

# **The Right to Be Heard**

## **Review of the Quality of Independent Mental Health Advocate (IMHA) Services in England**

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### **Research Report**

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## ***A note on terminology***

Participants used a range of terms to refer to people using IMHA services. These included 'patient', 'client' and 'service user' and 'survivor' and we have left these in the quotes as expressed by participants.

We have used the terms 'qualifying patient' to describe those people entitled to access IMHA services, and we describe those qualifying and using IMHA services as the 'advocacy partner' or the 'IMHA partner'. We use the term 'service users' to refer to people who use mental health services in general, including those who do not qualify for IMHA services. We use the term 'carer' to refer to family members and friends who have specific caring responsibilities in relation to a service user.

## ***Abbreviations and Terms***

Advocacy partner or IMHA partner	Qualifying patient using IMHA services
AMHP	Approved Mental Health Professional
Best interests	Making a judgment, on behalf of someone who lacks capacity, about their best interests
BME	Black and minority ethnic
CAMHS	Child and Adolescent Mental Health Services
CMHT	Community Mental Health Team
CPA	Care Programme Approach
CPN	Community Psychiatric Nurse
CQC	Care Quality Commission
CSO	Clinical Studies Officer
CTO	Community Treatment Order
DOLS	Deprivation Of Liberty Safeguards: safeguards for people deprived of their liberty but not covered by the Mental Health Act 1983 safeguards
ECT	Electroconvulsive Therapy
ENC	Equalities National Council
Equality analysis	An analysis of the effect of policies on different groups protected from discrimination by the Equality Act 2010
Equality impact assessments	A method for examining the main functions and policies of an organisation to see whether they have the potential to affect people differently and to enable an organisation to address existing or potential inequalities.
FTE	Full Time Equivalent
ICAS	Independent Complaints Advocacy Service
IMCA	Independent Mental Capacity Advocate: a statutory advocate, introduced by the Mental Capacity Act 2005, to safeguard the

**Abbreviations and Terms**

	interests of people lacking capacity
IMHA	Independent Mental Health Advocate/Advocacy
LGBT	Lesbian, Gay, Bisexual and Transgender people
LSU	Low secure unit
MDT	Multi-disciplinary Team
MH Act	Mental Health Act
MHRN	Mental Health Research Network
MHRT	Mental Health Review Tribunal: an independent judicial body that operates under the provisions of the MH Act 1983 (as amended by the MH Act 2007). Its main purpose is to review the cases of patients detained under the MH Act and to direct the discharge of any patients where the statutory criteria for detention are not met
MSU	Medium Secure Unit
Nearest relative	This term is used in the MH Act 1983 to define someone who has certain rights and responsibilities to someone detained under the Act
NIHR	National Institute of Health Research
NHS	National Health Service
NIMHE	National Institute for Mental Health (England)
NMHDU	National Mental Health Development Unit
Non-instructed advocacy	Non-instructed advocacy takes place when the person is unable to instruct or tell the person what they want
PAG	Project Advisory Group
PALS	Patient Advice and Liaison Service
PCT	Primary Care Trust
PICU	Psychiatric Intensive Care Unit
Qualifying	People who are detained under the MH Act who are eligible to

## ***Abbreviations and Terms***

patients	use IMHA services
RC	Responsible Clinician
Reasonable adjustments	The Equality Act 2010 requires that reasonable adjustments should be made by public services to enable disabled people, including people with mental health conditions, so that they get the same standard of service as non-disabled people
Safeguarding	Safeguarding refers to measures that can be taken to protect children and adults and who are vulnerable, as required by the Safeguarding Vulnerable Groups Act 2006
SCT	Supervised Community Treatment
Section 2	Admission under the 1983 MH Act for assessment for a maximum of 28 days
Section 3	Admission under the 1983 MH Act for a treatment for up to six months, renewable for a further six months and then one year at a time
Section 4	Admission under the 1983 MHA in cases of emergency for a maximum of 72 hours.
Section 5	Compulsory detention of informal patients already in hospital for a maximum of 72 hours by an approved clinician or up to six hours by a suitably qualified nurse.
Section 57	Provisions relating to specific treatments such as psychosurgery, requiring both individual consent, confirmation that consent is valid and a second medical opinion.
Section 58	Provisions relating to specific treatments, such as extension of medication beyond three months or Electroconvulsive Therapy (ECT), requiring second opinion appointed doctor (SOAD).
Section 136	Police powers to remove people found in public places to a place of safety
TUPE	Transfer of Undertakings (Protection of Employment) regulations 2006 protects employees' terms and conditions when a business goes through a transfer or takeover.
UCLan	University of Central Lancashire

## ***Executive Summary***

This review of the quality of Independent Mental Health Advocate (IMHA) provision across England was commissioned by the Department of Health. A team of independent researchers including four academics and nine co-researchers with experience of using mental health services undertook the study, which lasted eighteen months from 2010. Using different methods, the experiences and viewpoints of those with experience of IMHA, advocacy services, and health and social care professionals were explored in-depth.

### **STUDY AIM**

The main aim of this study was to look at how IMHA services are providing help to patients under the 2007 Mental Health Act (MH Act), what makes for a good IMHA service and what factors influence the quality of service provided. This information should be of value to mental health service users, their families, IMHA commissioners and providers, and mental health services.

### **BACKGROUND**

Advocacy is a vital mechanism for ensuring that vulnerable people can get their voice heard and have their rights protected. It aims to empower people to have greater control and choices in their relationship with services. To be effective, advocacy must be independent of service provision. The development of advocacy is consistent with the government's aim of promoting control and choice and safeguarding the rights of vulnerable people.

An Independent Mental Health Advocate (IMHA) is a specific type of mental health advocate, granted specific roles and responsibilities under the 2007 Mental Health (Amendment) Act (MH Act). Their role is to help qualifying patients understand the rights and safeguards to which they are entitled, and help those patients exercise their rights through supporting their involvement in decision-making. It followed the introduction of another form of statutory advocacy, the Independent Mental Capacity Advocacy (IMCA), which was introduced by the Mental Capacity Act 2005 to safeguard the interests of people lacking capacity.

Mental health services should enable IMHAs to meet patients in private. Further, IMHAs must be able to attend meetings between patients and professionals involved in their care and facilitate access to mental health notes as appropriate. The recently published NICE Guideline (National Institute for Health and Clinical Excellence, 2011) on improving the experience of service users of adult NHS mental health services recommends that mental health services ensure access to advocacy services for all hospital patients, including IMHA services for detained patients.

IMHA services do not replace other advocacy and support services available to the service user and should work in conjunction with them. These services do not affect the individual's rights to seek legal advice and patients have the right not to use an advocate. IMHA services are for qualifying patients directly and not for relatives or carers; although they may of course be in contact with families and carers at the patient's request.

Primary Care Trusts became responsible for ensuring the availability of IMHA services in April 2009 and, under the Health and Social Care Act 2012, this will pass to local authorities in 2013. It was originally estimated that 42,000 people qualify for IMHA services with the majority being based in hospital and aged over 18. The Count Me In census (CQC, 2011a) of in-patients has consistently found that overall occupancy rates are disproportionally higher for specific Black and minority ethnic (BME) groups, with twenty-two percent of inpatients from BME groups, and detained patients from these communities may be particularly vulnerable but face particular difficulties in accessing appropriate advocacy.

While studies of independent advocacy have been undertaken, largely in hospital settings, evaluative research in this field is sparse. Variations in terms of the quality and capacity of mental health advocacy services have been noted. A small number of existing studies considering provision for people from Black and minority ethnic (BME) communities have raised questions about equity of access and style of provision. Further there are no universally adopted quality standards to guide the effective commissioning and provision of IMHA services.

## **METHODS**

This study used different methods to gather information about how IMHA services are working in practice. The study was undertaken in two stages. The first stage involved: a focused literature review; 11 focus groups held across England with a range of stakeholders - advocates, mental health service users, IMHA partners, carers and mental health professionals; and shadow visits to IMHA services. This first stage enabled us to develop draft quality indicators for IMHA services.

The second stage of the study involved gathering data in eight case study sites (mental health providers) to understand the experience of qualifying patients, the commissioning and delivery of IMHA services and their relationship with mental health services. The eight case study sites were selected to reflect differences in the local population and the way IMHA services were organised and delivered. In each case study site the following methods were used to collect data on the experience of IMHA services and how they were working:

- A questionnaire to IMHA providers in the study site.
- Analysis of key documents including service specifications, engagement protocols and reports from the IMHA providers.

- Interviews with qualifying patients (both IMHA partners and non-users); IMHA providers; mental health professionals; commissioners; and professionals involved in the administration of the MH Act.
- Analysis of the IMHA records and mental health records for a small sub sample of consenting qualifying patients.

In total 214 people were interviewed and this included 90 qualifying patients, 61 of whom had experience of using IMHA services.

There were a number of difficulties recruiting people to take part. This mainly reflected the lack of routine information being kept and/or shared about who was eligible for and who was using IMHA services. This is a key finding of the study as it has implications for understanding the access and uptake by different groups of individuals.

## **PATIENT AND PUBLIC INVOLVEMENT**

One of the hallmarks of this research has been the partnership with mental health service users. From a diverse team of 13 people, 10 of us have used mental health services, including experience of being detained in inpatient settings including secure services. This meant that we had a range of skills and experiences to draw on in interpreting the data. At the same time we had to think about how this shaped our approach to the research task.

The study was also undertaken in partnership with Equalities National Council, Aawaz and Manchester African Caribbean Mental Health Services, who were involved in the Project Advisory Group or the Service User Reference Group. The Project Advisory Group provided guidance to the project and involved mental health service users from Comensus, which is a University-wide forum at University of Central Lancashire (UCLan) supporting the involvement of service users and carers in teaching and research. A Service User Reference Group was established for the project and this group helped develop the questions we asked and commented on the findings and what they could mean.

## **KEY FINDINGS**

### **Experiences of the Mental Health Act**

The ninety qualifying patients we interviewed came from all walks of life, had a variety of personal circumstances and were using a broad range of mental health services.

Many of the qualifying patients that we interviewed described the process of detention under the MH Act as frightening and disempowering. Several instances where force had been used either to admit people to hospital or to administer

medication were recounted. Very few people talked about positive experiences of detention under the MH Act or of mental health services, during this time.

### **Access to IMHA Services**

We found differences in the access to and uptake of IMHA services, particularly between qualifying patients in urban and rural sites, and between those in secure services, acute inpatient care and in the community on Community Treatment Orders (CTOs).

There was a strong consensus that those who need the IMHA service the most, access it the least. Specific groups of people that may be under-served by IMHA services are:

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

We found that, unless a specific effort was made to understand the needs of these different groups and how they might access IMHA services, qualifying patients may not know about the service or decide that it was not for them. Indeed, the reasons given by qualifying patients for not using IMHA services largely reflect a lack of awareness or understanding of the service and thus how it can help. This is contrary to the views of staff, who emphasised that qualifying patients exercised choice about using IMHA services, based on having received and understood information about the service.

From the case notes we analysed we identified a number of missed opportunities when IMHA support might have resulted in a different outcome, for example in relation to leave or medication.

Self referrals and referrals by nursing staff were the most common. The main reason service users gave for accessing the service was to have a voice and to come off a Section. This was framed in similar terms by IMHAs but mental health professionals identified rights under the Mental Health Act and the absence of, or conflict, with families or carers as the main reasons.

Access and uptake of IMHA services is influenced by:

- Understanding of the purpose of IMHA services and the role.



- Availability of IMHA services, based on adequate resources matched to local need.
- Promotion by mental health services.
- Receptiveness of qualifying patients including trust and familiarity in the service.
- Tangible commitment to equality of access, e.g. through working in partnership with community organisations and making sure interpreting services are readily available.

Leaflets or posters can be useful but it was clear that relying on promotional materials only is inadequate. Efforts to increase access and uptake need to reflect the main factors identified above.

### **Understanding of IMHA services**

Service users and carers do not always understand the purpose or role of IMHA services and can confuse it with Independent Complaints Advocacy (ICAS) or a support worker role. Although some service users have a well developed understanding of the purpose and role of IMHA, there was also scepticism about whether it exists to maintain the status quo.

We found that in all of the case study sites just over half of the mental health professionals were unable to name the service or an advocate, reflecting limited experience, complex advocacy provider configurations and recent organisational changes. This was particularly marked for community staff. Areas of misunderstanding and confusion for mental health professionals included:

- Confusion with the IMCA role.
- Assuming that IMHA services are only for people detained under the MH Act who lack capacity.
- The difference between IMHA and other forms of advocacy, particularly generic mental health advocacy.
- The scope of the role in relation to a broader range of practical and social issues facing service users.

A substantial number of staff interviewed did not fully understand that they had an obligation to promote the service and knowledge about the IMHA's right to access notes, and to support participation in decision-making was generally poorly developed.

The view of mental health professionals, particularly nurses, that they have an advocacy role is widespread. This is usually framed as best interests advocacy linked to their duty of care and is fundamentally different from the concept of independent advocacy. A substantial number of mental health professionals we interviewed did

not appear to understand this. In such instances, staff can view the IMHA role as superfluous and means that they may be reluctant to facilitate access to IMHA services or take extra steps to ensure IMHAs are involved with the service user in key meetings. Some mental health professionals, however, have a well developed understanding of how their role differs and can co-exist with the IMHA role and will take extra steps to promote the IMHA service and create a welcoming environment. Thus, we found that the understanding of advocacy and the IMHA role by mental health professionals shapes their attitudes and relationships to IMHA services.

The training that the majority of staff had received was generally cursory, usually as part of a general overview of the MH Act. The exception to this was the systematic approach to training in the High Secure service and that delivered for AMHPs.

### **Landscape of IMHA Services**

Provision varied greatly according to - type of organisation providing IMHA; the menu of advocacy services provided; number of IMHA providers in an area; and number of IMHAs within the service.

The interface between mental health services and advocacy was clearly more complex in some parts of the country – some related to multiple IMHA providers covering diverse populations, while others related to just one provider.

Few advocacy services or advocates offered both IMHA and IMCA, but it was common for IMHAs to also operate as generic mental health advocates enabling a holistic and flexible approach.

The underlying ethos of IMHA is that it upholds individuals' rights, support is person-centred, independent, free of charge, and, centrally, that its purpose is to give qualifying patients a voice.

The IMHA workforce was predominantly female and White, which meant services were generally limited in the extent of choice they offered, although this was not generally raised as an issue by service users.

The gender, ethnicity and disability of IMHAs were of far less importance to IMHA partners than the training and general personal qualities of IMHAs.

On the whole IMHAs were considered to be highly skilled, experienced advocates, and it was the minority who felt they should be more knowledgeable about diagnostic labels and treatment.

On average three out of four IMHAs had completed the IMHA module of the National Advocacy qualification, but in one service just a third of IMHAs were trained and in another just a quarter were.

There were major discrepancies in IMHAs' caseloads - from eight to 55 cases, with no clear reason as to why this would be so, other than available resources.

Commonly, IMHA cases were kept open for between one to three months, and the majority were not time limited.

### **Provision of IMHA Services**

In practice IMHAs undertake a plurality of roles, and are involved in a wide range of activities to differing extents in both hospital and community settings in order to ensure service users/patients exercise their rights and that their voice is heard. Their role is a complex one conducted within a challenging legal and service context. Part of the dilemma for IMHAs is that the role is a statutory one and there are boundaries which, for some IMHAs, get in the way of acting in a holistic way.

IMHA had raised the profile of mental health advocacy and, to some extent, broadened understanding and had thus strengthened advocates' involvement in key aspects of the process of detention.

IMHA partners perceived IMHAs as "godmotherly", "a hammer", "a lever"; and in a negotiating role as "a diplomat", "a bridge" and as "WD40" in the system.

Key aspects of the IMHA role were: providing information; supporting service users at Tribunals, CPA, managers' hearings and ward rounds; and accessing patients' notes/records. The right to access patient notes/records had rarely been exercised at any site.

Very few service users had an Advance Directive and none of the IMHAs interviewed affirmed any involvement in supporting service users with drawing one up.

Non-instructed IMHA was fairly uncommon, and several IMHAs felt uncomfortable acting in a non-instructed way. They would do all they could to establish the person's wishes and preferences, and to ensure that non-instructed advocacy did not become 'best interest' work.

IMHA and safeguarding appear to exist in parallel worlds and the role of IMHAs in relation to safeguarding procedures needs further investigation and guidance.

### **IMHA services and the diversity of qualifying patients**

The development of IMHA services is based on a model of instructed advocacy provided by mainstream advocacy providers. This may inadvertently disadvantage qualifying patients who have specific needs including people from BME communities, older people, children and young people and those with sensory impairments.

IMHA services tend to be confident about their capacity to respond to the diversity of qualifying patients but our findings indicate some key gaps in provision that need to be addressed.

The proportion of children and young people accessing IMHA services was relatively low and the variation reflected differences in commissioning and whether specific provision had been developed.

The uptake of IMHA by older people, particularly those requiring non-instructed advocacy varied across the sites with only one advocacy provider in one site having developed specific expertise in providing IMHA for older people with dementia.

The commissioning and provision of IMHA services largely fails to recognise the particularly negative experiences and perceptions BME communities have of mental health services. There was a general lack of culturally appropriate services, which goes beyond thinking about language, to having a deep and accurate appreciation of cultural issues. There were few examples of partnership working with BME organisations or upskilling these organisations to provide IMHA services.

