



Independent mental health advocacy is still developing in England since it was introduced in 2007, and this article reviews progress so far

The right to be heard: independent mental health advocacy services in England

The controversy surrounding the Channel 4 *Cutting Edge* documentary 'Ian Brady: Endgames of a psychopath', screened in August, about mass murderer Brady and his 'mental health advocate' – who allegedly took a sealed envelope containing details about where the body of one of his victims is buried – exposed a general lack of understanding about the nature of mental health advocacy, at the same time as raising public interest in the role.

But what is the state of mental health advocacy in England? The University of Central Lancashire recently undertook a large-scale study of independent mental health advocacy (IMHA) services, which details the role in relation to the psychiatric system and makes the case for good quality independent advocacy. In this article we provide a snapshot of the main findings from the study. The full report can be found at: http://www.uclan.ac.uk/schools/school_of_health/the_right_to_be_heard.php

IMHA and the Mental Health Act

Self-determination is a fundamental principle, enshrined in law and in health and social care policy. With its origins in the service user movement, advocacy serves to promote greater self-determination and empower people to have greater control and choices in their engagement

with services. The importance of the active participation of people in planning their care and treatment while detained under the Mental Health Act (MH Act) is one of the key principles on which the MH Act rests. Thus, IMHA services were introduced by the MH Act (2007) to safeguard the rights of people detained under the MH Act (1983) and to enable them to exercise their rights through supporting participation in decision-making.

The IMHA role

Helping patients to obtain information about and understand the following:

- Their rights under the MH Act
 - The rights that other people (e.g. nearest relative) have in relation to them under the MH Act
 - The particular parts of the MH Act that apply to them (e.g. the basis upon which they are detained) and which therefore make them eligible for advocacy
 - Any conditions or restrictions to which they are subject (e.g. as a condition of leave of absence from hospital, a community treatment order or a conditional discharge)
 - Any medical treatment that they are receiving or might be given and the reasons for that treatment, or proposed treatment

KEY WORDS

Independent Mental Health Advocacy
Mental Health Act
Self-determination
Service users
Empower
Choice
Control
Enabling
Recovery

AUTHORS

Karen Newbigging, Mick McKeown and Karen Machin on behalf of the IMHA project team, University of Central Lancashire

Target audience

Mental health service users and carers, independent mental health advocates, mental health professionals, service providers and commissioners.

Take-home messages

- Good quality IMHA services are easy to find and contact, and have the confidence and trust of the service user. They enable the person to express their views and be active participants in their care and treatment under the Mental Health Act.
- IMHA services need to be commissioned in an informed way: investment needs to match local need and potential demand, and should be grounded in an understanding of the particular barriers that different groups face.
- IMHA services need to involve people with lived experience in their design and take account of the diverse populations that they serve. They should reach out to communities and factor their specific needs into the way in which the service is provided.
- Mental health services play a crucial role in providing an enabling context within which IMHA services are delivered. The attitudes of mental health professionals and their understanding of advocacy can make a difference to whether qualifying patients access the service.

- The legal authority for providing that treatment, and the safeguards and other requirements of the MH Act that would apply to that treatment
- Helping patients to exercise their rights, which can include representing them and speaking on their behalf
- Supporting patients in a range of other ways to ensure that they can participate in the decisions about their care and treatment.

The numbers of people detained under the MH Act (1983) has steadily risen over the past 20 years and, although only recently introduced, the numbers of people being placed on community treatment orders (CTOs) reflects this trend.

Additionally, care regulator the Care Quality Commission (CQC) has consistently reported disproportionate rates of detention, negative experiences, dissatisfaction and poorer outcomes for people from black and minority ethnic (BME) communities, particularly black African and black Caribbean men (CQC, 2011). People detained under the MH Act are particularly disempowered and as a consequence may find it difficult to get their voice heard and have their rights protected.

“No matter how coherent, how rational, how considered my arguments and my explanations for events are that assumed level of incompetence undermines it because you’re given sub status.” (Non-IMHA user)

This has all sorts of consequences and may contribute to people being unable to fully participate in choices about their treatment under the MH Act and thus lead to poorer outcomes. These include negative consequences for the individual and for the service, such as incurring higher costs through people being detained for longer because of apparent non-compliance or a failure to resolve issues that are critical for the service user.

