



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

Literature review March 2022

People with a learning disability and autistic people who are inpatients in mental health, learning disability and autism specialist settings have access to a range of different advocacy supports. Some of these advocacy services are set out in law and so people have a legal right to access them. In this chapter we will capture the key publications and research that relates to advocacy with people with a learning disability and autistic people.

Research has shown that any people with a learning disability and autistic people are placed in inpatient hospitals which can be inappropriate and a long way from home. Ideally, people should only be staying in these settings on a short-term basis but often their stay is too long, in many cases for months or years, in wards which are not appropriate, are not therapeutic environments and where the care is not personalised. The literature also shows that in many cases, people and their families are not provided with the information and support they need. This can, and often does, lead to significant distress and potentially to people communicating this distress via behaviour which can be challenging to care providers. (Care Quality Commission (CQC), 2020b; Department for Health and Social Care (DHSC), 2021).

Most people who are admitted to a mental health hospital and detained under the Mental Health Act, for however long, are entitled to independent advocacy from an Independent Mental Health Advocate. This is supported by National Institute for Care and Excellence (NICE) guidelines (2016; 2018) which state that people with a learning disability and autistic people should have access to independent advocacy in inpatient mental health settings. Advocacy is vital in inpatient settings and can support people to understand what is happening, voice their concerns and needs and participate in decision making. Advocacy can also be helpful for families supporting their loved ones (NDTi, 2012; Blackbelt Advocacy, 2021).

Whilst there is significant anecdotal and local evidence that advocacy is an effective support to people, advocacy remains an under-researched topic with minimal research and/or evaluation studies conducted, and research measuring the difference advocacy has made to people's lives is almost non-existent (Manthorpe et al., 2005; Manthorpe & Martineau, 2010; Ridley, 2018).

The lack of investment into research and evaluation of independent advocacy continues to be challenging for commissioners and providers of independent advocacy who want and need a strong evidence base to support sound funding decisions in relation to advocacy services.

A study looking at impact and outcomes of independent advocacy for children found that understanding of outcomes varied widely between different sites, groups and individuals (University of Central Lancashire (UCLAN) & National Children's Bureau (NCB), 2016). One problem found in this study was that there was no systematic way of capturing data and evidence. A lack of data on assessing and using advocacy has been found more recently by Mercer and Petty (2021) based on Freedom of Information (FOI) requests to all Local Authorities and CCGs across England.

Perry (2013) summarises that advocacy is useful and that it 'empowers' the individual, however, how this occurs cannot be specified. More recently Mercer & Petty (2021) write that the lack of data collected means it is very difficult to understand the potential impact that advocacy can have.

In 2014, Uclan published the only comprehensive analysis of IMHA services. The main aim of this study was to look at how IMHA services provided help to patients under the 2007 Mental Health Act, what makes for a good IMHA service and what factors influence the quality of service provided. It found:

- differences in access to and uptake of IMHA services, particularly between people in urban and rural sites, and between those in secure services, acute inpatient care and in the community on Community Treatment Orders (CTOs).
- those who need the IMHA service the most, access it the least. This included people with learning disabilities.
- unless a specific effort was made to understand the needs of different groups and how they might access IMHA services, people may not know about the service. This was particularly important for people from black and minority ethnic communities, people with learning disabilities, older people, with dementia, people who are hearing impaired or deaf, children and young people, people on CTOs and people placed out of area.
- people with learning disabilities who rely on mental health service professionals to access advocacy are at a disadvantage.

Advocacy and Individual Outcomes

Four articles or reports have published findings on advocacy outcomes in relation to advocacy with inpatients in mental health settings (these were not specific to people with a learning disability or autistic people). The first article was a research project evaluating the

specialist IMHA service for people in two specialist mental health and challenging behaviour units (Palmer et al., 2012). The research consisted of qualitative interviews with a self-selecting sample of ten long-term inpatients. Findings from this study indicated high levels of trust between the advocate and resident leading to increased satisfaction. People who were inpatients reported an increased sense of wellbeing, self-efficacy, and empowerment through using the service.