The staffing profile of IMHA services – predominantly female- may limit choice on the basis of gender. It was not clear how significant this was, although in general gender was not identified as important. It was more likely to be identified by women, and reflected either cultural issues or a need for relational security.

IMHA services do not routinely capture information about the sexual orientation of qualifying patients and this makes it difficult for them to evaluate their approach.

Where advocacy services for people with learning difficulties were commissioned separately from IMHA services, there were disadvantages for qualifying patients with learning difficulties accessing IMHA.

It was suggested that the cultural issues for deaf people need to be considered alongside language and communication, and that deaf IMHAs, should be available to provide IMHA services within specialist mental health units for deaf people.

Where the advocacy needs of qualifying patients are not being met, this gap in provision may well be filled by a community organisation that is not funded to do so.

### **The Mental Health Services Context**

There was a broad consensus around the need for a positive working culture between advocates and mental health services. This can be formulated as part of the commissioning process or an engagement protocol, but grass-roots relations will be worked out largely on the basis of whether there is mutual understanding and realistic expectations of each others' roles.

Relationships between IMHAs and mental health professionals are complex and multi-faceted. The organisational culture and disposition towards advocacy of mental health professionals impacts upon the extent to which the mental health context is supportive of IMHA provision and takes steps to actively welcome it.

Some mental health professionals clearly welcomed the IMHA role in protecting the rights of service users under the MH Act; others clearly experienced it as challenging, even irritating and inappropriate.

Accounts of positive relationships reflected an understanding of the needs for IMHA provision; its utility and potential outcomes for qualifying patients. On the other hand, negative accounts of relationships were often framed around uncertainty or lack of achievement of desired outcomes, and certain aspects of the way the IMHA service was delivered.

Where there are positive working relationships advocacy is understood and appreciated and any challenges to mental health professionals are dealt with equanimity.

On occasion there is resistance and conflict and this can lead to complete fractures in working relationships between IMHA and mental health services.

Previous experiences and history of advocacy involvement with services, often predating the introduction of IMHA, can be influential in the current reception afforded advocacy.

Understanding of advocacy, the IMHA role in relation to the mental health professional's role and best interests emerged as critical in influencing how mental health professionals viewed, responded and supported IMHA interventions.

### **Making a difference**

Both service users and mental health professionals recognised the main benefit from IMHAs was ensuring service users had a voice. As expected, IMHA had empowered service users to exercise their rights by, for example, appealing the Section, accessing legal representation, and participating in CPA, Managers' hearings, ward round meetings and Tribunals. For some service users, the outcome of IMHA was that they were more accepting of the status quo because the IMHA had helped them understand that this was the way to achieve the outcome they wanted

Similar to other studies, this research found a key distinction between the impact of IMHA in terms of the *process* and *outcomes* with most impact identified being in relation to the process. While a concrete outcome (such as changing the level of restriction, or lifting the Section) might not be what is always achieved, there was a high level of satisfaction with the process of IMHA. While there were examples of

IMHA impacting on individuals' care and treatment, it was less likely overall to be thought to increase participation in decision making

A minority of service users and some mental health professionals in reality could only identify minimal or no impact from IMHA

Proxy or crude measures of outcome to assess the effectiveness of IMHA would be unhelpful. Any measurement needs to take account of the complexity and incorporate measures of both process and outcome. This will include a range of measures, both qualitative and quantitative for multiple perspectives on the process and impact of IMHA services.

### **Commissioning IMHA Services**

The critical role that participants considered commissioning plays in the development of good quality IMHA services was clear, from all the data sources.

It was suggested that Primary Care Trusts had been poorly prepared for the introduction of IMHA service in 2009, with some extending contracts on a short-term basis with existing providers. Since then, approaches to commissioning IMHA services had become more systematic with a number of PCTS testing the market in the last year. Most had detailed service specifications, based on the National Institute for Mental Health England (NIMHE) guidance, although these differed in terms of whether they focused on IMHA services only or included IMHA as an element of a more comprehensive approach to advocacy provision.

There was little evidence of commissioning based on needs assessment and equality impact assessment and there was evidence in the case study sites that specific needs had not been considered. In particular, gaps were evident in relation to people from BME communities, people with learning difficulties, older people, children and young people. Further, it was evident that generally service users, particularly qualifying patients, were not being directly involved in the commissioning process or in monitoring contracts.

The basis for the level of investment was thus typically unclear. We estimated that 50,000 people a year qualify for IMHA services. The current level of investment in IMHA services appears to be inadequate and relies on some qualifying patients not taking up the service and IMHA services or mental health services gatekeeping access.

Commissioning arrangements for people placed out of area were confused and commissioners, mental health providers and IMHAs requested clarity. We identified a number of instances where independent sector providers, were commissioning the IMHA service, which is clearly inappropriate but an expedient solution to promoting access.

Concerns were expressed by IMHA services about the practice of spot purchasing as it threatens the financial viability of IMHA services and compromises strategic planning. Tendering processes can privilege larger organisations over smaller ones and this can inadvertently disadvantage smaller community based organisations that may be particularly well placed to respond to specific diverse needs.

### **Determining the Quality of IMHA Services**

A key finding from this study indicates that the quality of IMHA services is dependent on the quality of commissioning and the mental health provider context within which the service is delivered. Knowledgeable service users and their families and carers have a key role to play in designing and promoting access to IMHA services.

Our findings enabled us to identify a number of domains that determine the quality of IMHA services. There are 30 quality indicators are organised around the eight themes, which reflect our key findings:

- Effective commissioning for IMHA services.
- Availability and accessibility of IMHA services.
- IMHA service characteristics.
- Organisation and management of IMHA services.
- The IMHA role.
- Meeting diverse needs.
- Monitoring and outcomes of IMHA services.
- The role of and relationship with mental health services.

These indicators provide a basis for commissioners and IMHA providers together with mental health services to review the quality of local provision.

### **RECOMMENDATIONS**

The full report contains a number of detailed recommendations from our research, which are summarised here. These recommendations are particularly important, given the commissioning of IMHA services will change from PCTs to local authorities in 2013. This process of transition needs to build on learning from the implementation of IMHA services and identified best practice.

## **Recommendations for Government**

1. A re-emphasis of the core values and principles underpinning the MHA of self-determination and participation in decision-making needs to be supported by full policy implementation of IMHA services.
2. Access to IMHA services need to be clearly understood, framed and promoted as a right.
3. There is a need to consider IMHA in relation to other forms of advocacy given the changing context.
4. The provision of IMHA services has not yet reached its full potential. Measures are needed to further improve access and ensure adequate investment.
5. Systematic information requirements should be introduced across England to capture data on numbers of qualifying patients and referrals to IMHA services.
6. Consideration should be given to establishing an opt-out rather than an opt-in system to promote access to IMHA services.
7. There is a need to clarify the arrangements for commissioning and providing IMHA services for people placed out of area, in the independent sector and in NHS services that have a national catchment area.
8. Although there is variation in the quality of IMHA services, it is important that existing good practice is recognised and IMHA networks supported to disseminate and further develop this.

## **Recommendations for the Care Quality Commission**

1. We propose that the CQC further adopt the quality indicators to provide a basis for reviewing the quality of local IMHA services.
2. It would be helpful if mechanisms could be established for IMHA providers to highlight a clear breach of an entitlement under the MH Act 1983, having reached the limits of local resolution.

## **Recommendations for Commissioners**

1. Commissioners need to undertake a thorough needs assessment to determine the local needs for and required configuration of IMHA services. This assessment needs to pay particular attention to groups and communities who may encounter particular barriers in getting their voice heard and take account of patterns of detention under the MH Act, particularly for BME communities.



2. Commissioners play an important role in facilitating access for under-served groups through commissioning small local providers and facilitating collaborative working with community organisations.
3. Investment in IMHA services needs to provide a sustainable basis for delivery and, in line with good practice guidance, we recommend that this is for a minimum of three years to enable IMHA services to develop to their full capacity.
4. The investment in IMHA provision should include adequate infrastructure costs and the costs of training, support and development for staff.
5. There needs to be an agreed and standardised system for capturing information on both process outcomes and impact outcomes.
6. Commissioners should involve a range of IMHA partners in the commissioning process and actively explore opportunities for co-production with service users, their families and carers and community organisations.
7. Requirements in relation to the role of mental health services providing an appropriate context for IMHA services should be included in contracts for mental health providers.

### **Recommendations for Mental Health Services**

1. Mental health services need to take steps to ensure that all relevant staff understand that access to IMHA services is a right and are aware of the purpose of IMHA.
2. Mental health services need to ensure a supportive context within which IMHA services can operate effectively.
3. MH Act administrators, as well as ward and community based staff, should ensure they have up to date information about IMHA services in their area especially where there are multiple providers.
4. Mental health professionals working with those on CTOs should receive training about their obligation to inform qualifying patients about IMHA, and protocols for referral should be developed.
5. The variable relationships between MH Act administrators, mental health staff and advocacy services should be noted and steps taken to optimise learning from good practice.

### **Recommendations for IMHA services**

1. IMHA services and mental health services need to agree a systematic method for recording and evaluating uptake.
2. IMHA services should be consistent in recording equalities data to enable them to properly monitor and improve uptake by different groups.
3. Proactive strategies should be developed for improving access and provision for under-served groups, including those on CTOs. These include partnership arrangements with community organisations that are trusted and thus well placed to meet specific needs.
4. Information about IMHA services should be promoted and disseminated through service user and carer networks.
5. Advocacy services should review promotional materials – posters, leaflets, DVDs –ensuring these are accessible and effective, and should involve mental health service users in any redesign.
6. Advocacy services could help improve understanding of, and access to, IMHA by publicising anonymised case studies demonstrating the use and impact of IMHA (including by those on CTOs and non-instructed advocacy).
7. IMHA services should review and ensure a systematic approach to non-instructed advocacy through training and learning from each other through advocacy networks and sharing best practice.
8. IMHA services should review and ensure that the quality of record keeping is in line with current good practice and enables the service to identify outcomes for IMHA partners.
9. Training and preparation of the future generation of IMHAs is needed and consideration of opportunities for career progression in order to retain and develop high calibre staff.

### **Recommendations for Service User, Carer and Community organisations**

1. Service user, carer and community organisations could create and respond to opportunities to engage in raising awareness amongst service users around human rights and advocacy in mental health services.
2. Self organised user groups need to consider the nature of alliances with advocacy organisations.

3. We hope these organisations will critically engage with the reflections from this study about the balance between the potential for advocacy to promote personal agency and the peril that it acts as another form of social control.

### **Recommendations for Higher Education and Training providers**

1. Pre-registration training should explicitly address the meaning of advocacy in the context of the professional role for health and social care professionals.
2. There is a need for the development of an academic focus for advocacy which would develop the theory and practice of advocacy and build capacity of advocates to lead their own research agenda.

### **CONCLUSIONS AND FURTHER RESEARCH**

This research has found that the IMHA role is valued and appreciated by service users, although its potential is not fully realised. This study has identified key factors that influence the quality of IMHA services. It is clear from the study that action to strengthen this has to be three pronged:

1. Through improving commissioning so that the investment reflects the diversity of need and potential demand.
2. By developing supportive mental health contexts, primarily through training, and associated activities to develop an accurate appreciation of the role of IMHA, and fostering constructive working relationships between IMHA providers and mental health staff.
3. By strengthening the capacity of advocacy services and partner organisations to provide IMHA services to deliver high quality IMHA services to the full range of qualifying patients, specifically people whose rights under the MH Act may be particularly jeopardised, including those who require non-instructed advocacy.

These developments will be facilitated by investment in raising the awareness of service users, carers and health and social care mental health professionals in relation to individuals' right to IMHA services, and developing a rights-focus that maximizes the potential for self-determination, in the context of the legislative framework.

Future research is needed to:

- Explore the many gaps in the evidence base for mental health advocacy and follow up some of the key findings of this study in more detail.
- Investigate the impact of IMHA services and the influence of contextual factors, particularly organisational models for delivery.

- Conduct service evaluations that provide information about access and uptake of IMHA in specific contexts and for specific groups.
- Explore the role of advocacy in promoting empowerment of individuals as opposed to pacifying unease with compulsion into services.
- Review the different forms of training and to evaluate the impact on IMHA practice and mental health professionals' understanding and disposition to advocacy.
- Conduct action research or appreciative inquiry approaches to develop and enhance the relationship between advocacy services and mental health staff, being cognisant of the problems identified in this study.

## 1. INTRODUCTION

Independent Mental Health Advocates (IMHAs) were introduced in the Mental Health (Amendment) Act 2007 (MH Act) to enable people detained under the MH Act 1983 to exercise their rights and to participate in decisions about their care and treatment. They provide an additional safeguard for the person's autonomy in respect of decision-making under the MH Act. Whilst the concept of independent advocacy is not new, the IMHA role is distinctive and previous evaluative research in the field sparse. Studies have been undertaken largely in hospital settings and a small number of studies in relation to Black and minority ethnic (BME) communities have raised questions about equity of access and style of provision for the diverse range of mental health service users. Variations in terms of the quality and capacity of advocacy services have also been noted and there are no universal quality standards to guide the effective commissioning and provision of IMHA services.

The overarching aim of the research was to review the extent to which IMHA services in England are providing effective and appropriate help to patients under the MH Act 1983 (as amended by the MH Act 2007) as intended. The research set out to understand whether IMHA services are providing accessible, effective and appropriate advocacy support for the diversity of qualifying patients. It also sought to identify the factors that determine the quality of IMHA services, from the perspectives of service users, IMHAs, mental health professionals and commissioners. The intention behind the study was to obtain robust evidence to inform the commissioning and delivery of high quality IMHA services.

This was a multi-method study, involving two main stages of data collection. The first stage involved a focused literature review, eleven focus groups held across England with a broad range of stakeholders - advocates, mental health service users, IMHA partners, carers and mental health staff- and shadow visits to develop draft quality indicators for IMHA services.

The second stage of the study involved gathering data from eight case study sites (mental health providers) to understand the experience of qualifying patients, the commissioning and delivery of IMHA services and their relationship with mental health services. These findings enabled us to refine and develop the quality indicators.

The research was led by the University of Central Lancashire (UCLan) in partnership with Equalities National Council, Aawaz, Manchester African Caribbean Mental Health Services and Comensus, a service user group at the University. The research team comprised four academic staff and ten service users, one of whom was a member of academic staff. The service user researchers (referred to in the report as co-researchers) had experience of being detained under the MH Act, including in secure settings.

This report provides an overview of the method and details the findings and is also available in summary form. The first three chapters provide the background to the study, a description of the method and research participants, and an analysis of the methodological challenges in undertaking this type of study. The questionnaires and interview schedules used in data collection are available at

[www.uclan.ac.uk/schools/school\\_of\\_health/the\\_right\\_to\\_be\\_heard.php](http://www.uclan.ac.uk/schools/school_of_health/the_right_to_be_heard.php).

The findings from the different data sources (focus groups, IMHA questionnaire, documentary analysis, interviews and case note analysis in the case study sites) have been synthesised in the subsequent chapters as follows:

#### **Chapter 4: Experiences of Qualifying Patients**

This chapter reports the findings from service users, and carers, on their experiences of the MH Act, and of mental health services.

#### **Chapter 5: Access to IMHA services**

This chapter looks at how qualifying patients find out about IMHA services, who is using IMHA services and the factors that promote access and uptake.

#### **Chapter 6: Understanding of IMHA services**

Understanding advocacy and the role that IMHAs play is crucial to determining access and uptake, and thus this chapter explores these findings in some detail.

#### **Chapter 7: IMHA service landscape**

This chapter paints a picture of the IMHA service landscape, drawing on information gathered from the survey questionnaire of IMHA providers and interviews with different stakeholders.

#### **Chapter 8: Provision of IMHA support**

This chapter focuses on different aspects of the IMHA role. It explores the complexities of this role and reports the dilemmas experienced by IMHAs in practice.

#### **Chapter 9: IMHA services and the diversity of qualifying patients**

This chapter pulls together the findings to consider how well the diverse needs of qualifying patients are being met, and the measures that commissioners and IMHA services are taking to strengthen this.

#### **Chapter 10: The mental health services context**

This chapter discusses the findings on the relationship between IMHAs and mental health services. Mental health services have a critical role to play in promoting access to IMHA services and providing a supportive context within which they can operate.

### **Chapter 11: Making a difference**

This chapter reports the findings of the outcomes of IMHA services for qualifying patients and other stakeholders. The chapter also considers how outcomes are being framed.

### **Chapter 12: Commissioning IMHA services**

This chapter looks at how IMHA services are being commissioned and the implications for local authorities for commissioning IMHA services from 2013.

### **Chapter 13: The Quality of IMHA services**

This chapter draws together all the findings to outline quality indicators for the commissioning and provision of IMHA services.

### **Chapter 14: Discussion**

This chapter discusses the findings and draws out the implications for policy, practice and future research.

### **Chapter 15: Conclusions and recommendations**

This final chapter makes recommendations for government, commissioners, IMHA services, mental health services and service user and carer organisations based on the findings.

The quotes used in this report are drawn from different stakeholders across the focus groups and the case study sites, which have been anonymised to protect participant identity. They have been chosen to illustrate particular points made across other data sources or to compare and contrast different responses.

## 2. BACKGROUND

### 2.1 Introduction

This section provides the background to the study. It is in two parts, with the first part providing a summary of the relevant legislative and best practice guidance for IMHA services and the second an overview of relevant research.