Overall, there has been relatively little research on mental health advocacy to guide commissioners or providers of IMHA services on what constitutes high-quality provision. The good practice guidance published by the National Institute for Mental Health England (NIMHE, 2008; NMHDU, 2009) was based on codes of practice and standards developed during 30 years of experience in the advocacy movement (see, for example, Action For Advocacy www.actionforadvocacy.org.uk/).

Accessing IMHA services

Since the introduction of IMHA services, access has been identified as a problem. In 2010, the CQC found that nearly one in five (18%) wards did not have access to IMHA services, and that some staff, who had a duty to explain the IMHA service to patients, did not understand it (CQC, 2010).

Early experiences of commissioning IMHA services highlighted that particular groups found access to IMHA services problematic, particularly people from BME communities (Hakim & Pollard, 2011) and people placed out of area (CQC, 2010). Furthermore, some IMHA services reported that their funding was inadequate to cover the demand for their services and that some commissioners had cut back on non-statutory advocacy. All of this raises questions about

commissioning and providing of IMHA services to ensure that all those who qualify are able to access them. This is an opportune time to consider this given that the responsibility for commissioning IMHA services passes to local authorities in 2013, as a consequence of the Health and Social Care Act.

Determining the quality of IMHA services

Our study was commissioned by the Department of Health to ascertain the extent to which IMHA services in England are providing accessible, effective and appropriate support for the diversity of qualifying patients, and to better understand the factors that affect quality. It was intended that the study would obtain robust evidence to inform the commissioning and delivery of high-quality IMHA services.

The research was undertaken by a team from the University of Central Lancashire that involved 10 mental health service users from different ethnic backgrounds and with experience of being detained under the MH Act.

The methods used were designed to gather information on the experience of and outcomes from IMHA services and included focus groups, interviews and analysis of case notes in eight case study sites in England, selected to reflect differences in local populations and the way IMHA services were organised and delivered. Nearly 300 people took part in the study including more than 100 who qualified for IMHA services, as well as mental health professionals, IMHAs and commissioners.

The need for and value of advocacy services

The need for advocacy for people in psychiatric units, long identified by mental health service users, was found to be ever-present. People ordinarily able to speak up for themselves can find the experience of detention disabling and disempowering. Many people we interviewed described adverse experiences of admission and detention under the MH Act, including force being used during admission and to administer medication, despite people’s obvious vulnerability at a time of personal crisis.

We found that when people used advocacy services they generally found it valuable, serving to build their confidence to articulate their views as well as creating the conditions for a more respectful dialogue between mental health service users and professionals.

This need was not restricted to those detained under the MH Act as informal inpatients can also experience barriers to active participation in their care and treatment. As a result, the National Institute for Health and Clinical Excellence (NICE) (NICE, 2011) and the Welsh Government (2011) recommended that advocacy should be widely available to all mental health service users in psychiatric units. The Centre for Social Justice (2011) has also identified advocacy as an essential safeguard for people from BME communities prior to admission when compulsion under the MH Act is being considered.

Access to IMHA services

Although there is a clear need for advocacy we found that, overall, less than half the number of qualifying patients in our case study sites were accessing IMHA services. The exception was a secure service where people were automatically referred to the IMHA service on admission and there were few people entering or leaving the service.





People on CTOs were much less likely to access IMHA services, with less than 5% doing so in two of the study sites. There were also differences in the access to, and uptake of, IMHA services in urban and rural sites – with poorer access in urban sites reflecting higher detention rates and a more diverse mix of qualifying patients – and between secure services and acute inpatient care, reflecting lengths of stay. It was also evident that specific groups were not being well served by IMHA services, including:

- People from BME communities
- People with learning disabilities
- Older people with dementia
- People who are hearing impaired or deaf
- Children and young people
- People placed out of area.

The reasons for this appeared to be two-fold. First, none of the commissioners in our case study sites had undertaken a needs assessment that had examined the diverse needs of qualifying patients. For example, the issues in relation to the higher use of MH Act, including CTOs, for some BME groups had not been considered.

Second, IMHA providers, although expressing a commitment to equal opportunities, tended to operate on the basis that one size fits all. Indeed, we found that, unless a specific effort was made to understand the needs of different groups and how they might access IMHA services, qualifying patients may not know about the service or might decide that it was not for them.

A range of other factors also influenced access to IMHA services, including the service users' familiarity with and trust in the service, and the measures taken by mental health and IMHA services to promote the service.

