

Safeguarding and Closed Cultures – are advocates really keeping people safe?

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Strengthening the role of advocacy in Making Safeguarding Personal



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



Kate Mercer and Gail Petty

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in partnership with:



Advocacy in closed cultures....



Advocacy has always been a safeguard

People's voices

People's needs

People's preferences

People's rights

People's uniqueness

People's safety

What else???




But, recently
reports and
our review
found.....

...that at the moment, advocacy isn't always the effective component of safeguarding people in closed cultures that it should be. There are many reasons for this

The session we're going to start the conversation - explore closed cultures and how we can provide the best advocacy possible to people who live within and experience them





An ask for this session

- Open hearted
- Let's create a safe space
- Together we can make difference
- Willing to be uncomfortable
- Willing to learn and change
- Be Brave
- Be Vulnerable
- Be Curious
- Be Perfectly imperfect
- Start from a position that values people

What else?



Taken from the NHSE review – people’s experiences

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

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

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



Taken from the NHSE review – people's experiences

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

“If you have a problem and you'd like to speak to advocacy, I want to speak to them. They say sorry, call tomorrow. It goes to the advocacy control centre - it's their policy” Person who accesses advocacy

“I asked for an IMHA to visit my son, but they [advocacy provider] told me they would only visit if he asked them to. He doesn't have much speech and certainly wouldn't be able to do this. They told me I had misunderstood IMHA” Family member

“They aren't very independent. The advocate has an NHS pass and keys to the ward” person using advocacy



Taken from NHSE review – from advocates

“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”

“We do not provide ongoing advocacy – its issue based and then we close the case. People can re-refer but have to wait on a short waiting list again”

“Most of our advocacy is short term, rights based - like telling people what their rights are and Tribunals. We don't really get involved in the broader care and treatment plans or longer decisions”

“The whole sector has become so far removed from peer advocacy It feels like I'm working for McDonalds, we are just providing a service.”



Taken from NHSE review – from advocates

None of this is okay, but it's become normal

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

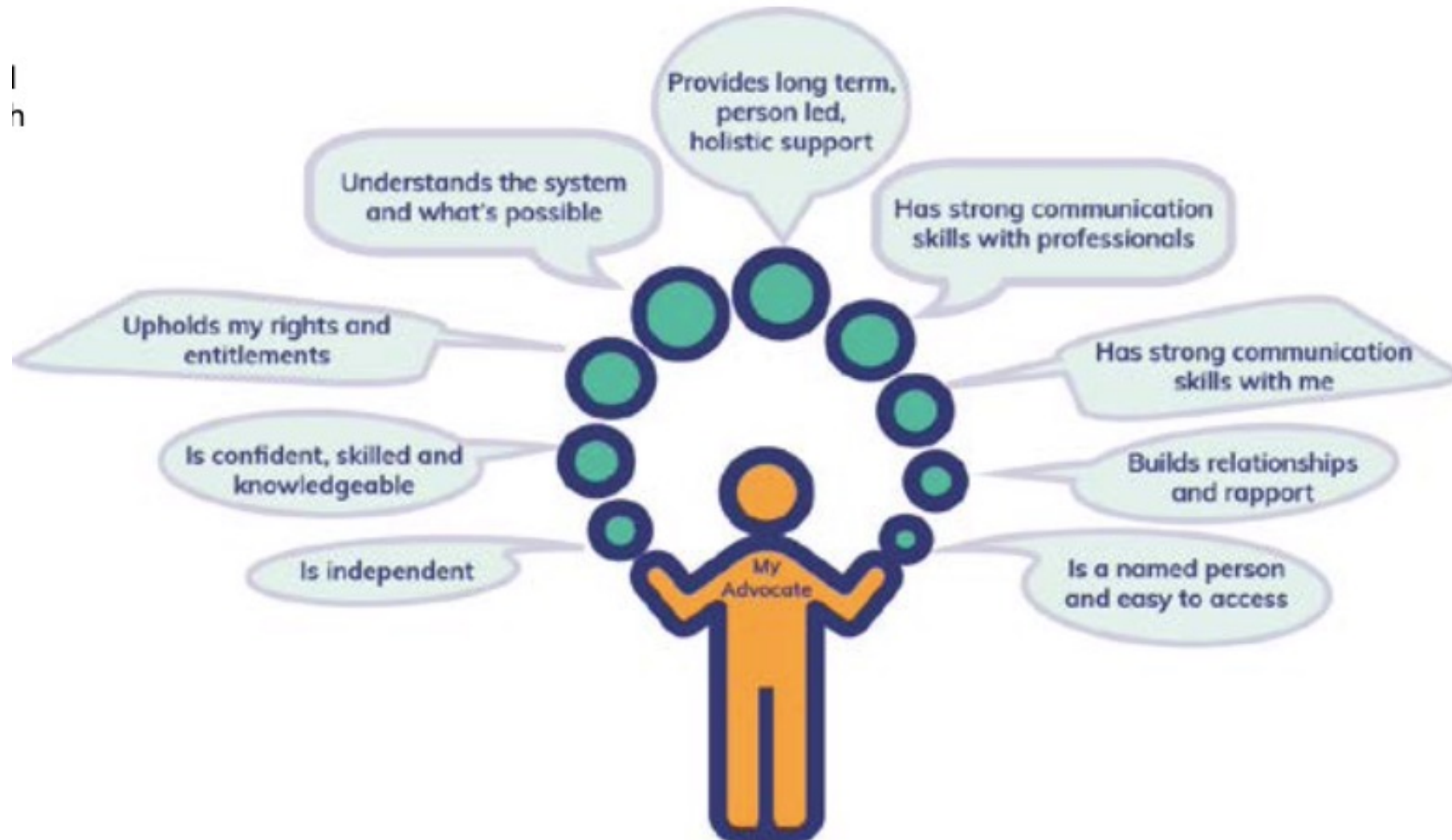
“We get a phone call and go over; we don't have a presence at all. There is a generic advocacy service on site, but they aren't IMHA. This is ridiculous for the patients and confusing”