The second article was a research project evaluating the IMHA service in a high secure mental health hospital (Eades, 2018). The study specifically looked at self-determination within the inpatient population as this is related to psychological wellbeing. Questionnaires were co-produced with inpatients and consisted of questions providing quantitative and qualitative data. Data was collected from 115 inpatients and findings showed an increase in self-determination in 70% of inpatients. There were also increases in satisfaction in aspects of autonomy, competence, and all aspects of self-determination. This could be linked to a positive impact on psychological wellbeing.

The third report looked at the impact and outcomes of independent advocacy for children and young people (UCLAN & NCB, 2016). This study, commissioned by the Children's Commissioner for England, consisted of a brief survey of advocacy providers and in-depth case studies of six settings. The settings were chosen based on their understanding of outcomes and their methods for measuring them. One of these case studies was of an advocacy service for young people with mental health issues and the settings included inpatient care for young people detained under the Mental Health Act and an adolescent forensic/secure mental health facility. Whilst results were not reported by setting individually, it is possible to attribute quotes and findings to individual settings. These showed that for this setting young people were satisfied with the advocacy service they received, they felt their individual outcomes were achieved and they increased their self-confidence resulting in an increased ability to participate.

The fourth and final report looked at advocacy provision for children and young people (Children's Commissioner for England, 2019). Information requests were sent to Directors of Children's Services in local authorities across England and children and young people were spoken to. Whilst the report encompassed findings from a variety of settings some were from inpatient mental health settings. Generally, children reported that independent advocates were important in ensuring health professionals listened to them, that they felt empowered, and their confidence was increased. In addition, often the advocate enabled them to secure a good result or positive outcome to a specific problem. A case study of good practice in a young person's and children's inpatient setting was provided with examples of how advocacy provided good outcomes for children and young people.

The findings from these studies demonstrate that it is possible to set and report outcomes for individuals from individual advocacy services. It should be noted that these studies

represent findings from small samples, within a small number of settings and mainly based on self-report measures from questionnaires or interviews.

Advocacy at the Service Level

A number of reports discuss advocacy services. Whilst these reports were not necessarily peer-reviewed research reports, the findings they report were based on analysis of secondary data such as reviews and reports and primary data such as requests for data, interviews, and visits to settings.

Every year the Care Quality Commission produce an annual report monitoring the implementation of the Mental Health Act. The recent reports for 2018/2019 and 2019/2020 found that there were ongoing difficulties with providing IMHA support making access to the service difficult. This was even more so during the COVID-19 pandemic, with the service being limited due to measures in place to protect patients at a time when the service was even more crucial (CQC 2019; 2020a). The lack of provision has been highlighted in other reports. Baroness Holland in her thematic review of Care and Treatment Reviews (C(E)TRs) found that there was a lack of specialist advocacy (DHSC, 2021) and for those in inpatient mental health settings access was variable (CQC, 2020b). This is also the case for young people and children with limited, and even rationing of, independent advocacy provision (Children's Commissioner for England, 2019). However, this is not a new phenomenon with reports of variable IMHA services being reported less recently (Newbigging et al., 2015; Social Care Institute for Excellence (SCIE), 2015).

Another apparent reason for the lack of provision and access to advocacy services is that it is often not clear who is providing the service which results in a lack of referral. In addition, advocates may not be informed of patients on wards, so it is not provided (DHSC, 2021; CQC, 2020b; Blackbelt Advocacy, 2021).

These issues often arise because mental health staff do not know about advocacy in general, the different types of advocacy, nor understand the role of the advocate (Carver & Morrison, 2005; CQC, 2019, Blackbelt Advocacy, 2021; DHSC, 2021). As Newbigging et al., (2015) state, uptake of IMHA services is reliant on understanding of the role of the advocate and having a positive attitude towards advocacy services. In turn, this leads to improved communication and positive working relationships between ward staff and advocates which leads to a more effective service ultimately benefitting people receiving the advocacy service (McKeown et al., 2014).