Self-determination is an important principle enshrined both in law and health and social care policy. It is reflected in the concept of recovery, shifting the emphasis from diagnosis to wellbeing, hope and personal strengths (Maddock & Hallam, 2010). Like recovery, advocacy has its origins in the service user movement (see for example, Wallcraft, Read & Sweeney, 2003). It often developed in response to negative experiences of the mental health system to enable people with mental health problems to have a voice and determine what happened to them, particularly in relationship to services. It is widely recognised that the experience of mental illness and engagement with statutory services, and in particular compulsory detention and treatment, can compromise the confidence and capacity of people to speak up for themselves. Service user activists and critical theorists in particular have also observed that the voice of mental health service users has been silenced on the grounds of irrationality.

Advocacy is thus rooted in an understanding of unequal relationships between service users and the services that support them, and is concerned with seeing the world from the service user's perspective (Silvera & Kapasi, 2002). Thus definitions of advocacy emphasise enabling people to have a voice, be involved in decision-making and have their interests represented. Often this is in order to achieve a different outcome, particularly increasing choices through having a broader range of options to consider, having access to new services or protecting the rights of an individual. Thus advocacy is now widely promoted as a mechanism for safeguarding autonomy and self-determination and protecting rights for people experiencing mental health problems (WHO, 2003). Under disability legislation, most recently the Equality Act 2010, advocacy can also be considered a reasonable adjustment to enable people to fully participate in decisions about their care and treatment and thus enable people with mental health problems to have access to the same standard of service as non-disabled people.

The Mental Health Act 2007 amended the Mental Health Act 1983 to introduce a statutory duty to provide IMHA services for patients subject to compulsion under the Act. As proposed by Barnes & Brandon (2002), IMHA is a distinct form of advocacy for people detained under the 1983 Mental Health Act. It followed the introduction of another form of statutory advocacy, the Independent Mental Capacity Advocacy (IMCA), which was introduced by the Mental Capacity Act 2005 (implemented in 2007) to safeguard the interests of people lacking capacity.



The policy landscape has changed dramatically in the intervening years since mental health advocacy came to the fore with the development of service-user led initiatives, such as the Nottingham Advocacy Group (Barnes, 2007). Advocacy now occupies a place in the local configuration of health and social care services, not just for people with mental health problems but for health and social care users more generally. The Health and Social Care Act 2012 proposes to give a greater voice to patients. HealthWatch when introduced will be commissioned by local authorities to provide an independent voice for service users and carers, and aims to ensure that the voices of the most marginalised groups are heard and will signpost people to independent advocacy (Department of Health, 2012). This focus on advocacy brings benefits to disadvantaged groups but also has the potential to increase professionalisation and conformity to a particular model (Henderson, 2004).

## 2.2 Independent Mental Health Advocacy

The framework for commissioning and provision of IMHA services is provided by the following key publications:

- MH Act (amendment) supported by the Code of Practice (Department of Health, 2008a).
- Guidance on what constitutes appropriate experience and training for IMHAs (The Mental Health Act 1983 (Independent Mental Health Advocates) (England) Regulations 2008; Standards: appropriate experience and training, Department of Health<sup>1</sup>).
- Guidance on the access to notes by IMHAs (Department of Health, 2009a) and their role in Tribunals (Ministry of Justice, 2011).
- Two publications from the National Institute for Mental Health England (NIMHE) providing best practice guidance: one for commissioners (NIMHE, 2008) and one for providers (NIMHE, 2009).

The commissioning and operation of IMHA services takes place within the context of the five guiding principles laid out at the beginning of the Code of Practice. These include the participation of all patients in planning and developing and reviewing their own treatment and care.

### 2.2.1 Purpose and role of Independent Mental Health Advocates

The core purpose of the IMHA role is to protect the rights of people detained under the MH Act 1983 and provide an additional safeguard by helping qualifying patients to obtain and understand information about the legal provisions to which they are

<sup>1</sup> See

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_092056.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_092056.pdf)

subject, the rights and safeguards to which they are entitled, and help those patients exercise their rights through supporting participation in decision-making. Arguably, part of the rationale for IMHA was to respond to ethnic inequalities in the use of the MH Act, which were becoming increasingly apparent (Count Me In Census for example; CQC, 2011a). Further, the introduction of IMHAs could ameliorate the expected negative impact of the changes to the MH Act (widening definitions of mental illness, reduced threshold of what constitutes treatment, Community Treatment Orders etc), which many believed would have a disproportionate impact on people from BME communities (Vige, 2009).

Section 130A of the MH Act 1983, as amended by the MH Act 2007, requires that the appropriate authority makes arrangements for IMHAs to be available to support patients qualifying for this service in England and Wales. Figure 1 provides a summary of the role.

1. Under the Act, the support which IMHA's provide must include helping patients to obtain information about and understand the following:
  - ⌘ Their rights under the Act.
  - ⌘ The rights which other people (e.g.: Nearest Relative) have in relation to them under the Act.
  - ⌘ The particular parts of the Act which 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, as a condition of a community treatment order or as a condition of conditional discharge).
  - ⌘ Any medical treatment that they are receiving or might be given and the reasons for that treatment (or proposed treatment).
  - ⌘ The legal authority for providing that treatment, and the safeguards and other requirements of the Act which would apply to that treatment.
2. Helping patients to exercise their rights, which can include representing them and speaking on their behalf.
3. Supporting patients in a range of other ways to ensure that they can participate in the decisions about their care and treatment.

**Figure 1: The role of IMHAs<sup>2</sup>**

<sup>2</sup> Source: Code of Practice (Department of Health, 2008a)

In summary, Section 130B of the MH Act 1983 provides an IMHA with certain rights in order that they may undertake their role. These include:

- Meeting qualifying patients in private.
- Meeting professionals concerned with the qualifying patient's care and treatment.
- Accessing a patient's records, including information, which patients themselves may have no right to see. Supplementary guidance (Department of Health, 2009a) provides further detail and makes it clear that IMHAs may only access records for the purpose of providing help to a qualifying patient and where the patient, or arrangements under the Court of Protection, consents.

IMHA services do not replace other advocacy and support services available to the service user and should work in conjunction with them. These services do not affect the individual's rights to seek legal advice and patients have the right not to use an advocate. IMHA services are for qualifying patients directly and not for relatives or carers, although they may of course be in contact with families and carers at the patient's request and may indirectly be a support to carers and family through their support to the person using mental health services.

IMHA can be instructed or non-instructed. Non-instructed advocacy will take place when people are unable to express their wishes clearly because they lack mental capacity. In such instances, the IMHA will represent the patient's wishes (as much as they are known) and ensure that his or her rights are respected. In those instances where a person qualifies for both IMHA and IMCA, the role of the IMCA is in line with the statutory guidance and will involve for example, decisions related to medical conditions (i.e. not covered by the MH Act).

### **2.2.2 Qualifying patients**

Patients, who are eligible to use IMHA services, i.e. qualifying patients, are:

- Patients detained under the MH Act 1983 (even if on leave of absence from the hospital).
- Conditionally discharged restricted patients.
- Patients subject to guardianship.
- Patients subject to supervised community treatment orders (CTOs).

Other patients, who are informal, are eligible for IMHA services if they are:

- Being considered for a treatment to which Section 57 applies (i.e. treatments requiring consent and a second opinion).

- ✎ Under 18 and being considered for ECT or any other treatment to which Section 58A applies (i.e. treatments requiring consent or a second opinion).

Patients detained under emergency sections (for example Section 4) do not qualify for IMHA services, although of course may use other advocacy services. The Commissioning Guidance indicates that commissioners may wish to extend support for informal patients, on wards or units where patients are identified as particularly vulnerable.

### **2.2.3 Provision of IMHA services**

Under IMHA regulations, someone can only act as an IMHA if they are employed as an IMHA by:

- ✎ A PCT (or other body) responsible for commissioning IMHA services, or
- ✎ An organisation commissioned by such a body to provide IMHA services.
- ✎ Have appropriate experience or training or an appropriate combination of experience and training.

The guidance includes an expectation that IMHAs will normally have completed the IMHA module of the independent advocacy qualification by the end of the first year of their practice. If an IMHA has any other professional involvement with the person's treatment, other than acting as an IMHA, then they will not be able to act as an IMHA for that patient. Further the regulations specify that the commissioning body must be satisfied that an IMHA meets these requirements.

IMHA providers should draw up an engagement protocol which is a three way-agreement between the IMHA service, the mental health service provider and the commissioner as to the ways in which the IMHA will work with mental health services. This would include how IMHAs would interact with qualifying patients for example running formal drop-in sessions on wards or in community settings, publicising the service and establishing links with community groups offering support to particular groups of service users, for example BME communities or older people. The NIMHE guidance (2009) provides good practice for IMHA providers on providing effective IMHA services.

### **2.2.4 Role of mental health services**

The Code of Practice places a duty on the managers of the hospital in which the person is being detained to inform qualifying patients about IMHA services as soon as is practically possible. In the case of conditionally discharged patients and informal patients who qualify, it is the responsibility of the responsible or approved clinician and for those on guardianship, the responsible Local Authority to inform qualifying patients. Hospital managers also have duties under the MH Act to inform patients about their legal situation and their rights, and in practice these duties will be

delegated to the appropriate staff. Approved mental health practitioners (AMHPs) and responsible clinicians should consider requesting an IMHA to visit a qualifying patient if it seems unlikely that the patient is unable or unlikely to make the request themselves. However, they should not do so, if they know or strongly suspect that the patient does not want IMHA support (NIMHE, 2008).

Mental health services also have to provide access to wards and enable IMHAs to meet patients in private, as appropriate. Further IMHAs must be able to attend meetings between patients and professionals involved in their care and facilitate access to mental health notes as appropriate.

The NICE guideline (National Institute for Health and Clinical Excellence, 2011) - Improving the experience of care for people using adult NHS mental health services - recommends that mental health services ensure access to advocacy services for all hospital patients, including IMHA for detained patients. The authors also recommend that advocates provide feedback to mental health services on any issues of concern.

### **2.2.5 Commissioning IMHA services**

The Mental Health Act 1983 (Independent Mental Health Advocates) England Regulations 2008 directed PCTs to commission IMHA services for qualifying patients. PCTs are allowed to exercise this duty with other PCTs and to include IMHA services within the scope of partnership arrangements under Section 75 of the National Health Services Act 2006. Commissioning IMHA services needs to take place within the framework of good practice for commissioning, which until 2010, was the world class commissioning programme (Department of Health, 2008c), for PCTs and for those PCTs commissioning in partnership with the local authority, the commissioning framework for health and wellbeing (Department of Health, 2007). Specific commissioning guidance published by NIMHE (2008) provides further explanation of the legislation and good practice advice to support commissioners in implementing their duty.

It was estimated that 42,000 people will qualify for IMHA services with the majority being based in hospital and aged over 18 (Department of Health, 2009b). The remainder are most likely to be on a CTO, with less than 500 being on a Guardianship Order<sup>3</sup>, with the numbers declining as a possible consequence of the introduction of CTOs and Deprivation of Liberty Safeguards (DOLS).

The Count Me In census of inpatients has consistently found that overall occupancy rates are higher for specific BME groups (i.e. Black Caribbean, Black African, other Black and White/Black Caribbean groups) by 20% to 36% (Healthcare Commission, 2008) and the final census found 23% of inpatients are from BME communities (CQC,

<sup>3</sup> 409 people were placed on a Guardianship Order in 2009; 420 in 2010 and 389 in 2011 (NHS Information Centre, 2011a).

2011a). People from specific BME communities (Black Caribbean and White/Black Caribbean) are more likely to be admitted via the criminal justice system and have the longest hospital stays leading the Care Quality Commission to conclude that detained patients from these communities may be particularly vulnerable (CQC, 2011a). The regulations place a legal requirement on commissioners to consider issues of equality and diversity when designing and commissioning IMHA services, reflecting the disproportionate percentage of qualifying patients from specific BME groups, identified in the Equality Impact Assessment for the Draft Mental Health Bill (Department of Health, 2009b). In practical terms, this means that the needs of diverse groups of qualifying patients need to be explicitly recognised in tender documents, service specifications and monitoring arrangements.

The Health and Social Care Act indicates that the responsibility for IMHA services will pass to local authorities from April 2013.

The distinctive nature of the IMHA role and the duty on managers and clinicians raises issues in relation to the:

- Understanding and awareness of the role by mental health services, mental health service users and their families.
- Skills and competencies necessary to undertake the role.
- Organisational arrangements for the provision of equitable high quality IMHA services.
- Relationship to existing provision and future developments.

and

- The capacity of commissioners to commission effective and accessible IMHA services.

### **2.2.6 Care Quality Commission (CQC) Inspection of the Mental Health Act**

As part of the CQCs annual review of the operation of the MH Act, it has looked at access to IMHA service for qualifying patients for the last two years (CQC 2010; CQC, 2011b). In 2010 the CQC found that nearly one in five (18%) wards did not have access to IMHA services. In the last visit it found that qualifying patients had regular access to an IMHA on 65% of wards visited and were informed that the IMHAs would come when requested on 85% of wards. They also found that some staff, who had a duty to explain the IMHA service to patients, did not understand it. Further, they also identified that problems continued with commissioning arrangements for IMHA services, particularly for patients placed out of the area, and identified an impasse in some instances with no practical IMHA provision for some out of area patients. Further, they found that some commissioners had cut back on non-statutory advocacy and that some IMHA services reported that their funding was inadequate to cover the demands for their services. The most common concern raised on MH

Act commissioners' visits was whether patients and their 'nearest relative' were aware of the IMHA service.

### **2.3 Current policy context**

Advocacy now has a central place in health and social care policy, which is increasingly focused on self-determination and active participation in decision-making about care and treatment. Advocacy is also seen as a strategy for social justice in terms of promoting citizenship and human rights as well as representing the interests of more vulnerable or marginalized groups. The recent mental health policy "No Health without Mental Health" (HM Government, 2011) reflects broader health and social care policy in its emphasis on health service users being able to take decisions about their own healthcare. It thus points to the importance of advocacy to enable mental health service users to fully participate in decisions about their care and treatment. This includes compulsory detention and treatment as reflected in the underlying principles for the MH Act and as embodied in the IMHA role.

A further aim of current mental health policy is the promotion of equality and reduction of inequalities; including tackling inequalities in the way services are provided as well as inequalities that result in poor mental health. This clearly has implications for the design and provision of IMHA services. It means undertaking an equality analysis to ensure that no groups are going to be disadvantaged by the service design and delivery. It also means that advocacy can be viewed as a reasonable adjustment to enable the diverse range of people with mental health problems to participate in their care and treatment under the MH Act.

The recent report from the Centre for Social Justice (2011) picks up the theme of inequality and focuses on addressing the negative experiences of BME communities in the mental health system and in particular in relation to the Mental Health Act. The report strongly recommends the right of advocacy before detention and the immediate appointment of advocates trained to understand the needs of BME clients and their experience under the Mental Health Act, particularly in relation to Section 136. Further the authors recommend that the number of advocates available is increased sharply and explores the ways in which community-based organisations could contribute to strengthening mental health advocacy in its broadest sense for BME communities, and access further training to become IMHAs. Finally there is a proposal that advocacy support should be available for carers, particularly in relation to mental health law.

### **2.4 Previous research**

Whilst the concept of independent advocacy is not new (Steven & Symington, 2009), evaluative research in this field is sparse, with the majority of studies being descriptive. It is possible to map the available research as follows:



- Studies relating to statutory mental health advocacy.
- Studies that have mapped advocacy needs and/or provision at a local or regional level.
- Evaluations of mental health advocacy in specific settings.
- Studies of mental health advocacy for specific populations.

As well as the studies referred to here, we looked at a small number of reports from IMHA services. These form an important body of grey literature and can inform the local process of service development if small scale evaluations of the process or impact of IMHA services have been undertaken.

#### **2.4.1 Statutory mental health advocacy**

Barnes and Brandon (2002) employed the Delphi method to establish a consensus on the essential characteristics required of mental health advocacy. Their proposed model of independent specialist advocacy was individual (i.e. one-to-one) advocacy only; to be clearly focused on those subject to the MH Act and needing "to operate within a spectrum of advocacy provided in a locality to meet a broad range of needs" (2002:21). This model has underpinned the introduction of statutory IMHA services.

Concerns about awareness of entitlement to advocacy and potential shortfalls in advocacy services to meet anticipated needs in relation to mental health legislation have been expressed within a Scottish context (Rushmer & Hallam, 2004; Grant, 2004). A subsequent study by Ridley, Rosengard, Hunter et al (2009) suggested that service users had been able to access advocacy when they wanted to, but pointed to the development of a two tier advocacy service as a consequence of the strategic prioritisation of advocacy services by commissioners to meet the requirements of mental health legislation in Scotland.

In England, a recent study of the commissioning and provision of IMHA services (Hakim & Pollard 2011) found that the process of introducing IMHA services had felt rushed and many PCTS had continued to contract with existing providers. Continuing with existing advocacy providers means that BME providers were disadvantaged in this process leading to a noticeable failure in addressing key issues for BME users. The consequence of this combined with inadequate needs assessment has meant that people from BME communities can be disadvantaged in their access to IMHA services. Indeed Hakim and Pollard (2011) conclude that IMHA services were not fully catering for BME communities, commenting that IMHA providers appeared '*relatively comfortable with this position*' (2011: 5).