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

“We have huge waiting lists for IMHA support due to not enough funding for advocates so sadly we can't support everyone who need the support”



What people and families want



CQC Out of Sight 2020

- Access to high-quality advocacy varied across the hospitals we visited and that the role of an advocate was not consistent.
- There was some confusion between the provider and commissioner about who the advocate was, or which organisation provided the services. This led to people being denied access to the service. In some cases, there was no evidence that advocacy had been offered to people. Even where people were allocated an advocate, they were not always engaged in decisions about the person's care.
- There were examples of where the advocate was not informed of certain people on wards.
- When people did have access to advocates, there were examples where advocacy was of a poor quality, where advocates were not upholding people's rights.
- Advocates were also under pressure themselves and felt they did not have enough time to support everyone that they were responsible for.



Thematic Review of the Independent Care (Education) and Treatment Reviews (Baroness Hollins) 2021

Advocates were involved in some, but not all IC(E)TRs. There was concern about the quality and/or independence of advocacy for some people and particular concerns for people who do not have families and the lack of independent specialist advocacy.

Overall, where advocacy was in place the quality was felt to be 'poor to alright'.



Safe and wellbeing reviews: thematic review and lessons learned 2023

The reviews indicated that not enough was being done to support people to maintain links with friends and family, or to access support from an independent advocate

Concerns were raised about timely access to advocacy and the quality of advocacy services. It often fell to family members to be advocates in place of professional advocacy

One of the main points was that the availability and quality of advocacy for people in hospital is generally inconsistent.



Safeguarding Adults Review on Whorlton Hall Executive Summary 2023

An illusion of advocacy provision for people with learning disabilities and/or who are autistic, and who are inpatients or at risk of being admitted to specialist hospital

Current arrangements for the commissioning and oversight of advocacy services and the skill requirements of independent advocates, are inadequate for people with learning disabilities and/or who are autistic, who are in-patients in specialist mental health hospitals or who are at risk of becoming in-patients. This leaves people in the most high-risk settings, the least well served and creates a false security that advocacy is in place.

What is a
closed
culture?



The CQC defines it as: a poor culture in a health or care service that increases the risk of harm. This includes abuse and human rights breaches.

The development of closed cultures can be deliberate or unintentional – either way it can cause unacceptable harm to a person and their loved ones.

Closed cultures are more likely to develop in services where:

- people are removed from their communities
- people stay for months or years at a time
- there is weak leadership
- staff lack the right skills, training or experience to support people
- there is a lack of positive and open engagement between staff and with people using services and their families

In these services, people are often not able to speak up for themselves - this could be through lack of communication skills, lack of support to speak up or abuse of their rights to speak up



How do we
spot
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Closed cultures implies secret and unknown:

While this can be true, in reality poor practice can be routine and systemic, seen by families and visiting professionals, 'in plain sight';

Unacceptable conditions can be normalised as visitors 'have seen worse';

While it appears much neglect can be unintentional due to poorly trained staff, numerous reports appear to demonstrate an abuse of power in small, mean but witnessed ways.





Why does it matter?



People have died and been harmed... experiencing unnecessary trauma and abuse

- Human Rights - and advocacy is all about upholding and securing rights
- Rights to liberty and freedom – unnecessary or overly restrictive practices
- Rights to dignity, privacy and respectful care
- Rights to family life
- Right to life
- Right to live free from abuse and the fear of it (inhumane and degrading treatment)
- Rights to adjustments and participation

Why should we care?



Independence, Hypernormalisation and Isomorphism....

What are the risks and
challenges?



What can we do to maintain and strengthen independence (guard against isomorphism)?



What can we do to
maintain awareness and
curiosity (guard against
hypernormalisation)....





What can we do to support open cultures in settings we visit?



What can we do to support open cultures in our own organisations?



Be present

- Spend time with people, build relationships, get to know how people respond. Know how to communicate with people with different needs - Notice changes
- Talk to other people who know the person well (with permission or if non-instructed)
- Question if you're unable to see people
- Drop in and move freely
- Cover gaps in service
- Get to know people and the environment, deeply. What's the culture? How are people spoken about? Are people involved in their care? What does it look like, smell like feel like? Notice changes
- Identify if anything is hidden
- Build relationships with staff – be known to them
- Ask questions
- Facilitate feedback – challenge and good practice
- Systemic advocacy
- What else?



Some practicalities

- Report, report, report
- Record, record, record
- Talk, talk, talk about what you see, hear, smell, feel when you are visiting people, in supervision, team meetings, reflective practice
- Think about culture in your organizations' – is it safe, open, reflective? Is there transparency and accountability?
- Reflect on rights and restrictions - Revisit Human Rights regularly. Understand trauma and the use of segregation and restraint.
- Update safeguarding training regularly
- Training
- Ask Questions – a lot
- Understand what person centered, strength-based care looks like and sounds like. Identify and talk about the good as well. Normalise best practice.
- Language
- Don't ignore your gut
- Partnerships, CQC, SAB, families etc
- What else?



My
colleague,
Peter Bates

We don't need training. Our moral compass functions perfectly well, and we knew straight away that Mengele was wrong, Tuskegee was wrong, Whorlton Hall was wrong. We might need help with complex areas.... but so do you. Finally, we all need to learn how to disagree well and find the high road that lies beyond our individual preferences.



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