A further issue in the delivery of advocacy services is the quality of the service being offered. In their review of mental health inpatient settings, the Care Quality Commission (2020b) stated that advocacy services for inpatient were often of poor quality and one report found that the quality was often described as 'poor to alright' (DHSC, 2021). However, where there

are high quality advocacy services these are distinguished by advocates taking the time to get to know people and offering a personalised service.

The quality of advocacy services is highly reliant on the individual advocate and, again, there are issues. Whilst there are many advocates of high and outstanding quality, Blackbelt Advocacy (2021) outlines three areas where advocates need to develop their skills:

- The first is a lack of understanding of autism and learning disabilities resulting in advocates being unsure about working with this population.
- In addition, they are also unaware of the broader context related to provision of services for autistic people and people with a learning disability.
- Finally, advocates need to ensure they have the requisite skills to work in advocacy supporting people. This includes working with young people and children, as often advocates are underqualified to work with this population (Children's Commissioner for England, 2019). The skills needed to work with young people and children, especially younger children, are often underestimated, not only by advocates, but by people in general. Alongside this is the reluctance, by advocates, to work with families who can support advocates in long-term planning and getting the person out of hospital (Blackbelt Advocacy, 2021).

Another problem related to the quality of advocacy services offered is some advocates focus on issue-based advocacy. Blackbelt Advocacy (2021) list the problems associated with this approach and the impact on quality, but, overall, this prevents advocates taking a long-term and personalised approach to their work with people. Finally, there is the issue of independence of the advocate mentioned in several reports (CQC, 2020b; DHSC, 2021; Blackbelt Advocacy, 2021). This may result in cultural changes in the work of the advocate with closer working with medical staff rather than the people they are supporting, increased use of medical language and staying too long in one setting which results in a normalisation of the setting which is unhelpful for those they are working with. Overall, this can lead to a lack of challenge and questioning of the hospital service and the advocate not enabling people to voice their concerns and needs.

Commissioning of Advocacy

Various reports also provide evidence on the commissioning of advocacy. There is clear evidence that advocacy is under-resourced and under-funded, arguably especially for people with a learning disability (Roberts et al., 2012; Newbigging et al., 2017; 2021; Blackbelt Advocacy, 2021). There appears to be a lack of data on the commissioning of advocacy services for autistic people. With advocacy not being funded to the level it should be this automatically impacts on quality of provision. In addition, with a lack of understanding of duties regarding commissioning there are often constraints placed on the advocacy that is commissioned with hours and/or issues being limited. For autistic people and people with a learning disability this is problematic as often, due to communication

issues, there is a requirement for non-instructed advocacy which can be more time consuming (Blackbelt Advocacy, 2021; Mercer & Petty, 2021).

The lack of understanding advocacy and the role of the advocate highlighted above, often filters down to commissioning and there is evidence of a lack of understanding in what is being commissioned and who is commissioned to undertake advocacy work (Newbigging et al., 2017; 2021; CQC, 2020b) with additional evidence that advocates are not involved in C(E)TRs (DHSC, 2021). In addition, there is often little, or no, advocacy commissioned for children and young people (Mercer & Petty, 2021). Whilst it should be clear who is commissioning advocacy services there is evidence that there is variability in who is commissioning including from private hospitals (Blackbelt Advocacy, 2021; Mercer & Petty, 2021). This results in a lack of clarity regarding who is being commissioned with the potential for multiple, or no, advocates being commissioned and, depending on who is commissioning, the independence of the advocate is compromised. All these issues are compounded by the fact that there is a lack of monitoring data on commissioning of advocacy so trying to gain clarity is difficult (Newbigging et al., 2017; 2021).

Conclusions and Recommendations from the literature review

From this literature review it is clear there is a paucity of literature and robust evidence relating to advocacy, in its many forms, and inpatient care of people with a learning disability and autistic people in mental health, learning disability or autism specialist hospitals (Manthorpe et al., 2005; Manthorpe & Martineau 2010; Macadam et al., 2013; Perry, 2013; Ridley, 2018). The limited evidence does tell us that advocacy makes a difference to those who receive it (Palmer et al., 2012; UCLAN & NCB, 2016; Eades, 2018; Children's Commissioner for England, 2019). However, there is a need for more research and evaluations of advocacy to be commissioned.