Finally a small scale study of IMHA provision to residents in two specialist forensic settings, suggest that the service's approach, combining formal advocacy methods with a proactive ethos, has a positive impact on engagement. Furthermore, the study highlights the



importance of building trust in the service to the formation of positive relationships (Palmer, Nixon, Reynolds et al, 2012).

#### **2.4.2 Mapping advocacy needs and/or provision either at a local or regional level**

Two regional mapping projects (Foley & Platzer, 2007; Rai-Atkins, Jama, Wright et al, 2002) identified issues in relation to equity and style of provision to ensure that the diverse needs of mental health service users can be met. Foley & Platzer (2007) identified a mismatch between the provision of mental health advocacy and needs at a local level, with gaps in provision for minority groups or those with specialist needs.

#### **2.4.3 Evaluating mental health advocacy in specific settings**

The majority of these studies are descriptive or process evaluations of advocacy, typically hospital settings, including secure care environments (Barnes & Tate, 2000; McKeown, Bingley & Denoual, 2002). There has been only one study (Rosenman, Korten & Newman, 2000) that has attempted to evaluate the outcomes from mental health advocacy. This study used a case control design to compare the outcomes for hospitalised patients for an experimental model of personal advocacy compared with routine rights-based advocacy in Canberra, Australia. The results indicated better outcomes for the experimental group in terms of risk of further detention, attendance for aftercare, experience of staff and patients of the detention.

A small number of studies have identified difficulties inherent in the practice of advocacy, including a limited understanding of the role of advocates, their training (Lacey & Thomas, 2001) and opposition from mental health staff (Carver & Morrison, 2005). These studies point to the need for training for mental health staff.

#### **2.4.4 Mental health advocacy for specific populations**

Rai-Atkins, Jama, Wright et al, (2002) found that the mental health advocate role was less developed for minority groups, reflecting a lack of resources for BME advocacy, an imbalance of power and a lack of understanding amongst mainstream mental health advocacy services of cultural issues. Mainstream advocacy services were often inaccessible and inappropriate for the needs of BME service users but BME organisations were significantly less well-developed than mainstream services.

Similarly, Newbigging, McKeown, Hunkins-Hutchinson et al (2007) identified a lack of awareness about entitlement, different understandings of advocacy, poor partnership working between advocacy services and BME organisations, and attitudes of mental health services to advocacy provision alongside mistrust of statutory provision as barriers to access for African and Caribbean men.

PACE, a charity promoting the mental health and emotional wellbeing of the lesbian, gay, bisexual and transgender community in London, undertook a small scale study

to evaluate its mental health advocacy service (PACE, 2008). This study found that combining the dual role of mental health advocacy within an LGBT service was valued by clients, who particularly valued involvement in the service.

Overall then, there is little in the way of evaluative evidence to enable commissioners and advocacy providers to address implementation challenges and to ensure access to high quality and effective IMHA services for qualifying patients. The small number of studies of the implementation of the other form of statutory advocacy (i.e. IMCA) services identified a lack of awareness of the legislation by health and social care practitioners and a number of operational dilemmas faced by organisations providing IMCA services (Redley, Luke, Keeley et al, 2006).

#### **2.4.5 Standards and guidelines for the provision of advocacy prior to 2009**

Although the research is scant, the advocacy sector has developed standards and guidelines for good practice. These largely focus on what advocacy providers need to deliver high quality independent advocacy services. They stress the importance of the independence of advocacy services from service providers with Advocacy 2000 distinguishing structural, operational and psychological independence.

In 2008, Action for Advocacy introduced the Quality Performance Mark, building on two previous publications, namely Quality Standards for Advocacy Schemes (Action for Advocacy 2006a) and a Code of Practice for Advocates (Action for Advocacy 2006b). This identified quality indicators in seven areas:

- Independence
- Clarity of purpose
- Confidentiality
- Equality, accessibility and diversity
- Empowerment and putting people first
- Accountability and complaints
- Supporting advocates

Appraisal for the QPM involves self-assessment, desk assessment and a site visit. The second edition of the workbook (Action for Advocacy, 2010) includes an IMCA specific review. Such guidelines offer a useful framework for assessing the quality of IMHA services.

**Background – Summary**

Mental health advocacy is not new and developed through the service user movement in the UK. Independent Mental Health Advocacy (IMHA) is a specific form of advocacy, and Independent Mental Health Advocates are granted specific roles and responsibilities under the 2007 Mental Health (Amendment) Act. Their role is to help qualifying patients understand the legal provisions to which they are subject under the 1983 Mental Health Act, and the rights and safeguards to which they are entitled, and help those patients exercise their rights through supporting participation in decision-making.

Advocacy now has a central place in health and social care policy. It is seen as a strategy for social justice in terms of promoting citizenship and human rights as well as representing the interests of more vulnerable or marginalised groups. Local authorities will assume responsibility for commissioning advocacy services, including statutory advocacy, from April 2013.

Recent mental health policy emphasises the importance of advocacy in enabling service users to participate in decision-making in relation to their own care and treatment. Further the recent report from the Centre for Social Justice promotes advocacy before detention as a positive step to tackle inequalities and negative experiences of people from BME communities in relation to the MH Act.

Evaluative research in this field is sparse. Studies have been undertaken largely in hospital settings and a small number of studies in relation to black and minority ethnic communities have raised questions about equity of access and style of provision. Variations in terms of quality and capacity have also been noted alongside an absence of accepted quality standards to guide the effective commissioning and provision of IMHA services.

Although the research is scant, the advocacy sector has developed standards and guidelines for good practice. These largely focus on what advocacy providers need to deliver high quality independent advocacy services, with Action for Advocacy introducing a Quality Performance Mark in 2008.

### 3. STUDY DESIGN AND METHODS

This was a multi-methods study, to provide an in-depth investigation of the quality of IMHA services in England. Quantitative methods were used to gather data about how IMHA services are provided and who uses them and qualitative data to explore the experiences of IMHA services from different perspectives. This chapter provides an overview of the research objectives, the study design, research methods and limitations of the study. One of the hallmarks of this study was the partnership with mental health service users, and the different methods for this and wider stakeholder engagement are also described.

#### 3.1 Aims and objectives

The overarching aim of the research was to review the extent to which IMHA services in England are providing accessible, effective and appropriate advocacy support to the diversity of qualifying patients under the MH Act 1983. The research also sought to identify the factors that determine the quality of IMHA services, from service user, commissioner and provider perspectives.

The specific objectives were to:

- Develop measures of service quality for IMHA services.
- Identify and describe the provision of IMHA services, the IMHA workforce, and the role of IMHAs and their relationship with other services.
- Evaluate equity of access to effective and appropriate IMHA services.
- Review the effectiveness of measures to strengthen accessibility, appropriateness and acceptability of IMHA services to reflect the diversity of qualifying patients.
- Identify the outcomes or impact for service users from using IMHA services.
- Explore experiences and views of a diverse range of qualifying patients of IMHA services, both instructed and non-instructed advocacy.
- Explore the views of commissioners and providers of advocacy services and staff working in the service provider context within which advocacy services are located to explore the factors that determine the quality of IMHA services.

#### 3.2 Scope

The scope of this research was limited to IMHA services in England. It covered all patients detained under the amended MH Act 1983, who are eligible for support from IMHA services (i.e. qualifying patients). This included people with and without capacity and children under the age of 16. The research was therefore undertaken in a range of hospital and community locations as appropriate.

### 3.3 Study design

As the aim of this study was to provide a rich and detailed understanding of the experiences of IMHA services from different perspectives and the factors that influence the quality of IMHA services, we decided that we needed to use a range of methods to capture this. A case study design was adopted as this is particularly appropriate for examining phenomena that are complex and dynamic and enable a real-time exploration of these (Yin, 2003). However, we decided that some initial work was needed to develop the framework for data collection and analysis in these case study sites and thus designed the study in two stages, with the first stage generating a framework of quality indicators for us to explore in detail at the second stage.

**Stage 1:** The focus was identifying dimensions and benchmarks of quality for IMHA services. It involved examining research and expert evidence through a focused literature review, observations of IMHAs in practice and focus groups with a range of stakeholders, to enable differences and similarities between data sources and perspectives to be explored. A set of draft quality indicators were developed from this first phase and these were tested with a panel of stakeholders. The indicators were then refined and they provided a framework for data collection and analysis for the second stage of the study.

**Stage 2:** This comprised eight case studies of IMHA services to capture both quantitative data and in-depth qualitative data about the experiences and operation of IMHA services.

The aim in selecting the case study sites was to achieve diversity in the characteristics of qualifying patients, service configuration, arrangements and contexts for advocacy provision, and to ensure information rich cases. Through this design and the use of semi-structured qualitative interviews, we have been able to provide a rich description and analysis of IMHA services in England.

### 3.4 Research methods

#### 3.4.1 Stage 1: Developing indicators of service quality for IMHA services

This stage had four elements:

##### ☞ Focused literature review

A focused and systematic review of the literature relating to evidence for standards and codes of practice for advocacy services, including IMHA services, was undertaken to inform the development of quality indicators for IMHA services. The review considered:

☞ Dimensions of quality and critical implementation issues for IMHA services.

- Dimensions of quality and critical implementation issues/questions for (generic) mental health advocacy services.
- Dimensions of quality and critical implementation issues for Independent Mental Capacity (IMCA) services.

Quality indicators for (generic) mental health advocacy and IMCA services were reviewed as they had the potential to apply to IMHA services. The literature sources and databases examined included: Health Management Information Consortium (HMIC); Social Care Online/SCIE; Social Care Institute for Excellence (SCIE); Google Scholar; Department of Health/Publications/Policy and Guidance; National Institute for Health Research (NIHR); [www.goodadvocacypractice.org.uk](http://www.goodadvocacypractice.org.uk); Care Quality Commission; NHS Confederation; National Mental Health Development Unit; INVOLVE Research Database; Action for Advocacy; Planet Advocacy; Mental Health Today; Mind; Open Mind; Diverse Minds; Community Care; Afiya Trust BME Advocacy Bulletin; Scottish Independent Advocacy Alliance.

The search terms used were 'advocacy', 'mental health' and 'quality'. Sources were included if they were judged to be relevant to the overall research focus. Papers and reports were identified and are listed in Appendix 4 and the findings are summarised in Chapter 2 and provided a basis for the indicators outlined in Chapter 13.

### ➤ **Focus groups**

Eleven focus groups were held in locations across England (North West, Yorkshire, East of England, East Midlands, South West and London) to ensure a reasonable geographical spread and targeted at specific groups of stakeholders (IMHA partners, IMHA providers, mental health services and commissioners) as well as two groups that aimed to have a mix of stakeholders.

The focus groups explored the experience of IMHA services, dimensions of quality and potential quality indicators for IMHA services, and the factors influencing the quality of commissioning and provision and thus service user experience of IMHA services. The specific lines of inquiry reflected the research questions and were developed by the research team from the focused literature review and through discussion at project team meetings. They were refined through a process of consultation with the Project Advisory Group and the Service User Reference Group. They covered:

- Knowledge and understanding of the IMHA role and IMHA services.
- Views on the contribution of IMHA services.
- How IMHA services work in practice.
- What impact IMHAs have for individuals and on mental health services.
- How service users' experience of IMHA services be improved.

- Dimensions of quality for IMHA services.
- Factors influencing the quality of IMHA services.

Information about the research and the focus groups was posted on key websites (Action 4 Advocacy, National Mental Health Development Unit and the Afiya Trust, National Service User's Network) and also via local networks. Two IMHA providers helped with the recruitment of IMHA partners who met the criteria for inclusion in the focus groups (i.e. experience of detention under the MH Act 1983 and capacity to consent). Both were successful in identifying a number of IMHA partners that were willing to participate, although in one instance less than half arrived to participate in the group. In addition, recruitment to a focus group targeted at BME service users was facilitated by one of the partner organisations, Equalities National Council (ENC). All service users were reimbursed for their travel expenses and a fee offered in appreciation of their time and contribution.

The focus groups were taped and the transcripts imported in to NVivo (QSR, 2012) for coding and analysis. A draft report summarising the findings was sent to all focus group participants for comments. This draft report is available as a project resource at: [www.uclan.ac.uk/schools/school\\_of\\_health/the\\_right\\_to\\_be\\_heard.php](http://www.uclan.ac.uk/schools/school_of_health/the_right_to_be_heard.php).

### ➤ **Shadow visits**

Four 'shadow' visits to IMHA services were undertaken to provide a richer understanding of the IMHA role, the contexts they are working in and the pertinent quality issues. Sites in four different geographical locations were identified for the visits from the Action for Advocacy website and three of the sites had been awarded Action for Advocacy's Quality Performance Mark. Two of the sites were also case study sites and in these instances we were able to undertake observations in a secure setting, a Young persons' unit and of a situation involving a Guardianship order. In the other sites we observed the IMHA in acute inpatient settings and on an older persons' ward. The visits involved:

- Observation of the meetings between the IMHA service and service users, subject to their consent.
- Observation of discussion with mental health professionals related to specific qualifying patients.
- Observation of IMHA team meetings and supervision sessions as appropriate.
- Review of the notes kept by the IMHA service for service user participants, subject to their consent.

In recording our observations, the research team paid attention to: the characteristics of the qualifying patients being seen by IMHAs; the issues that were raised and the way in which the IMHA responded; relationships between IMHAs and IMHA partners and mental health professionals; the organisation and planning of work and



dilemmas encountered in practice. The information from these shadow visits was primarily used to inform the development of the interview schedules for the case study visits and to sensitise the team to the issues raised by qualifying patients and the day to day working of IMHA services.

### ☞ **Development of draft quality indicators**

The development of the quality indicators for IMHA services has been an iterative process. A thematic analysis of the data from the literature review, the focus groups and the shadow visits was undertaken and the results from the different sources synthesised to develop draft quality indicators for IMHA services. The draft indicators were then reviewed by a Stakeholder Panel (see 3.9.3 and Appendix 3). The indicators were circulated in advance of a workshop and the workshop participants reviewed different indicators working in small groups. This feedback was used to further refine the indicators, which then provided a framework for the data collection process for the second stage of the study. They were then used to inform the development of the interview schedules for the qualitative interviews, indicate categories of data to be searched for in the document review and provide a framework for the analysis of the case study data. They have been further refined in the light of the case study findings and are available in Chapter 13, as a resource for commissioners and practitioners.

## **3.4.2 Stage 2: Comparative case studies of IMHA services**

### ☞ **Identification and recruitment of case study sites**

Eight case study sites were recruited to reflect the range of contexts for people qualifying for IMHA services and a brief description of each of the sites is provided in Appendix 5. Demographic information and information on the use of the MH Act was reviewed to identify potential sites (i.e. MH Trusts) and additional consideration given to the organisational arrangements for IMHA provision (generic/mental health/alongside IMCA/BME/Size) and mental health provision. Efforts were made to also ensure a geographic spread across England and the final eight sites included:

- ☞ Two NHS mental health Trusts in inner city locations.
- ☞ Two NHS mental health Trusts in urban locations.
- ☞ Two NHS mental health Trusts in a mix of sub-urban and rural, including coastal areas.
- ☞ One independent provider of medium and low secure services for people placed out of area.
- ☞ One NHS provider of high, medium and low secure services.



The sites were spread across England and located in the East of England, East Midlands, London, North West, North East, South West and the West Midlands. Four of the sites had good representation of different BME communities, and across the sites asylum seeking and refugee communities, economic migrants and travelling communities were also represented. The case study in these sites was defined as the mental health provider organisation as some providers related to more than one IMHA service. There was variety in the organisational arrangements with the boundaries for the Trust matching those of the PCT and the IMHA service in two locations whilst in others there were several IMHA providers commissioned by several PCTs, raising issues around consistency and quality.

In each of the case study sites a particular focus for provision was identified, reflecting key issues identified from the first stage. This was done either in the selection of the initial case study site (for example identifying an independent sector provider to look at IMHA provision for people placed out of area) or by targeted recruitment of participants (for example people from BME communities). The issues explored in this way were IMHA provision:

- Across the age spectrum.
- For diverse communities.
- For people on Community Treatment Orders (CTOs).
- In settings with different levels of security (from low to high).
- For people placed out of area.

### ❧ **Data collection**

In each case study location, data on the accessibility, effectiveness and appropriateness of IMHA services, and the dimensions of quality identified from the first phase, of the research, was collected. The process for this is outlined in Appendix 6 and the questionnaires and interview schedules can be found at: (available at [www.uclan.ac.uk/schools/school\\_of\\_health/the\\_right\\_to\\_be\\_heard.php](http://www.uclan.ac.uk/schools/school_of_health/the_right_to_be_heard.php)).

Data collected in each sites was:

**Description of mental health advocacy provision** using a structured questionnaire designed with the internet software programme Survey Monkey to gather information about the principles and operation of IMHA services covering:

- Key principles.
- Current organisational arrangements.
- Resources available, including staffing.
- Services provided, including attention to services provided across different practice locations, covering inpatient care and community care services.

- Equalities monitoring.
- Mechanisms for service user involvement.
- Arrangements for governance and quality assurance.

**Descriptive analysis of relevant local policy and procedural documentation** to ascertain stated philosophy and aims of the advocacy services, commissioning and operational arrangements. The documents included:

- Service specifications, tender documents and supporting information from commissioners.
- Engagement protocols between the IMHA service and the MH Trusts.
- IMHA service descriptions and annual reports.
- Monitoring reports and evaluations.