“Well I heard that she was doing a good job, the lady who was here and she's very passionate about her work so... I heard a lot of good things about her so I thought I would give it a try and see if she could help me.” (IMHA partner)

The one critical factor for access was an understanding of the IMHA role. Service users did not always understand the purpose of IMHA services or confused it with the Independent Complaints Advocacy Service (ICAS) or a support worker role. A small number of service users felt that the real purpose of IMHA services was to maintain the status quo.

Mental health practitioners varied in their understanding of their obligations under the MH Act to promote the service, with some being completely unaware of this. There was also confusion with the independent mental capacity advocacy (IMCA) role, with some professionals assuming that IMHA services are only for people who are both detained under the MH Act and lack capacity.

Some mental health professionals appeared to be gatekeeping access to IMHA services by making judgments about who might benefit, rather than understand that this was a right.

One way of addressing many of these access difficulties would be to provide IMHA services on an opt-out rather than an opt-in basis, meaning that all qualifying patients would have the opportunity to meet with an IMHA and could decline the offer, once they have adequate information. It is important, however, that this offer is not a one-off and that consideration is given to the timing

of it and to reiterating the offer; proactive and visible IMHA services – with time and capacity to visit wards and teams regularly – is one way of facilitating this.

Access to IMHA services could be improved by ensuring:

- A needs assessment to underpin commissioning of IMHA services to reflect local needs
- An equality impact analysis to identify whether and how particular groups might be disadvantaged
- A systematic method for recording and sharing information between mental health and IMHA services
- An opt-out rather than opt-in system to overcome gatekeeping and other barriers to access
- Availability of promotional information in a variety of formats, created in partnership with potential IMHA users
- Mental health professionals understand their obligations in relation to promoting IMHA services and the purpose and role of advocacy
- Community organisations are commissioned to provide culturally appropriate IMHA services
- Availability of bilingual advocates – including British Sign Language – and access to trained interpreters if this is not possible
- Support for peer promotion of IMHA services including awareness raising for service user and carer groups.

Making a difference to care and treatment

Service users and mental health professionals recognised the main benefit of IMHAs was ensuring service users had a voice. IMHAs had empowered service users to exercise their rights by, for example, appealing the section, accessing legal representation, and participating in a Care Programme Approach meeting, managers' hearings, ward round meetings and tribunals:

“She came in to see me and started talking to me. She said ‘have you got a review?’ and ‘what are your problems?’ and went through everything with me... and so we started talking and as you're talking you start to think, oh yeah, I should say this.” (IMHA partner)

For some service users, the outcome of the IMHA intervention was that they came to accept their detention under the MH Act because the IMHA helped them to understand that this was the way to achieve the outcome they wanted: “It's not changed anything that's happening here at all... [But] it's made me feel better within myself because people are treating me as a human being and not a bit of dirt under their feet... It gives you confidence within yourself.” (IMHA partner)

While a concrete outcome, such as changing the level of restriction, or lifting the section might not be achieved, there was a high level of satisfaction with the process. Thus it is possible to distinguish the impact of IMHA in terms of the process and the tangible (action orientated) outcomes. We found more evidence for positive experiences of impact identified in terms of the process, resonating with the findings of Townsley, Marriott & Ward (2009).

Proxy or crude measures of outcome to assess the effectiveness of IMHA would therefore be unhelpful, and any measurement needs to incorporate process and outcome measures. These will include individual service user-defined outcomes – for example, feeling that

they know more about their rights or have been able to participate in decision-making more fully – as well as aggregated outcomes, such as an increase in the number of successful appeals.

The role of mental health services

The Code of Practice places specific responsibilities on mental health services to promote access to IMHA services and create an environment in which the IMHA can fulfill their role. Mental health professionals who appreciate the link between effective expression of service users' views and their subsequent wellbeing and recovery value the involvement of IMHAs. Where there are positive working relationships, advocacy is understood and appreciated, and any challenges to practitioner staff are dealt with with equanimity:

“No, the person I work with personally seems very much on the ball and very challenging, which is good. I mean it's what we're here for, we should be challenged, we need to be challenged, we should always be challenging the system for the benefit of the patient, we need to be kept on our toes.” (Approved mental health professional)

Reports of conflict in the relationships between mental health professionals and IMHAs were not uncommon, and often reflected a lack of appreciation of the latter's role, especially its independence from the care team, or a negative disposition towards advocacy. Mental health professionals may view themselves as the person's advocate or view advocacy as working against an individual's best interests, or they may deem the advocate naïve, dismissing their role and expertise.