This should include both qualitative and quantitative studies, and studies focused on advocacy for children and young people rather than the reliance of case studies and anecdotal evidence which currently exists (Macadam et al., 2013; UCLAN & NCB, 2016; Eades, 2018).

Evaluation of advocacy also needs to have a focus on outcomes, both at the individual and service levels (Newbigging et al., 2017; Ridley, 2018). Currently, there is no national set of outcomes for the provision of advocacy as this is somewhat difficult; however, there are outcomes frameworks which could be utilised to provide a national framework (NDTi, 2016a; 2016b; UCLAN & NCB, 2016). Any evaluation studies should also be coproduced with people with a learning disability and autistic people (Macadam et al., 2013; Watts, 2017; Ridley, 2018). As a minimum there should be national collection and monitoring of data of advocacy services so that some analysis and understanding can be gained of the commissioning and provision of advocacy (CQC, 2019; 2020b; Blackbelt Advocacy, 2021).

In terms of access to, and delivery of, advocacy there needs to be a fundamental review and investment in advocacy for, not only for people with a learning disability and autistic people in mental health, learning disability or autism specialist hospitals, but also more generally (Carver & Morrison, 2005; Newbigging et al., 2017; 2021).

This should also include mapping of providers so there is clarity regarding what is available and where (Macadam et al., 2013).

There are calls for enhanced access to advocacy for people with a learning disability and autistic people and for greater access for children and young people within these groups as well as more generally (UCLAN & NCB, 2016; Children's Commissioner for England, 2019; [Voiceability](#) & Mercer, date unknown). In addition, advocacy should be provided on an opt-out basis rather than opt-in basis so that everyone who should receive advocacy gets it and that referrals do not get lost (DHSC, 2021; Blackbelt Advocacy, 2021).

There should be minimum standards for the provision of advocacy (DHSC, 2021) and further training for advocates working with people with a learning disability and autistic people (Blackbelt Advocacy, 2021). The training should encompass working with children and young people as well as adults, working holistically, working with families, personalisation of advocacy and the need to be independent (Children's Commissioner for England, 2019; DHSC, 2021; Blackbelt Advocacy, 2021).

In addition, any training should be coproduced and co-delivered with people with a learning disability and autistic people (DHSC, 2021). As well as the training of advocates, there needs to be training of mental health staff and others working in inpatient care with people with a learning disability and autistic people in mental health, learning disability or autism specialist hospitals. Training should cover what advocacy is and its value as well as the role of the advocate (Carver & Morrison, 2005; Newbigging et al., 2014; 2017; Blackbelt Advocacy, 2021). This would enable enhanced communication and relationships between advocates and staff ultimately benefitting those being supported by advocates (McKeown et al., 2014).

Finally, in relation to commissioning, as already stated there should be a national database of commissioning of advocacy as well as a national agreement on commissioning of advocacy for people with learning disability and autistic people to ensure they get the service they need (Children's Commissioner for England, 2019; Mercer & Petty, 2021; VoiceAbility & Mercer, date unknown)

In conclusion the following recommendations can be made:

- More research and evaluations of advocacy need to be commissioned.
- Evaluation of advocacy needs to have a focus on outcomes.

- Evaluation studies should be coproduced with people with a learning disability and autistic people.
- There should be national collection and monitoring of data of advocacy services.
- A review and investment of advocacy for inpatients with learning disability and autistic people in mental health, learning disability or autism specialist hospitals, as well as of advocacy more generally, should be undertaken.
- There needs to be enhanced access to advocacy for people with learning disability and autistic people and for greater access for children and young people within these groups.
- Advocacy should be provided on an opt-out basis.
- Training for advocates working with adults, young people and children with learning disability and autistic people should be provided.
- Training should be coproduced and co-delivered with people with learning disability and autistic people.
- Training about advocacy should be provided for mental health staff and others working in inpatient care with people with learning disability and autistic people in mental health, learning disability or autism specialist hospitals.
- There needs to be a national database of commissioning of advocacy as well as a national agreement on commissioning advocacy for people with learning disability and autistic people.



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