**Semi-structured qualitative interviews** to access the range of perceptions of the quality and effectiveness of IMHA provision from various stakeholder perspectives. These interview schedules were designed to elicit respondents' experiences of IMHA services and their thoughts on the various factors that promote or impede effective IMHA services and what contributes to the quality of advocacy. Specific interview schedules were developed for the different groups of stakeholders: IMHA services, IMHA service users; qualifying patients who had not used the IMHA service: commissioners and mental health professionals.

The interviews with IMHA partners explored:

- Understanding of independent mental health advocacy and IMHA services.
- Experience of using advocacy services.
- Access to IMHA services.
- Experience of using IMHA services.
- Views of local IMHA services, including how well the service met advocacy needs/protected rights and the quality of the service offered.
- IMHAs role in relation to Advance Directives, where they existed.
- Views on what would make a quality IMHA service.
- Outcomes from IMHA services.
- Recommendations for IMHA services locally.

In addition, people who qualified for IMHA services but who had not used the service were interviewed to explore their knowledge and awareness of IMHA services and the reasons why they had not used the service. Service user participants were also

invited to complete a brief questionnaire to enable a profile of service user participants to be developed.

**Review of mental health service documentation:** a sub-sample (29%) of mental health case notes for service users who were interviewed, subject to their consent, were critically analysed. For IMHA partners, the mental health case note analysis considered information on:

- How and when the person was informed of access to IMHA services.
- The outcome of these activities, including evidence of the impact of advocacy services on routine care delivery and/or the administration of the MH Act 1983.

For qualifying patients who had not used IMHA services, their notes were reviewed to identify critical points in their engagement with mental health services when they could potentially have benefited from IMHA support.

**Review of IMHA service records:** a sub-sample (20%) of IMHA service records were also analysed for IMHA partners who were interviewed, subject to their consent. These notes were explored for evidence of:

- The process of advocacy work.
- Information relating to patient's wishes.
- Advocacy outcomes.
- Service user satisfaction with outcomes.
- Nature and quality of the record keeping.

Case note analysis was undertaken in four of the case study sites, where access to both mental health notes and the IMHA notes was relatively easy to arrange and in one of the sites this was undertaken by the CSO (Clinical Studies Officer). In another site, the IMHA notes only were reviewed. In total, 14 pairs of notes (i.e. both mental health and IMHA case notes) for IMHA partners; 12 case notes for non-IMHA users and 4 IMHA notes only were analysed.

## ❧ Identification and recruitment of participants

**Questionnaire respondents:** all advocacy providers in the area of the case study site were invited to complete the questionnaire and were e-mailed a link to complete the survey online. Responses from a total of 18 services out of a potential 22 were received, and of these 78% provided a full response.

**Interviewees:** a total of 214 interviews were undertaken, 42% with qualifying patients, with 27% of the total sample of people interviewed having experience of using IMHA services. In each case study site interviews were undertaken with an average of 27 (range =17to 35) participants. In one site, an elaborate research governance process and difficulties with staff recruitment restricted the overall size of

the sample to 17. However, in general, the research participants in each site included 10-15 qualifying patients per site (both IMHA partners and non- IMHA users) and an additional 10-15 interviews with other key informants including advocates, commissioners, clinicians, ward staff, managers, and community-based health and social care staff. Subjects were sampled purposively on the basis of their roles as above. The study was adopted by the Mental Health Research Network and recruitment to the study was facilitated by the Clinical Studies Officers (CSOs) in the majority of the study areas. Prospective professional interviewees were identified with reference to the local situation and were sent information about the study and invited to participate. For service users, the criteria for inclusion were:

- Qualifying for support from IMHA services, as defined by the MH Act (Amendment) 2007.
- Capacity to consent.

Three methods were used to recruit qualifying patients with the aim of ensuring informational rich cases:

- A purposeful stratified sample (Sandelowski, 2000) was identified from the pool of qualifying patients from 1 April 2009 to 31 March 2011 and 150-200 people were written to with information about the study either asking for permission to pass on details to the research team or inviting direct contact with the team. The sampling frame is provided in Appendix 7.
- A purposeful stratified sample was identified from the IMHA service data base of qualifying patients and individuals were written to with information about the study asking for permission to pass on details to the research team.
- The IMHA service, mental health provider or specific community organisation identified potential participants who were given information about the study and permission sought to pass on their details to the research team.

Case Study Site	Recruitment methods used
A	Purposeful stratified sample of mental health provider data of anonymised detentions of people from BME communities qualifying for IMHA services Via service user involvement team Via advocacy services for South Asian community
B	Via IMHA services Via South Asian community development project
C	Purposeful stratified sample of mental health provider data of anonymised detentions of people qualifying for IMHA services Via service user involvement forum
D	Via IMHA services
E	Purposeful stratified sample of mental health provider data of anonymised detentions of people qualifying for IMHA services
F	Purposeful stratified sample of mental health provider data of anonymised detentions of people qualifying for IMHA services
G	Via the mental health service provider
H	Purposeful stratified sample of IMHA data of anonymised list of IMHA partners

**Table 1: Recruitment methods used in each case study site**

### 3.5 Survey of independent sector providers

A short survey of independent sector providers was undertaken to establish what arrangements were in place for qualifying patients in their care. The main purpose of this was to establish who was commissioning and providing the service and was undertaken in response to the fieldwork in the case study site that focused on an Independent Sector Provider to understand the broader picture in respect of arrangements for qualifying patients in independent sector provision. Providers were identified via the website and an e-mail requesting information sent to their head office. We asked the following questions:

1. Are qualifying patients able to access an IMHA?
2. When was this established?
3. Who provides the IMHA service?

4. Who commissions this provision?
5. Any comments on this provision?

Twelve responses were received, usually from individual services. The findings from this are considered in Chapter 12 on commissioning IMHA services.

### **3.6 Study participants**

Nearly 300 (N = 289) people took part in this study with 75 participants in the focus groups (including 3 telephone interviews with participants from a cancelled focus group) and 214 people from across eight case study sites. This included over 100 service users (n= 104), 98 of whom qualified for IMHA services. The remaining participants included IMHAs, both managers and staff; IMHA commissioners and mental health professionals from hospital and community settings with a range of disciplines represented.

#### **3.6.1 Focus group participants**

Eleven focus groups involved 75 participants and Table 2 provides an overview. The recruitment of commissioners to the focus group proved particularly difficult and feedback indicated that the timing of the focus groups was difficult as many PCTs were undergoing changes in response to the Health and Social Care White Paper in late 2010. The views of commissioners (both PCT and Local Authority) were therefore sought during the second stage of the study. One of the focus groups was cancelled because of the limited number of participants and the remaining three participants were interviewed by phone.

Focus	Participants
Service users	18 participants: one focus group for BME mental health service users (n =5, London); two focus groups for IMHA partners (n =3, Hertfordshire and n = 5, North West ), 2 mixed stakeholder groups (n =1, Yorkshire and n =1, South West) and 3 telephone interviews (West Midlands)
Carers and family members	9 participants in one focus group with a Gujarati interpreter (East Midlands)
IMHA providers	41 participants in 4 focus groups for IMHAs, including one for BME advocacy providers) (North West and London) and in 2 mixed stakeholder groups (Yorkshire and South West)
Mental health staff	6 participants in a focus group for mental health staff (North West) and one in a mixed stakeholder focus group (Yorkshire)
Commissioner	1 participant in a mixed stakeholder focus group (Yorkshire)

**Table 2: Overview of focus group participants**

### 3.6.2 Case study participants

#### Questionnaire respondents

A total of 22 advocacy providers were identified across the case study sites and invitations were sent to 20 as 2 did not respond to the initial contact. Of these 20 (95%) 18 responded, 78% of which provided a full response to the questionnaire. The advocacy providers included both local, regional and national advocacy providers and the range of advocacy services provided varied. Further detail on the nature of these organisations is provided in Chapter 7.

#### Interviewees

A total of 200 interviews were undertaken with 214 participants, with a small number of joint interviews, for example two staff together or a service user and a family member. The majority of interviews were face to face (94%) either in the mental health service (usually an inpatient facility), community facility (Community Mental Health Team (CMHT) or Assertive Outreach service), or in their home, with the remainder being telephone interviews.

An overview of participants is provided in Table 3. As this indicates, both managers and staff working in IMHA services were interviewed, with the majority of the managers also working as IMHAs. A small number of advocates (4) not qualified as

IMHAs were also interviewed and this was usually to understand the advocacy needs of a particular client group in the case study area, i.e. people from BME communities.

Fewer carers than originally anticipated were interviewed, mainly reflecting the service users' wishes that they did not want contact with their family or carers to be made or because they were not involved to any great extent.

The commissioners that were interviewed were mainly from PCTs and in three sites included commissioners who were commissioning IMHA services jointly with the Local Authority.

The mental health professionals interviewed had a broad range of roles, including responsibilities in relation to the MH Act, a solicitor and hospital managers (n = 3) as well as MH Act Administrators (n =3) and AMHPs (n =10) were interviewed. A small number of staff with responsibilities in relation to service user involvement and safeguarding were also included. Mental health professionals worked in a range of services including:

- High, medium and low secure services.
- Acute in-patient wards.
- Recovery and rehabilitation services.
- Community teams: home treatment, psychosis services, assertive outreach and crisis resolution.

The majority of mental health professionals interviewed were working in inpatient settings (44%) and included both ward managers and more junior staff. However, a number of professionals, psychiatrists, psychologists, occupational therapists and service managers also had responsibilities in relation to care and treatment of qualifying patients on those wards. Staff interviewed in the community included AMHPs, social workers and Community Psychiatric Nurses (CPNs) as well as team leaders or managers for community teams including assertive outreach, home treatment and community mental health teams (CMHTs).

One hundred and twenty qualifying patients were recruited to the study and interviews undertaken with 90 people, mainly reflecting difficulties making contact with the person to arrange the interview and, in a small number of cases, capacity issues. Two thirds of the sample of qualifying patients had used IMHA services. The majority of interviews were undertaken in English. Interpreters were used to translate into Hausa, Portuguese and Urdu. A profile of the qualifying patients interviewed is provided in Appendix 8.



Case study	Participants																	
	Commissioners	IMHAs		Mental Health professionals										Service users			Carers	Total
		Managers (IMHAs)	Advocates (IMHAs)	AMHP	MH Act role	Ward staff staff/managers	CPNs	OT s	Psychologists	Psychiatrists	SWs (Not AMHPs)	Community team	Service managers	IMHA partners	Non-IMHA	Other		
A	3	3(1)	3(2)	1	1	3	1	-	-	-	-	2	1	7	8	2	-	35
B	1	3(2)	2(2)	2	1	3	-	-	-	1	-	1	-	12	2	-		28
C	2	1(1)	2(2)	3	1	5	-	-	-	1	-	-	-	5	7	1	2	30
D	-	1(1)	3(1)	-	-	6	-	2	1	1	-	-	-	8	2		-	24
E	4	2(2)	2(1)	-	-	4	-	1	1	1	1	-	3	9	1		-	29
F	1	1(1)	2(2)	2	3	4	-	-	-	2	-	-	-	7	3		-	25
G	1	1(1)	3(3)	1	-	2	-	-	-	1	-	-	-	8	-	-	-	17
H	1	1(1)	3(3)	1	1	3	2	-	-	1	-	1	1	5	6	-	-	26
Total	13	13 (10)	20 (16)	10	7	30	3	3	2	8	1	4	5	61	29	3	2	214

**Table 3: Overview of participants by case study site**

The sample was relatively evenly balanced in terms of gender (M: F = 47:43) although it was expected that more men would have been recruited as one of the sites included gender specific secure provision for men. The questionnaire to capture additional demographic information was completed by 91% of the sample. From the questionnaire data, the age of participants ranged from 15-74 years with a relatively even spread across age groups. People under the age of 21 comprised 12% of the sample, compared with those over 65 who made up 6% of the total. Eighty per cent of the sample who completed the service user questionnaire were identified as British including Black British and British Asian: 30% of the sample were from a Black and minority ethnic community, including Black Caribbean (9%), Black African (5%), Mixed heritage (4%), South Asian (5%), White Irish (3%) with the remainder being White European or White Other. The majority of participants were British Citizens (91%) with 7% of the sample identifying as asylum seekers and 1% as refugees. Both the age and ethnic distribution reflect the purposive sampling methods adopted,

with particular efforts being made in specific case study sites to recruit people from BME communities and young people.

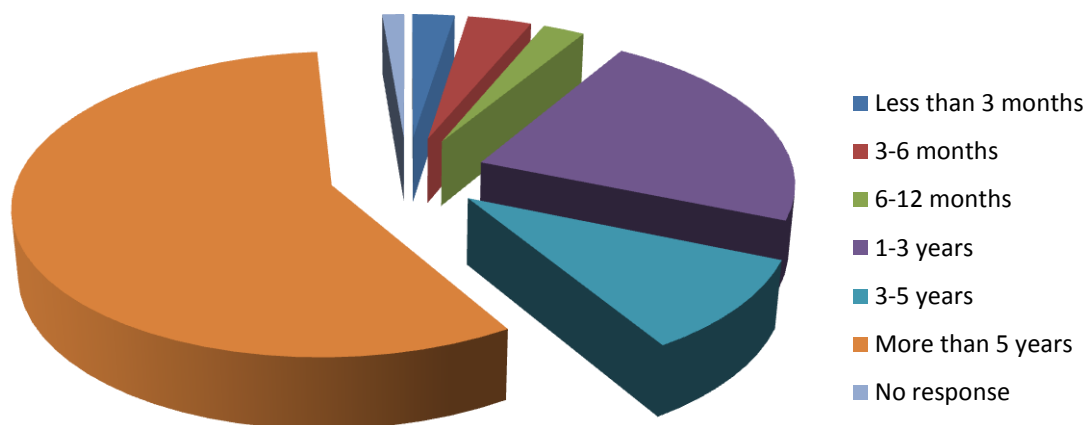
The majority (88%) identified English as their first spoken language with a range of other languages being spoken including Punjabi, Somali, Thai, French and Patois. Nearly three quarters (72%) identified English as their first written language with nearly 20% not answering this item and it is not clear whether this reflected issues with the design of the questionnaire or literacy issues.

Eight per cent of the sample completing the questionnaire identified their sexual orientation as gay or bisexual with no one identifying themselves as lesbian, although 3% indicated other in response to this question.

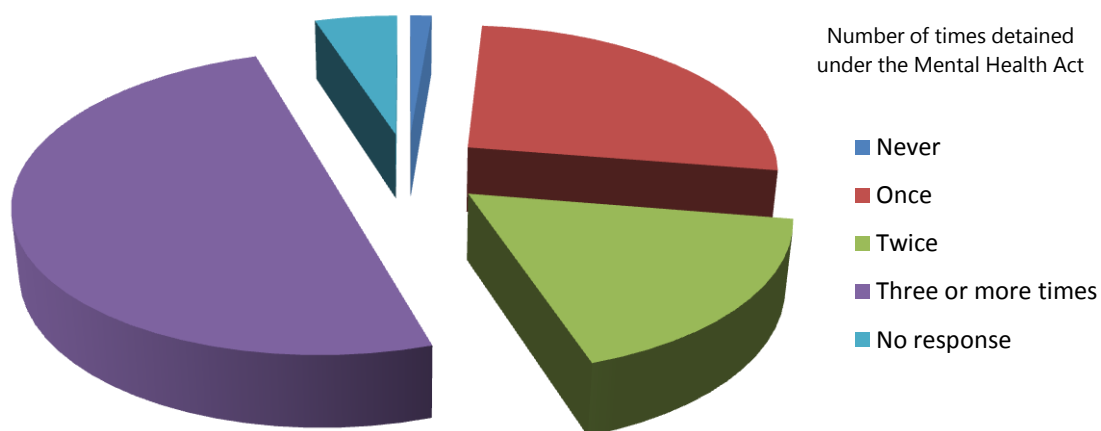
Nearly two thirds (65%) of the sample identified having a disability with over a third (35%) identifying this as a mental health condition ranging from loss of confidence to bipolar disorder to psychosis and schizophrenia. A learning disability was identified by 8% and Autism and Asperger's Syndrome by 5% of the sample completing the questionnaire. The remaining disabilities identified included physical disabilities leading to wheelchair use or restricted mobility; respiratory difficulties, sensory impairments and complex mental and physical health problems.

Of particular note was the length of contact with mental health services and the number of times that people had been compulsorily detained. Over half (58%) of the sample had more than five years contact with mental health services compared with less than ten per cent (9%) with less than a year of contact, as illustrated below in Figure 2. Half (50%) had been sectioned three times or more compared with a quarter (26%) who had been sectioned once, as illustrated in Figure 3.

At the time of using the IMHA service, 53% of the qualifying patients were detained in inpatient services, mainly acute inpatient wards but also older people's wards and assessment and rehabilitation services; 40% in secure services – including psychiatric intensive care, low secure, medium secure and high secure; learning disability forensic services and CAMHS forensic services - and a minority (7%) had been using community mental health services.