Commissioning IMHA services

It was evident that primary care trusts (PCTs) had been poorly prepared for the introduction of IMHA services, with some extending contracts on a short-term basis with existing providers. Since then approaches to commissioning IMHA services have become more systematic with a number of PCTs testing the market in the past year.

But we found little evidence of commissioning based on needs assessment and equality impact assessment or of service users, particularly qualifying patients, being involved in the commissioning process or in monitoring contracts. Thus the basis for the level of investment was typically unclear. We estimated that 50,000 people a year qualify for IMHA services. Our evidence suggests that the current level of investment in IMHA services is inadequate, and relies too heavily on some qualifying patients not taking up the service and/or on IMHA services or mental health services gatekeeping access.

The future for IMHA services

Advocacy can be a force for progressive and emancipatory change, tackling adverse experiences of particular groups and supporting a personal journey to recovery. But we also found that it may serve to maintain the status quo and reinforce the more restrictive elements of the MH Act, rather than create the space for a different form of dialogue with mental health services.

For IMHA to realise its emancipatory potential, there needs to be an environment in which the advocate can work constructively to support the service user's right to self-determination. This relies on the quality

of the individual advocate, the service they work for, the commissioning of the service, and mental health professionals and services who will enable access.

It is vital that this interdependence between commissioning, IMHA services and the mental health service context is fully considered in the transfer of the commissioning responsibilities to local authorities. This transfer creates an opportunity to review the provision of mental health advocacy in general and in particular the access to advocacy by other service users, including those at risk of compulsion, as advocated by NICE, the Centre for Social Justice and the Welsh Government.

It is time to reflect and build on the founding principles of advocacy and its roots in the service user movement. In doing so it is important to avoid the perils of over-bureaucratisation, while at the same time ensuring it becomes a major element of a progressive mental health system. This requires not only a significant investment in the advocacy sector, including community organisations and networks of diverse communities, but a seismic shift in terms of the attitude to advocacy and, more fundamentally, the right of all people experiencing mental health problems to self-determination. ■

Acknowledgements

We are grateful for comments on the draft from Laura Able and June Sadd and to other members of the IMHA project team, without whom this research would not have happened: Dr Julie Ridley, Dr Dina Poursanidou, Kaaren Cruse, Paul Grey, Stephanie de la Haya, Zemikael Habte-Mariam, Doreen Joseph and Michelle Kiansumba.

The independent report was commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

Care Quality Commission (2010) *Mental Health Act Annual Report: Monitoring the mental health in 2009/10*. Available at: <http://www.cqc.org.uk/public/reports-surveys-and-reviews/reports/mental-health-act-annual-report-2009/10> (accessed 23/08/12).

Care Quality Commission (2011) *Count Me In 2010: Results of the 2010 national census of inpatients and patients on supervised community treatment in mental health and learning disability services in England and Wales*. London: Care Quality Commission.

Centre for Social Justice (2011) *Completing the Revolution: Transforming mental health and tackling poverty*. London: Centre for Social Justice.

Hakim R & Pollard T (2011) *Independent Mental Health Act Advocacy*. Mental Health Alliance. Available at: http://www.mentalhealthalliance.org.uk/resources/Independent_Mental_Health_Advocacy_report.pdf (accessed 23/08/12).

Mental Health Act 1983. London: HMSO. Available at: <http://www.legislation.gov.uk/ukpga/1983/20/contents> (accessed 23/08/12).

Mental Health Act 2007. London: HMSO. Available at: <http://www.legislation.gov.uk/ukpga/2007/12/contents> (accessed 23/08/12).

National Institute for Health and Clinical Excellence (2011) *Service User Experience in Adult Mental Health: Improving the experience of care for people using adult NHS mental health services: Clinical Guideline 136*. London: National Institute for Health and Clinical Excellence. Available at: <http://guidance.nice.org.uk/CG136/NICEGuidance/pdf/English> (accessed 23/08/12).

National Institute for Mental Health in England (2008) *Independent Mental Health Advocacy: Guidance for Commissioners*. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_097681.pdf (accessed 23/08/12).

National Mental Health Development Unit (2009) *Independent Mental Health Advocacy: Effective practice guide*. London: NMH DU.

Townsend R, Marriott A & Ward L (2009) *Access to Independent advocacy – an evidence review: Report for the Office for Disability Issues*. London: HM Government: Office for Disability Issues.

Welsh Government (2011) *Delivering the Independent Mental Health Advocacy Service in Wales*. Available at: <http://wales.gov.uk/docs/dhss/publications/111222advocacyen.pdf> (accessed 23/08/12).

