



Review of Advocacy

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

Quotes from advocates in the anonymous surveys.

November 2021

1. Advocates were asked to share stories or examples of when they were able to provide effective advocacy for this group of people.

“I was able to challenge a CTO using chapter 20 of the MHA code of practice as the behaviour described was a form of communication rather than a mental health need and needed appropriate care planning rather than care and treatment under the MHA”.

“Allocated days were challenged when it was stated that the worker at the gym was trained in only one way of working, explained about restrictive practice and how indirectly this was occurring”.

“I suggested myself and "Bill" go for a walk & talk in the grounds before a review this was a strategy he identified in his person centred plan which prepared him for the meeting. Although "Bill" had his PCP with him, no one in the ward had looked at it. After the meeting "Bill" and I sat with his key person to ensure they understood what was in it and that it was part of "Bill" life story thus far”.

“Being IMCA trained and qualified it helps educate people and think differently. When I was an advocacy manager, I supported an advocate who was not an IMCA but on an IMHA case. A person with learning disability and who was autistic 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, completely new to the case was 'what is his concept of time?'. This had not been considered and I was able to offer advice in relation to a person's mental capacity to understand concepts. It turned out the person had no concept of time, so the plan was removed, and lessons were learnt”.

“Creating a profile of 'my bipolar' including signs of what to do, mania and depression etc. helped the advocacy partner to process and retain the information”.

“Using cue card or photos, building a rapport with them over time so that you become more familiar with them, and they can learn to trust you”.

“We have an advocate who has an autistic brother so has valuable personal experience. As part of his CPD, he has completed extensive learning disability/autism-related training. We have started to refer cases to him as a 'specialist' advocate in the same way we have 'specialist' advocates who work with children and young people. He has carried out really effective advocacy with this client group. However, there are pro's and con's with this approach”.

“Where clients are unable to access legal representation for hospital manager's hearings, the advocate is usually called upon. In these circumstances, I find advocacy to be most effective as it provides a platform to help the person express their views about their care and treatment”.

“In an MDT bringing examples of case law to the table makes them think more on what they should be doing”.

“By asking questions whether the MDT had considered the impact of the environment on patients erratic behaviour was able to crystallise differences between bipolar relapse and autistic meltdown”.

“I have used a laptop to show clients online videos explaining their detention and s.132 rights in a very simplified way. Also, I have used talking mats on one occasion”.

“I have a good Knowledge of AAC and was able to effectively communicate with my client and advocate their wishes”.

“Spending time with a patient face to face assists understanding, especially if the advocacy role is non-instructed. People have views and wishes to express if we listen effectively. I have worked with a number of young people on the autistic spectrum who were able to demonstrate their abilities once the boundaries of the environment were clear. Some of the work has been with staff teams to respond differently”.

2. Advocates were asked to share stories or examples of challenges to providing effective advocacy for this group of people. Many stories and examples were given.

“Person with learning disability on an ATU. Is a Muslim and wanted to pray. This was asked for over 2 months ago initially when he first made his wishes known to advocate. Still there is only a 'plan' in place for how to facilitate this and he has not been supported to pray beyond watching it and listen to prayers on TV, despite regular questions and pushing of ward staff by advocate. The small things make up someone's world. What was difficult was getting the system to work harder and faster - individual staff I spoke to were very supportive and said that right things, but then nothing happened with any speed”.

“In one case the person with autism had so many services involved in her care and treatment it became difficult to get past roadblocks towards her discharge. There was no one individual tasked with overseeing communication between teams and the individual”.

“Being asked to speak with "Sally" in a room that was small, dirty, no windows and or used as a storage area. I requested that we should be moved to the Managers office which was much more pleasant & accessible. This caused an issue however when I explained calmly that we would sit on the far side of the office where there was a coffee table and two armchairs near the window that looked out on the sensory garden. We were shown into the manager’s office”.

“When IMCA/IMHA cases overlap, professionals can be confused and refer for the wrong type of advocate. I find doctors in MH hospital lack understanding of the MCA 2005”.

“One occasion where the advocacy partner kept repeating they wanted to go home, left numerous messages. When their situation was explained to them in a couple of methods; still a difficulty in retaining, understanding, weighing up information”.

“Sometimes involvement of family members can mean that an advocacy referral is not made, which can be problematic if the patient cannot ask for advocacy and where family members have differing views and wishes to those of the patient, especially where decisions are heavily influenced by family members e.g. placement”.

“Patients often change their mind, examples of this involve where they initially ask for staff for advocacy support and once arranged, they would then refuse to engage with the process. This can be challenging at times as significant work may be undertaken up until meeting the client. However, patience and perseverance can sometimes help in these situations to eventually find ways of supporting the client in the way that suits them”.

“I have advocated for people within mental health settings who are in seclusion. Getting down to the seclusion unit and trying to forge an advocacy relationship in such circumstances is very difficult”.

“I have been working with a young man who has 3 members of staff at all times in a private hospital. Their understanding of autism and advocacy is poor”.

“The people I've worked with who are autistic are very analytical and staff at the hospital often seem to feel challenged by this - they do not seem to understand that it's part of the autism rather than 'behavioural', my service users like answers to their questions to include rationale from policy and this can sometimes be very difficult to access and/or is not forthcoming from the hospital management”.

“I hope I do have some examples, but I cannot think of a success at the moment! That in itself is telling - is it me and my advocacy or the system of our advocacy service or the wards that is making it harder to see successes?”