**Figure 2: Contact with mental health services**



**Figure 3: Experience of detention under the MH Act**

### 3.7 Data analysis and synthesis

The qualitative data from the focus groups and interviews was analysed using standard qualitative data analysis methods, beginning with the identification of key themes and patterns (Silverman, 2001; Coffey & Atkinson, 1996). The initial process of identifying themes was driven partly by the research objectives and our observations and interpretations of participants' individual accounts. All members of the research team contributed to analysing the data. The process involved all the

team examining selected interview transcripts from focus groups on one occasion and interviews on another, to identify themes. Team members were then involved in interpreting the meaning of data segments during a two day workshop for this purpose. Thus we were able to capitalise on the service user input within the team and draw on various interpretive frameworks. Four team members, supported by three other team members, coded the majority of the data using the themes that had been generated. Data was then put on to NVivo software (QSR, 2012) by two members of academic staff, supported by an administrative assistant, who was familiar with NVivo. Three members of the academic staff and a co-researcher were responsible for producing written accounts, which were discussed within the team, with the Service User Reference Group and the Project Advisory Group.

The survey questionnaire data was summarised and compared between the sites where possible and using national data, as appropriate. The quantitative data from the service user questionnaire, used in the case study sites, was analysed using descriptive statistics with SPSS 18 (IBM, 2012).

The findings from all sources of data were synthesised and relationships between population characteristics, advocacy needs, organisational context, front-line practice and experiences of IMHA services and practice were explored within the data to develop a rich understanding of the experience and quality of IMHA services.

### **3.8 Research team**

One of the hallmarks of this research has been the partnership with mental health service users. The research team consisted of four academic staff, including one mental health service user, and nine co-researchers, who were recruited for their interest in advocacy and research, and experience of using mental health services, including detention under the MH Act, and experience of secure services. Members of the academic team also brought experience in the commissioning and teaching of advocacy, evaluation of mental health legislation and working in the mental health service sector.

Recruitment, training and support procedures for the co-researchers were designed specifically for the study with reference to national good practice. The researcher team comprised 3 men and 10 women and a broad mix of ethnic groups was represented by the co-researchers. Apart from the initial study design, the co-researchers were involved in all areas of the research process: the development of the research tools; data collection through focus groups and interviews; data coding and analysis, contributing to report writing, talks and dissemination of the findings. Training sessions were provided throughout the project and included a session that utilised the skills available in the co-researcher team.

Peer support came through the team meeting one another and there was a healthy exchange of ideas and information via email. Access to university library and facilities

was made available. The academic team discussed appropriate arrangements to identify the level of support required and, for example, data collection in the case study sites was undertaken in teams with two (or three) co- researchers plus one member of the academic team. Debriefing was a key part of the process and this was frequently taped to allow for further reflection and analysis.

We exercised choice about disclosing our service user identity to participants, but often shared this information with qualifying patients. The feedback that we received, from patient interviewees in response to an item on the questionnaire about being interviewed by a mental health service user, was overwhelmingly positive; with one woman commenting that seeing other mental health service users as researchers was an inspiration for her own recovery.

Whilst combining experiential knowledge and perspectives with academic rigour is promoted as generating new insights and knowledge (Beresford, 2005), there was also the potential for the quality of the data collection and analysis to be unduly influenced by this. We therefore worked hard to be reflexive, to identify prior viewpoints and to consider how they may have influenced the research process. It is our view that the research has been considerably enriched by service user involvement as a consequence of deeper insights into the experience of distress and detention. Furthermore, it has been strengthened by the direct accountability to service users, as most of the research team come from this background, and have consistently provided a challenge to assumptions, method, process and analysis.

### **3.9 Stakeholder involvement**

The following methods were used to involve a diverse range of stakeholders and interests in IMHA provision. These were vital in providing accountability and external scrutiny of the research process and the emergent findings and thus increasing the validity of the research.

#### **3.9.1 Project Advisory Group**

A Project Advisory Group (PAG) provided expertise and guidance and oversight of the delivery of the project, acting as a critical friend. Members included representation from professional bodies, mental health service users, a carer representative and others with specific expertise in relation to different BME communities. A full list of members is available in Appendix 1. The PAG met four times, commented on the questions for the focus groups and case study sites, the draft quality indicators and the draft report and supported the dissemination of the findings through their networks.

#### **3.9.2 Service User Reference Group**

Mental health service users were recruited to the Project Reference Group with adverts placed via local networks. The group members had a wealth of experience in

the field of mental health through use of mental health services and advocacy, as well as through links with Comensus (a service user and carer led network at UCLan), a local Hearing Voices group, Shift, Making Space and the Manchester African Caribbean Mental Health Services network (see Appendix 2). Six meetings were held in total and monthly project updates were circulated to keep members informed of key developments in the project. The Reference Group provided a forum for discussion and interpretation of emergent findings. Discussion at these meetings raised a number of critical questions that the research needed to address further, among others relating to:

- Entitlement to IMHA support and issues of accessibility of IMHA services.
- The remit and role of IMHAs, negotiation of role boundaries by IMHAs, limitations concerning the short-term/time limited and issue-based nature of IMHA support.
- The critical importance of adequate and comprehensive training for IMHAs.
- Knowledge/awareness about IMHA services among qualifying patients linked to promotion of IMHA services by mental health staff and proactive outreach work undertaken by IMHAs.
- Configuration of IMHA provision and links to generic mental health and other forms of advocacy.
- Professionalisation of mental health advocacy (through the introduction of IMHAs) and implications for service quality and outcomes.
- The work of IMHAs with people on CTOs.

Furthermore, at Reference Group meetings data from focus groups and interviews with various stakeholders undertaken were examined for key themes to explore how these themes could be used to inform the questions that needed to be asked during subsequent phases of the data collection.

### **3.9.3 Stakeholder Panel**

A Stakeholder Panel was recruited to review the draft quality indicators. The members were recruited from the Project Advisory Group and from other organisations not well represented on this. Appendix 3 provides the membership of the Panel. The group met once, specifically to consider the draft quality indicators.

### **3.10 Ethical considerations**

Ethical approval for the whole study was granted by Cambridgeshire 3 Research Ethics Committee and the International School for Communities, Rights and Inclusion Ethics Committee at the University of Central Lancashire. Site specific authorisation was sought, via the National Institute for Health Research Coordinated System for gaining NHS Permission (NIHR CSP), from the local NHS Trust and, if appropriate, the PCT. Research team members held research passports, which involved obtaining

enhanced CRB and occupational health clearance, to enable them to have an honorary contract or letter of access in the NHS sites. Ethical approval was also given for data collection in the independent sector site.

### **3.11 Methodological and practical challenges**

We encountered a number of issues in undertaking this study. In particular, participant recruitment proved particularly difficult. The study was adopted by the Mental Health Research Network (MHRN), and the Clinical Studies Officers (CSOs) provided some support with this, although the extent of support varied across the sites. Further, the local research governance processes impacted adversely on the timescale for the study, with approval needing to be secured from six internal committees in one instance.

#### **3.11.1 Participant recruitment**

Participant recruitment proved to be a major issue, both for the focus groups and in the case study sites. We had no difficulty in recruiting IMHAs to the focus groups reflecting both their interest and possible concerns about this research; as expressed during a number of the focus groups. The timing of the focus groups proved difficult for commissioners, given impending PCT reorganisation, and we therefore incorporated questions about the quality of IMHA services into the schedule for the commissioner interviews in the case study sites. Recruiting IMHA partners to focus groups proved particularly challenging and we worked with two IMHA services that advertised and mailed information out on our behalf. Despite this, one group only had three participants and the other five. Feedback from the IMHA services suggested that people may be keen to leave behind their experience of detention under the MH Act and not wish to revisit it. However, our impression was that knowledge and awareness of the IMHA role or services, both for service users and mental health staff, impacted on recruitment and data quality in both the focus groups and the interviews in the case study sites.

In the case study sites, the recruitment of service users was limited by the quality of information kept by the mental health provider and/or the IMHA service and, in particular, equalities information, with some Trusts and several IMHA services not appearing to record this routinely across all equality strands. We found no evidence in any of the sites of systematic methods for recording qualifying patients or referrals to IMHA services by mental health services, beyond what might be recorded in individual case notes. This is a key finding of the research and contrasts with the Department of Health requirements in relation to referrals to (Independent Mental Capacity Advocate) IMCA services.

This, combined with a lack of willingness to share information across the IMHA service and the mental health provider, meant that recruitment was not as targeted as we would have liked. Data protection issues were routinely cited by IMHA services



as the reason that they were not prepared to do this. In the one instance where this did happen, there were significant discrepancies between the advocacy services as to who was using the IMHA service and the Trust as to who qualified.

There were also obstacles in approaching qualifying patients and IMHA partners with two mental health providers expressing concerns about confidentiality in relation to inviting previously detained patients to take part. Further, two IMHA services made it clear that it would be difficult to identify people because they were largely self-referred from the ward, the contact could be fleeting or the service did not retain personal information and did not usually follow up people after discharge. Not surprisingly, it proved easier to recruit qualifying patients in secure settings where it was often clear that the IMHA service had a well-established relationship and presence. Our experience has thus raised two issues for the operation of IMHA services: first, the nature and quality of information kept on IMHA use by mental health providers and by IMHA services and second, the question of whether mental health providers and IMHA services should be sharing information about who qualifies for IMHA and the uptake of these services.

The qualifying patients who were recruited had other substantial contact with mental health services and had been detained under the MH Act on several occasions. This means they may have had a better understanding of IMHA services and hence were more willing to take part. Equally, it may have been the case that they had a particularly negative experience of the MH Act that they wanted to share. However, the quality of the interviews with qualifying patients varied enormously and there were a number of 'thin' accounts raising certain questions in terms of method. First, some participants had a poorly developed understanding of their own position in relation to the MH Act and of rights in general and IMHA services in particular. Second, a small number of participants had difficulties recalling details. Sometimes this was attributed to their mental health status at the time or the circumstances surrounding their detention. Asked about the use of IMHA services, this man, who the IMHA service indicated they had seen, responded:

*"I might well have done but I was just absolutely out of my mind, I mean they were just sedating me constantly."*

*Service user (Acute ward)*

It is also worth noting that some of the mental health services professionals were vague about the detail, which variously reflected their lack of experience of IMHA services or a lack of understanding of the role and this is explored in detail in Chapter 6.

*"I'm just wracking my brains when we've had these occurrences where, you know, where there are issues with clients and I know we've had Advocacy, I*



*can't just name it all to be honest with you"*

*Home Treatment Team Manager*

The partnership with mental health service users as co-researchers undoubtedly facilitated the interview process in a number of instances. However, we also considered whether one-off interviews were the best method for obtaining sensitive information and concluded that repeat interviewing might have yielded richer data.

The sensitivities and potential stigma that might impede both the recruitment of qualifying patients and what they were prepared to discuss was highlighted in relation to the recruitment of qualifying patients from South Asian communities. In two areas, we worked with either a community organisation or an advocacy organisation with specific expertise and networks within the South Asian community to recruit potential participants. In the first instance, the community organisation held a general awareness raising event to highlight and explore the meanings of mental illness, the IMHA role and becoming involved in our research. As a consequence, two women volunteered and one agreed to be interviewed. In the second instance, an advocate from the South Asian community approached several people, all of whom declined and he reported that, despite reassurance, individuals were fearful of taking part, reflecting their experiences of detention.

The interviews clearly had the function of promoting IMHA services and a number of qualifying patients, with no experience of IMHA services, expressed their intention to get in touch with the service or asked for further information. The research team also provided information about local services, including the IMHA service, to participants. Further, in response to a question on Advance Directives, several interviewees expressed interest in this and asked us to write down information for them to follow up. In addition, a number of staff commented that the interview had highlighted shortcomings in their knowledge base that they needed to address, for example, in relation to the IMHA's right to access notes.

We had originally anticipated interviewing more carers and family members but we found that many of the IMHA partners either did not have a carer or did not consent to them being interviewed. We also concluded that given the level of awareness amongst qualifying patients and mental health professionals, encountered early on in the data collection process, that pursuing interviews with carers was unlikely to provide insights into quality issues but would confirm the access issues. These had emerged clearly during the focus group with carers and they met again to provide a response to the draft focus group findings; with their feedback confirming the original findings.

Mental health professionals were identified and recruited by the CSOs in the case study sites and it is possible that those that volunteered may have had particular motives for participating; either holding particular views about advocacy services or

interest in research and established relationship with the CSO. However, we do not think that this has impacted upon data quality because of the range of views expressed, as illustrated in Chapter 10.

The recruitment of the IMHA services to the case study element was affected by the reorganisation and changes to IMHA providers which have taken place. One service declined to take part as they had only taken over the management and operation of the service two months previously. However, in four out of eight of the case study sites, some form of reorganisation had happened within the last six months of data collection starting or occurred during the data collection period. In most instances, staff moved over to the new organisation and therefore this did not impact adversely on data collection but provided insights into the commissioning process and different models for provision of IMHA services. The environment within which IMHA services were now operating meant that we encountered concerns about commercial sensitivities and thus a reluctance to share information, particularly in relation to income, and thus some of the survey questionnaires were incomplete.

### **3.11.2 Information on IMHA activity and impact**

Overall, our experience of routine information collection in relation to qualifying patients and use of IMHA service indicates that the basis for evaluating the uptake and impact of IMHA services was generally not in place. As discussed above, this impacted on participant recruitment.

The absence of systematic routine data collection also made it difficult to draw comparisons across the sites. It was evident from the questionnaire returns that IMHA services have different methods for recording activity; counting either the actual number of people or the number of cases, which could be the same person at different times. This has implications for the robustness of our conclusions and thus those which rely on this data are tentative. However, the patterns that they reveal, as opposed to the actual numbers, provide an insight into the operation of IMHA services. Further we also found that the quality of the information recorded by IMHAs was often lacking and the case notes we looked at often did not adequately capture information about the IMHA's activity or the outcomes of the IMHA intervention. As discussed in Chapter 11, further work needs to be done by advocacy providers and commissioners on meaningful outcomes for IMHA services.

### **3.12 Limitations**

This study relied heavily on qualitative data to provide a rich and detailed description of IMHA services in practice. As we did not undertake a national survey of IMHA practice it is not possible to confirm how representative the case studies are of the national picture. However, as one of the peer reviewers pointed out the extent of the detail and diversity of the sites generates confidence that most, if not all, issues have been identified.

The limitations of this study largely reflect the practical challenges that we encountered, as discussed above. These impinged on the recruitment of participants and took up a considerable amount of time and resources. Consequently there are some significant gaps in the participant profile: first the number of older people and second the number of carers recruited to the study. Further research is required into the quality of IMHA services viewed from these perspectives. We also did not observe as many instances of non-instructed advocacy as we had hoped and this partly reflected that this practice is more limited than we had actually anticipated. Again, this is worthy of further investigation. Finally, the difficulties in getting information about the service costs and the relatively sketchy recording by IMHA services of their activity and outcomes for IMHA partners meant that it was not possible to undertake a cost-benefit analysis.

### **Study design and methods – Summary**

The research aimed to understand:

- Whether IMHA services are providing accessible, effective and appropriate advocacy support for the diversity of qualifying patients.
- The factors that influence this.

The research team included people with experience of using mental health services and being detained under the Mental Health Act. Approval to undertake the study was granted by national and local Ethics Committees as necessary.

The research was undertaken in two stages and used a variety of methods to capture data. The first stage involved a focused literature review, focus groups held across England with a broad range of stakeholders and shadow visits in order to develop quality indicators for IMHA services. The second stage involved eight case studies of mental health provider organisations and involved collecting the following data:

- Key documents and reports.
- Interviews with qualifying patients, IMHA providers, mental health professionals and commissioners.
- Analysis of the IMHA records and mental health records for a small number of qualifying patients, who agreed to this.

In total, 214 people were interviewed and this included 90 qualifying patients. We faced a number of challenges in undertaking this study. Recruiting people who qualified for IMHA services was seriously impeded by the lack of systematic information on IMHA referral or use recorded by the majority of mental health providers in our sample and the reluctance of IMHA providers to share information with them about who is using the service. This is a key finding of the study as it has implications for reviewing access and uptake by different groups of individuals.

## 4. EXPERIENCES OF QUALIFYING PATIENTS

### 4.1 Introduction

In both the interviews and focus groups service users, carers and family members, talked about their life experiences, specifically experiences of mental distress and of the use of the MH Act and its impact on their lives. These accounts provide an important contextual backcloth for the provision of IMHA services and thus this chapter presents an overview of these findings.

### 4.2 Service user experience and issues

There was no 'typical' service user: participants included husbands, wives, parents, children, people who had held responsible jobs, including nurses and social workers, people who had been in prison as well as people with a wide range of service use, including community services, and a broad range of inpatient services (acute, PICU, forensic and secure services). They described a variety of life experiences including their family circumstances. Views on the family were varied: at one end of the spectrum families could be a support and a reminder of a life beyond illness while, for others, the family was a source of problems, including abuse and violence. Relationships within the family could be affected by the experience of distress itself:

*"Every time I do something they don't like, it's part of my mental health now."*

*IMHA partner (Acute ward)*

Several people wanted to make sure we understood the level of their education and understanding of the mental health system. Some people had learnt a lot from decades of personal experience, and others had qualifications and degrees in a range of subjects, including professional qualifications in health and social care. They all placed an importance on **being able to communicate their own point of view** and this was seen as critical to getting appropriate support. Participants were concerned that people who had less understanding or were less articulate may have more of a struggle in getting themselves heard. The effects of medication could also be a barrier to communication.

