioning the dominant culture. How often do we question, audit - even talk about this. Is this rewarded or punished - for instance hospitals complain about advocates who are then chastised rather than celebrated"

#6 An unhelpful reliance on issue based advocacy

"For people in restricted settings, advocacy may never end - there may always be issues ongoing whilst they are living in a restricted setting. In these settings advocacy is going to be a longer advocacy journey. We need to shift culturally from tasks to rights"

Overwhelmingly, statutory advocates rely on the model of issue based advocacy. This is where the advocacy is led by issues. Usually, the person using advocacy identifies the 'issue' and draws on advocacy to try and resolve the issue or achieve their goal. Within non instructed advocacy, the advocate usually identifies the 'issue' to work on. This causes many unwanted and unintended consequences which has an impact on quality:

- advocates dipping in and out of people's lives
- multiple advocates supporting a person throughout their time in hospital.
- advocates seeing people as single issues in need of fixing
- short term advocacy
- focus on mental health – or medical - issues in hospital
- little emphasis placed on systemic advocacy *
- limited opportunities to offer a 'watching eye'

"advocates want to 'do more' but line managers have to be focused on where time is spent and on what activities. This can create cultures where advocates are discouraged from going the extra mile and are encouraged to do the minimum, particularly where the service is underfunded"

What is needed is the opposite: longer term relationships which are based on a holistic understanding of what the person wants in their life and what is important to them. This is likely to include immediate issues of care and treatment whilst the person is in hospital but should equally include a focus on longer term goals, getting great homes and lives in the community and developing local networks, skills and relationships.

* Systemic advocacy describes when an advocacy organisation raises themes or issues that are system wide. Examples might include how the environment impacts on a group of people or staffing issues.

Conclusion

Independent advocacy has an important role to play in ensuring that people with a learning disability and autistic people receive the best care and support available. When it works well, advocacy can have a tremendous impact on getting people out of hospital and responding to human right concerns whilst a person is held in a restricted setting.

However too often advocacy is either not available when people need it or is not as effective as it needs to be.

Further work is needed to

- robustly fund advocacy
- improve the commissioning models
- clarify who should commission advocacy
- establish national monitoring of uptake and quality
- enhance the training offer to upskill advocates
- ensure training and monitoring is co-produced and co-delivered by experts by experience
- support mental health providers to understand and enable access to advocacy
- challenge the status quo within advocacy to ensure the dominant culture is one of independence
- enable advocacy to challenge robustly
- understand better approaches to working alongside families whilst advocating with the individual

The advocacy community must come together to address these concerns and resolve the problems outlined in this paper. But it cannot do it alone: it will need support and commitment from commissioners and mental health providers if it is to have the impact it needs to.

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Together

Warrington Speak Up

York Advocacy

Your Voice Counts

VoiceAbility

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