*"You can't think straight let alone take care of yourself. It's awful, you're like a body but you've got no, no brain. And it's all sedation, sedation."*

*Non-IMHA user (Older persons ward)*

Stigma and discrimination were also identified as barriers to effective communication. Discrimination within services can prevent staff hearing the views of people who use services and some participants described their experiences as being dismissed. This then has a further impact on their sense of self and confidence:

*"No matter how coherent, how rational, you know how considered my arguments and my explanations for events are, that assumed level of incompetence undermines it because you're given sub status."*

*IMHA partner (Acute ward)*

Experience of distress is very personal and service user participants described a range of feelings, reasons and histories. Accounts emphasised that their experiences were uncomfortable, unwelcome and, often, a surprise. Their descriptions included fear, vulnerability, panic, anger, aggression, paranoia, worry and feeling alone. Several people talked about the unpredictability of their distress, especially where it is linked to bipolar disorder. For some, their distress had involved strange beliefs or caused them to take actions which would have lasting consequences for the whole family. A few people talked about what had caused their distress and mentioned specific events such as childhood abuse. These personal experiences can have implications for how IMHA services are provided.

#### **4.2.1 Experiences of the Mental Health Act**

In describing their experiences of mental distress, several people recognised a need for support:

*"They need to find some sense, these people are going through turmoil, so what they actually need is some kind of link, some way to hold onto something."*

*Non-IMHA user (Acute ward)*

A small number of people referred to the containment that being on a Section offered them. However, service users in the focus groups and case study sites, described their experience of detention under the MH Act as often frightening and deeply disempowering. Detention under the MH Act is likely to be distressing in itself. By definition, it occurs when there is a risk to self or others, and when a person is considered to be experiencing a mental health problem. A minority of people were subject to Part 3 of the Act, used to transfer people from the courts or prison, but most people in the study sample were assessed in the community for admission to hospital. By definition, anyone detained under the MH Act is likely to disagree with its use at that time. However, for some participants, their previous experiences led them to understand that a Section is necessary for admission to hospital.

*"I asked for the CPN to section me before I got violent and everything like this."*

*Non-IMHA user (Acute ward)*

Others acknowledged that use of the Act and admission to hospital is helpful to them at certain points in their lives:

*"On the whole, I was glad I was in hospital because I knew if I wasn't in hospital I'd have cut myself to bits at home, so I knew I was in the right place."*

*IMHA partner (PICU)*

But even then, there were also mixed feelings:

*"I fundamentally object to the law, I disagree with not even the fact the law that she's working within it, even though it's helping me, I fundamentally disagree with it, I want it... you know I want it ended. You know 200 years ago they were hanging witches, I hope that in the next five years people like myself won't be discriminated like this."*

*IMHA partner (Acute ward)*

The majority of participants had been detained more than three times, as described earlier, but some people had been in hospital for under 28 days on a Section 2, whilst others had been in and out of hospital over many years:

*"I've been detained loads of times in 20 years, been detained about eight times."*

*Non-IMHA user (Acute ward)*

Other people had their Sections renewed so that they had remained in hospital for many years:

*"It's been 23 years under the MH Act. I always find it difficult to come to terms with that."*

*IMHA partner (Forensic service)*

People questioned whether it was appropriate to be in a hospital for a long period of time:

*"Now some of these people who are in here and they've not committed crimes and they're on Section 3s just for being on one, and they still have been here five, six years and it's only a six months section, it's been renewed like 12 times, been here six years and 12 ... I mean been here yeah six years and they've not committed crime so if they have never committed crime, I mean it's not a threat, a risk to the public in that respect. It seems to be like a web these hospitals; once you get caught up in it it's very hard to get back out of it."*

*IMHA partner (Medium secure unit)*

Some participants experienced the MH Act being used as a threat or as the only way to obtain inpatient care. Even for those people who are admitted voluntarily, there is an understanding that they cannot leave the hospital or the MH Act will be used to detain them:

*"I'm only staying here because I don't want to kick up fuss, if I leave again the police would bring me back in under the Mental Health Act."*

*IMHA partner (Acute ward)*

People emphasised that their views on their own recovery are rarely considered and consequently that they are in hospital for a long period of time; feeling that they will not return home:

*"It's very hard to let them know because they don't listen you know, so I know I'm on this ward for a reason but when I go and say 'oh I haven't had these horrible thoughts for seven months' the doctor would just sort of say 'oh well you know you've got to stay here. I think it's a hard one to get out into the community again.'"*

*Non-IMHA user (Medium secure unit)*

For people admitted under Part 3 of the Act, a return to the community can feel even more distant:

*"I think they don't want to take the risk of letting us out until they're 101% certain we're not going to commit a crime again, now whether that be we get released with terminal cancer or in a wheelchair or something, I think they'd be happy to release us then, if we were incapable of committing crime but whilst we're actually young and active I think they don't really want to risk it."*

*IMHA partner (Medium secure unit)*

The service users rarely described the original process of assessment. This is not surprising as, for many, it was a confusing time:

*"Two doctors came to me home, they said 'you're coming wi us' I said 'why?' they said 'cause you have to', so I was handcuffed, taken to hospital and from there brought here. I was informal so I thought 'well if I'm informal that means I'm a voluntary, you know I can come and go', so I went to go and they brought me back and said I'm sectioned."*

*IMHA partner (Acute ward)*

The police were often involved to take people to hospital, which was hard to understand for people who, until then, will have seen law enforcement as separate to the health care system:

*"Even if I was unwell, I tried to leave home and then they rang up the doctors, the doctors rang the police, they came to collect me from the train station, I was brought in here in a police van. I wasn't a criminal, I wasn't dangerous, I wasn't hitting anybody or being a threat."*

*IMHA partner (Acute ward)*



*"There's five Officers to hold down a five foot three woman and cuff her up, because I says 'no I'm not going in your van' they said 'yes you are' I said 'no I'm not going in your van' they said 'yes you are' I said 'no I'm not going in your van, I'm mental not a criminal'."*

*Non-IMHA user (Acute ward)*

In some instances, detaining people against their wishes had involved a level of force, which often felt excessive:

*"I had a lot of issues with the police because I got dragged through the courtyard into the... on the tarmac and all as I came in for was because I was ill ...I said 'I can't breathe' and they were dragging me, took me trainers off me so I couldn't walk properly, so I got dragged"*

*IMHA partner (Acute ward)*

This level of force was also experienced on the ward from nurses:

*"I was hurt when they restrained me and they put your arms behind you and push your head down and take you to a quiet room, I was hurt and I'm still hurt now, I'm receiving physiotherapy for it."*

*IMHA partner (Acute ward)*

This was the experience of both men and women, regardless of age. One woman in her sixties commented:

*"They pushed me roughly out of the way and I fell backwards onto a bed and that hurt my back. They were using far more force than was necessary and I wasn't being aggressive, nasty, I was just being obstinate, difficult."*

*Non-IMHA user (Older persons' ward)*

Several participants, including young people experienced receiving medication as an injection against their will and this often involved a degree of force:

*"It was a depot and I was restrained and I literally had my trousers pulled down and my knickers pulled down and then I was injected and left in the restraint room and I found that particularly undignified, I found that absolutely awful and then the next time they came to give it to me they threatened me with that and they said 'well you can either have five blokes holding you down like you had before or you can do it quietly in this room and we'll do it for you' so obviously I decided to do it quietly in the room because having five blokes holding you down, holding your wrist, holding your legs and you can see their shoes lined up in front of you where the rest are lining the door, is not very nice, so they threatened me with that."*

*IMHA partner (Acute ward)*

There was a strong sense that the experience could have been different and that they could have been treated with more humanity:

*"It is loss of dignity, I don't think I felt like a person, it made me feel like I was a nothing, ...I think a place of safety does not strip you of your identification, a place of safety is somewhere that is welcoming, that is warm, that's provided for each you know specific need, need to be a criminal goes to a cell, need to be an ill person, need to go to a comfortable place of protection or maybe if you actually sat down and put that person in a comfy room you might get a different effect from the environment ...it strips you of your identity."*

*Non-IMHA user (Acute ward)*

Many of the people we interviewed did not recall the process of assessment through to detention including admission to hospital. Where people did want to talk about it, it was likely to have been a particularly distressing and damaging experience that had remained in their memory. These very negative experiences were not balanced by descriptions of positive experiences, which were either not remembered, too painful to remember, or were not typical of the experiences of those in our study. This could skew our understanding towards detention generally being a more distressing and negative experience.

However, when people are frightened and bewildered, with little understanding of the process of admission and with no one to reassure them, it is, to some extent, likely to be a negative and disempowering experience.

#### **4.2.2 Experiences of mental health services**

Hospital is commonly assumed to be a place for a therapeutic intervention which will help the patient. Many of the people we spoke to felt otherwise, with an understanding that hospital was, at best, a place to reduce risk and ensure safety either of the individual or the community:

*"I think they were just keeping me there to keep me safe to stop me from killing myself, I wasn't actually getting better, I didn't stop feeling like I wanted to end my life, they were just containing me."*

*IMHA partner (Acute ward)*

For some people, the experiences were disempowering and their time in hospital, one of survival:

*"When you're put in hospital, everything goes to pot and you don't get any information, you don't get any help or whatever and if you try to access help they just ignore you and its just oblivion really so ... it's very unpleasant."*

*IMHA partner (CTO)*

Some service users were more positive about services, especially those who were living in medium or high secure services, and had come to some kind of acceptance. They also suggested that, as they had nothing to compare it to, they didn't know whether their experiences were exceptional or not:

*"You know you just take it in your stride and go on, it's just part and parcel of the day but it might not be, that might be the whole crux of the matter that's your problem you know."*

*IMHA partner (Secure services)*

*"I feel like I'm a bit level headed, I didn't kick a fuss, I didn't attack anybody or anything, I just ...you know 'I'll just go through with this' just accepted it even though I didn't want to accept it you know, I just said 'well I'm going through with it, once I get out of here I'll sort myself out.'"*

*IMHA partner (PICU)*

The views of service users were shared by carers and family members, who also drew attention to the lack of adequate services and community support:

*"My son's just had a bout of depression, went to see the doctor to talk it through, doctor doesn't have time, I'll just get the crisis team to ring you, they didn't get in touch with him till the following day and at that point it was coming up to the weekend and they said, well if they do come out all they're going to do is section you anyway and you don't really want to end up in there do you? That was the support that he was given."*

*Carer (focus group participant)*

In the focus groups, service users also drew attention to the poor quality of mental health services and cited examples of the negative attitudes and behaviour they had encountered in mental health services. In particular the lack of time and attention to understand and relate to them as individuals was highlighted, alongside feelings of isolation:

*"I just keep myself to myself and stay in my room a lot because I'm the only Black female patient here."*

*Non-IMHA user (Acute ward)*

People who had been detained under the MH Act emphasised the difference that choice makes:

*"It's a different feeling, you know, when you're doing something because you want to rather than feeling that you're still struggling against something that you may never get off."*

*IMHA partner (Acute ward)*

People who use services may be acutely distressed or experiencing the sedating effects of medication, so that they do not understand why they are in hospital:

*"I felt, you know that I was being kept under false pretences but when those things come on you're about the last person to realise it."*

*Non-IMHA user (Acute ward)*

This then impacts on people's ability to take in the information they are given, including the services they will receive and their treatment options, and effectively limits participation in decision-making around care and treatment. In response to questions about whether they had received information about IMHA, one service user commented:

*"If they did, it didn't go in anyway, it all went over my head. I just wasn't with it. I didn't know I had the right and I wasn't the type to pursue it anyway, I didn't have the courage or the inclination or my sense of my rights to do that."*

*Non-IMHA user (Older persons' ward)*

There was also a feeling that staff loyalties were primarily to each other:

*"I'd have complained to the staff first probably but then if you complain to the staff, that's a fellow colleague and they pick on you, you see what I mean, which is only human nature."*

*Non-IMHA user (Secure services)*

Aside from issues about treatment and need for information, a common issue brought up by service users was around maintaining their links to normal life outside the hospital. Leave is important to people within wards, to get fresh air, to smoke a cigarette or to have a change of scene. Service users also needed to have time off the ward to help them keep family links and to look after their personal affairs including finances:

*"I don't know when I've been paid since February this year gone, I don't know when I've been paid, how much I've been paid and all me bank statements, you know what I mean but I'm saying 'can I go home?' 'oh yeah, yeah' but no I can't go, I can't go, I need an escort to the bank to sort me statements and me money out."*

*IMHA partner (Acute ward)*

But even feelings towards leave can be ambiguous:

*"When they were forcing me to be there I desperately wanted to get out but when they said 'you've got unlimited, unescorted leave' I went out once, got*

*So frightened, went back and didn't go out again for another two weeks because I was too frightened to leave the hospital."*

*IMHA partner (Acute ward)*

These accounts provide a sense of the experiences that IMHAs will hear during the course of working with advocacy partners. The vulnerability of mental health service users, described in these accounts, reflects the legal authority invested in the mental health system. This potentially jeopardises the personal strengths and capabilities of mental health service users and reinforces the value of advocacy as a protection of their rights and capacity for self-determination. They also raise questions about the potential involvement of advocates in the assessment and at an earlier stage of the detention process.

### **Experiences of qualifying patients - Key findings**

- The qualifying patients we interviewed came from all walks of life, had a variety of personal circumstances and were using a broad range of mental health services.
- Many of the qualifying patients that we interviewed described the process of detention under the Mental Health Act as frightening and disempowering.
- There were several instances related where force had been used to admit people to hospital or to administer medication.
- Instances of positive experiences of detention were actively searched for in the data but they were largely absent.

Service users' experiences provided an insight into the issues that IMHAs will encounter and be asked to address.

## 5. ACCESS TO IMHA SERVICES

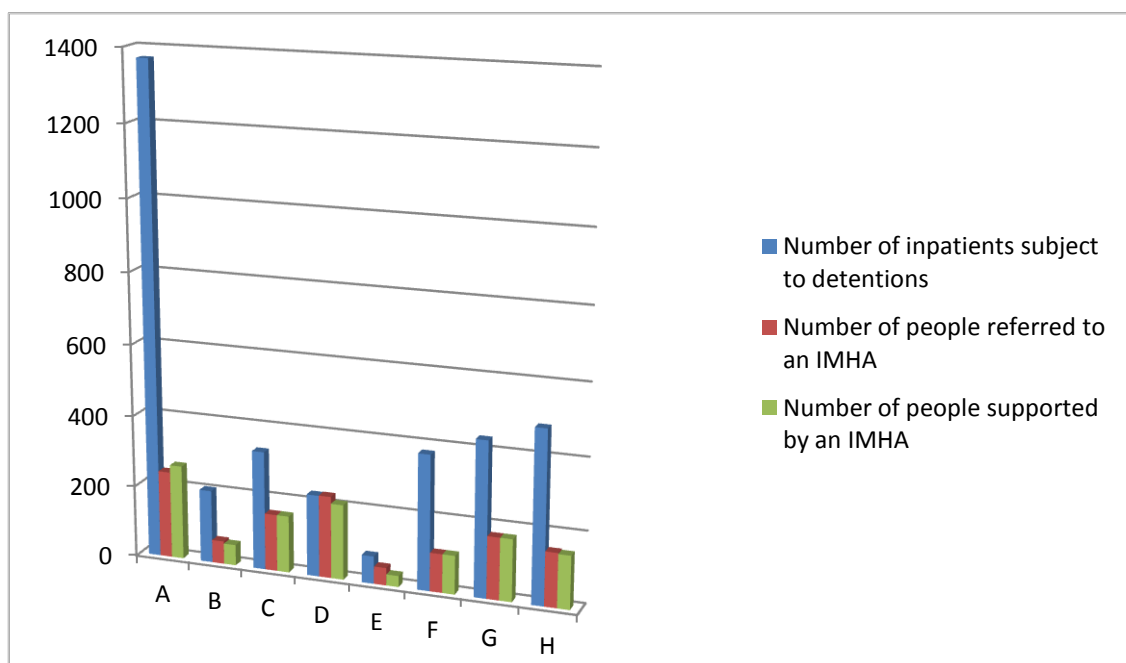
### 5.1 Introduction

The accessibility of IMHA services was a major theme from all the focus groups and the case study sites. Current arrangements were described by the focus group participants as a “classic sort of postcode lottery”, which resulted in geographical and other forms of inequity. Access to IMHA services and the factors that facilitate access were therefore explored in depth in the case study sites through the questionnaire, key reports and the interviews. The inclusion of twenty-nine qualifying patients who had not used IMHA services since their inception allowed the reasons for not using IMHA services to be explored.

Though not reported extensively in our study, it may be the case that numbers of qualifying patients might not use IMHA by choice because they are relatively satisfied with services or are confident in their own agency to raise concerns without assistance.

### 5.2 Use of IMHA services

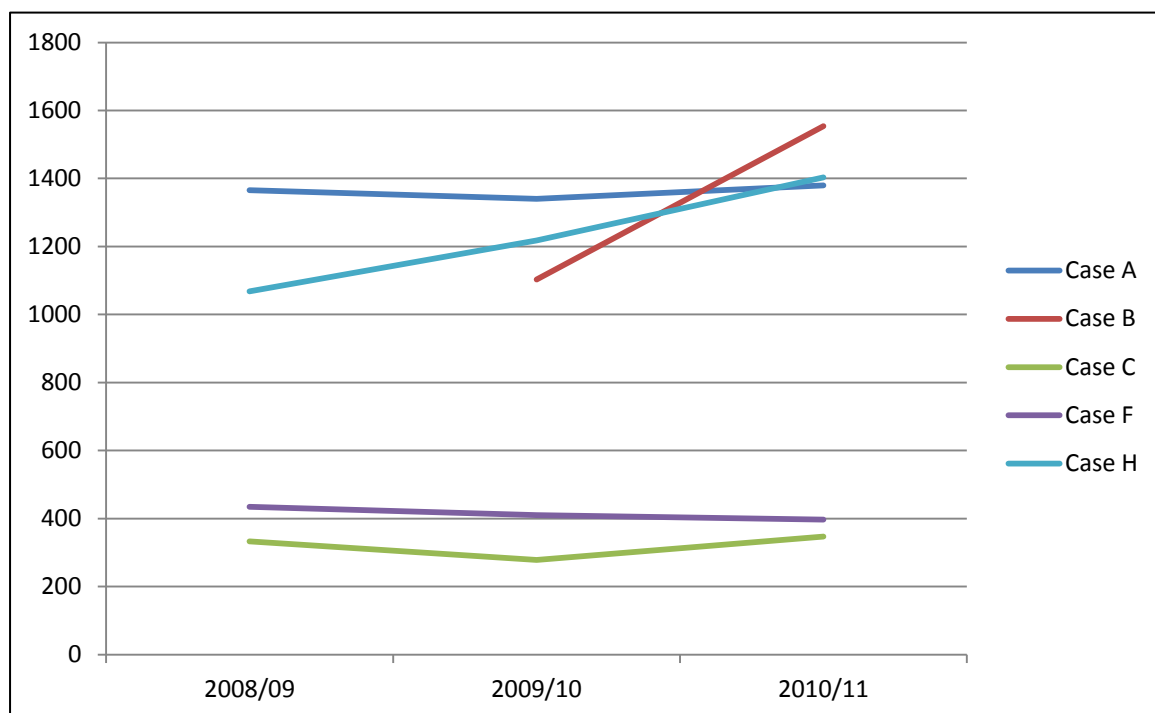
The completed questionnaire responses provided an indication of referral to and uptake of IMHA services and this was compared with the potential uptake, from data on detentions and Community Treatment Orders under the MH Act (NHS Information Centre 2011b), as illustrated in Figure 4 and Table 4.



**Figure 4: Number of people referred to and using IMHA services by case study site<sup>4</sup>**

<sup>4</sup> Source: NHS Information Centre (2011b): Mental Health Bulletin Annual Returns 2011. The figures have been adjusted to take account of patients on short-term Sections who would not qualify for IMHA services.

This data is tentative because some Trusts relate to IMHA services that are providing a service to other areas; however, it raises a number of points. First, the difference between rural and urban areas in terms of the number of inpatients subject to detention. Four of the sites were urban areas A, B, G and H but, for one (G), only the data for one locality is included. Figure 5 illustrates an increased trend in some sites for the number of inpatients subject to detention. The discrepancy between the potential number of qualifying patients and those who used IMHA services is most dramatically illustrated by Case A but is evident across the sites and more marked in the urban sites; with the use of IMHA services ranging from approximately 20% to 55% of the expected number, as summarised in Table 4.



**Figure 5: Number of detained patients in the urban and rural case study sites between 2008 and 2011<sup>5</sup>**

The high secure facility routinely refers all patients to the IMHA service and thus the referral to and use of IMHA service was higher in this site (D). It needs to be noted that that this population is relatively static with no new admissions in the last year. However, there can be difficulties in access for people in seclusion in secure units and this was raised in other sites by a small number of participants.

The similarity between the referral numbers and the use of IMHA services suggests either issues to do with recording by IMHA services or that most people when they encounter the services choose to use them.

<sup>5</sup> Source: Mental Health Bulletin Annual Returns 2011.

The numbers of people on CTO using IMHA services were generally low and this was raised in the focus groups and in case study interviews as a cause for concern. The exception to this is Site G, where the IMHA service reported that 55% of the qualifying patients on CTOs have used IMHA services in the last year.

Case study area	People using IMHA as % of number of qualifying patients detained in hospital	People using IMHA as % of qualifying patients on CTOs
<b>A</b>	19	5
<b>B</b>	33 <sup>6</sup>	25 <sup>7</sup>
<b>C</b>	48	0
<b>D</b>	92	N/A
<b>E</b>	33	Not available
<b>F</b>	57	11
<b>G</b>	40	55
<b>H</b>	40	20

**Table 4: Percentages of qualifying patients who were detained or on a CTO who were using IMHA services in 2010-2011**

All of the IMHA services responding to the questionnaire reported that they routinely record information on age, gender and ethnicity but this is not the case for disability or sexuality. However, not all respondents completed the items on the characteristics of the people using their service. Nevertheless, the available data is summarised in Table 5. As this indicates, slightly more men were using IMHA services in the case study sites than women although there was a perception in three of the sites that more women were using the service. As there is no data for two of these sites, it is not possible to comment but for the third site (H), there was not a huge difference overall, although one service in this site had nearly twice as many men as women using it.

<sup>6</sup> This is likely to be higher as there was data missing for one of the services in this site

<sup>7</sup> Ditto



Case study site	Gender	Age (%)			Ethnicity (%)					
	M:F	16 and under	17-64	65+	White British	Black African/ Caribbean	Asian	Chinese	Mixed Heritage	Other
<b>A</b>	1.63:1	1	93	6	48	26	15	0	6	5
<b>B</b>	1.23:1	0	71	17	89	2	7	0	0	2
<b>C</b>	Missing data									
<b>D</b>	Men only	N/A	99	1	78	8	1	0	3	10
<b>E</b>	1.11:1	N/A	97	3	87	8	3	0	2	0
<b>F</b>	1.15:1	7	66	27	93	4	3	0	0	0
<b>G</b>	No data	0	100	0	Missing data					
<b>H</b>	0.96	0	81	19	98	0	1	1	0	0

**Table 5: Characteristics of IMHA partners 2010-2011 in the case study sites**

In terms of age, the focus in most of the sites was on adults of working age, although two of the sites providing secure services did not take people under the age of 18. Site F is noteworthy as there was an IMHA who focused on working with children and young people both as inpatients and in the community. There was also an IMHA in Site A for children and young people, but exclusively focused on a Forensic Children and Adolescent Mental Health Service (CAMHS) unit. Older adults made up 0% to 28% of the total caseload in the last year and the variation between sites in relation to this is apparent, although they were less likely to be detained in secure services.

Similarly, the variation in uptake by people from BME communities was also evident and was lower than expected in two of the case study sites (B and H). The understanding of IMHA services and accessibility for people from BME communities was highlighted in the focus groups, particularly by BME advocacy providers, by IMHA services and mental health professionals. Notably it was also mentioned by a young woman of South Asian heritage, who described the difficulties that women who did not speak English were having on the ward where she was detained. She pointed to the lack of interpreters and lack of understanding on the part of the mental health professionals of particular women's needs as well as difficulty accessing IMHA services for these women.

When asked about variations in uptake, some participants commented on the difficulty in evaluating this because of a lack of information; with the IMHA service

being reliant on the mental health provider for information on qualifying patients and the mental health provider on the IMHA service for information about who is using it. This was particularly evident for people on CTOs and also inpatient wards but much less of an issue for secure services, where all the residents are likely to qualify for IMHA services.

Uptake by people on CTOs was expressed as a cause for concern in the focus groups and case studies, particularly by IMHAs. This needs to be placed in the context of relatively low numbers of people on CTOs, ranging from 30 people in one of the case studies (C) to over 150 in another of the sites (A). However, the data from the questionnaire responses indicated that the uptake of IMHA services by people on CTOs was low in many of the sites. IMHAs identified two reasons for this. First, they might not know who qualifies and that those people on CTOs who were using IMHA support tended to be people who had used the service as an inpatient. Thus, those people not already in contact with the IMHA service are reliant on mental health professionals bringing the opportunity to access IMHA services to their attention. Second, this could be problematic and was dependent on the awareness of mental health professionals and qualifying patients about eligibility for IMHA services for people on CTOs.

However, mental health professionals also suggested that the low usage could reflect the fact that being on a CTO is less restrictive and, therefore, individuals do not feel the need or their priority is to get on with their life. For example, one AMHP when asked about who makes most use of IMHA services responded:

*"Probably more inpatients, they probably use it more, view it as more important than the community. I think you tend to find when people move into the community, unless they're wanting to move on they don't tend to ... you know you'll offer then and they might have them but they don't always view it as important."*

*AMHP (Specialist in learning difficulties)*

Uptake of IMHA services by people on Guardianship was also identified as low and was particularly raised by those mental health professionals who worked with people with learning difficulties, as well as IMHAs in one of the sites where there was a higher number of people on Guardianship orders.

The general theme to emerge, as one focus group participant observed, was that people who may require IMHA support the most were least likely to access the service: *"hard to reach, easy to ignore"*.

There were a number of explanations given for this. First that the request for an IMHA service reflected a well-developed understanding of the system and required a degree of capacity and confidence to be able to self-refer:

*"Those who are most articulate or most insight-less have a tendency to instruct the advocate. Those who lack the articulacy who really need an advocate don't tend to think of it, or they're uncomfortable around people, or they wouldn't trust, they have more difficulties as you would expect, so the ones that need it most in my view don't tend to be ones that get it, whereas the ones who are hyper articulate are just sitting there doing the business and have made their needs very clearly known and are far more likely to have an advocate with them, than those who are mentally unwell."*

*Psychiatrist (Secure service)*

Second, variations in access were explained in terms of people's mental health presentation and several participants, particularly mental health professionals in secure services, expressed the view that people with a diagnosis of personality disorder were most likely to make use of the service and that this reflected their capacity to make use of resources or issues to do with dynamics between staff and the individual:

*"The type of patient that has an advocate often doesn't need an advocate, because they're quite streetwise, they can work their way round the system and they know about how to access advocates. Your average patient doesn't, whose got an enduring or a chronic or an acute mental disorder, they don't have that knowledge of how to do it and they don't have the confidence, the self-esteem to be able to phone somebody up or go on the Internet and do it, it's a lot of ... it's a lot ... the ones that I've experienced, patients that have used advocates, have had a significant ... well I say a personality disorder."*

*AMHP, (Home treatment team)*

Similarly, but to a lesser extent, people with a diagnosis of bipolar disorder were also viewed as more likely to access IMHA services. For other participants, it was not the condition per se but the individual's overall mental health status that determined whether or not they might access IMHA services:

*"The more well a patient becomes the more they start to think about their rights and they'll start to ask things"*

*Ward Manager, (Women's secure service)*

This points to a paradox: those that are most likely to need IMHA services, i.e. those who find it hardest to speak up for themselves and to participate in decision-making, are going to find it harder to request an IMHA, to understand the role and contribution or engage with the advocate. As one participant succinctly put it:

*"An individual who needs an IMHA often wouldn't have the capacity to contact them, hence the reason they need that person in the first place."*

*Occupational Therapist (Secure service)*

This was evident in the focus groups when concerns were expressed about access for children and young people, older people with dementia, people with a learning difficulty or autism, people from BME communities, particularly African and Caribbean men, and prisoners transferred from prison to hospital. Issues with communication were identified by case study participants and, in particular, not speaking English or having a sensory impairment were identified as specific barriers. In both instances, an understanding of the specific culture and appropriate support were viewed as critical:

*"So I have seen Advocacy Service used exceptionally well but it's usually with very well abled people, it seems to fall down when you've got somebody who's not so able to communicate their needs and hasn't got that support around them."*

*Clinical Team Leader (Acute inpatient service)*

The uptake of IMHA services reflects issues about the understanding of the IMHA role and has implications for the promotion of and referral to the service. The data relating to these is presented below and the implications for service design, delivery and the practice of IMHAs and the data relating to these is presented in subsequent chapters.

### **5.3 How people access IMHA services**

#### **5.3.1 Finding out about IMHA services**

Both advocates and mental health service professionals have a role in promoting advocacy, making sure service users and staff know how to contact the IMHA service and that staff within the organisation have sufficient knowledge of advocacy and their statutory duties to support it.

We interviewed several qualifying patients who were unable to recall seeing any information about the IMHA service or of being given any information by staff. Some mental health professionals were also vague about what information was provided and when and what they needed to know. This section provides our findings in relation to the different methods used to promote the service. Overall, it was evident that the situation is more complicated if there is more than one IMHA provider, not only in terms of having the right material available but also understanding which service is doing what.

Overall, participants identified five main methods for how they learnt about and accessed the IMHA service:

#### **☞ Promotional materials**

The need for accessible promotional materials in a range of formats available in the full range of mental health services was stressed by focus group participants and

across the case study sites. A relatively small number of people identified them as having been helpful and bringing the service to their attention. However, overall they did not appear to be a particularly effective strategy for enabling qualifying patients to understand and access the services and only a few people identified leaflets or posters as the way that they had found out about IMHAs.

There may be a number of reasons for this. First, the quality of the information we encountered was generally poor; it was sometimes unavailable, despite staff assurances that leaflets were readily available, or was out of date because there had been a recent change in the IMHA provider or the service had moved. There were few posters, other than leaflets on the wards that we visited, and the typeface on these was often small and might be difficult to read if on medication. On a secure ward for women, posters were not put up because of the risk of self-harm, and on other wards, staff commented that there had been a leaflet on the notice board but that these were regularly removed by service users. There were some notable exceptions to this. One IMHA service had developed an easy read version of the leaflet for people with learning difficulties whilst another site had a card available for the person to complete their details and post back and a couple provided service users with a leaflet on admission in a welcome pack.

Second, the concept of advocacy and the role of IMHA services can be difficult to understand, particularly on the first admission and if the circumstances surrounding this are difficult. This is compounded by the other information and printed material people receive on being detained under the MH Act at a time when they may be finding it difficult to concentrate and absorb new information:

*"You get a named nurse, you get all the information but sometimes the information ... well I know myself it was a good 10 days before I could even look at it you know and then for people that aren't that literate, it would be a problem. .... So the information is there but it tends to get lost, it tends to get lost in a wealth of other information that you're given that could be really quite frightening when you're not very well."*

*Non-IMHA user (Acute ward)*

Finally, it was also possible that levels of literacy for some service users may have made it difficult for them to engage with the materials.

It was easy to see how the quality of the promotional materials could be improved and the need for these to be accessible for the broad range of qualifying patients was repeatedly emphasised. It is suggested from the levels of understanding that these materials need to go beyond providing factual information about the service, what it does, where it is located and how to get in contact to help develop an understanding of its purpose and role. The following suggestions to improve the quality of promotional materials were made by participants:

- Easy read, colourful, well-designed posters and leaflets with pictures of the IMHAs, to enable service users to identify the IMHA, when they came onto the ward.
- Using questions, examples of issues and scenarios illustrating the purpose of IMHAs and how they could help would facilitate understanding of the role and purpose.
- DVDs in appropriate languages, including British Sign Language (BSL).
- Use of social networking methods to promote IMHA services and experiences of using them.
- Material targeted at the general public explaining the MHA, rights under the MHA and access to IMHA services.

Leaflets or posters can be useful if they have up to date information and there is an easy way of making contact with the service - either by phone or by the IMHA visiting the ward. However, it was also clear that relying solely on promotional materials is an inadequate strategy for promoting access.

### ☞ **Promotion by staff**

As noted earlier, there is an obligation under the MH Act for appropriate staff to inform qualifying patients about the IMHA service and this can go further than providing information to active promotion:

*"They do have a duty to tell the people but they've always been welcoming to us being on the wards and happy to go round and inform everyone that IMHA is here."*

IMHA

Across different units, even within the same site, there were variations in this practice. Some inpatient staff had adopted the practice of informing everyone about the service, as soon as was possible, after detention and this clearly reflected good practice, as identified during the focus groups. However, in some areas, the responsibility for promoting the service was sometimes rather vague. For example, in one of the sites, it was evident that the AMHPs would mention the service to the person on detention but then rely on nurses on the ward to follow this through and there was no apparent check on the extent to which this was happening:

*"I also feel sure that there are not many conversations at that point where the person says 'yes please could you refer me now', it's left holding at that and then I would ... I think people generally say to the staff in charge 'I've told them their rights and about having an IMHA, would you make the*

*Referral?’ and I think it’s probably that not a lot of us are making direct referrals at that point.”*

AMHP

As will be discussed later, nursing staff may then exercise judgment about whether they consider referral to the IMHA service to be appropriate. Thus, whether this happens depended on a good understanding of obligations under the MH Act and systems that encourage this.

In three case study sites, which included a High Secure Unit, automatic referral was happening, with the IMHA service being routinely informed of new admissions. In one of the case study sites, the commissioners had recently introduced the requirement that all qualifying patients should be referred to the service, as a result of identifying significant variations in uptake from monitoring data:

*“We had some wonderful flow charts at some point didn’t we? Basically it came down to staff attitude. And what we felt was that all staff should have that decision taken away from them, it should be the patient’s decision.”*

PCT and Local Authority Commissioner

Finally, some services were routinely sending information to people on CTOs but there was the suggestion that this may be ignored, and that a way of alerting the IMHA service to people on CTOs should be considered.

### **Proactive and visible IMHA services**

Being directly approached by the IMHA or seeing the IMHA around on the ward visiting other patients emerged as the most favoured method for finding out about the service and deciding whether or not to use it. The importance of regularly visiting wards and getting known by service users was identified, particularly by IMHAs in the focus groups and reinforced by service users that we interviewed in the case study sites:

*“Just where the advocate provides a regular visit to a ward, the wards of a unit so people get to know your face, they get to know that you do come and that you are reliable and I say to our advocates that, you know, when they’re new one of the things they have to do is hang around on the ward, just be seen, just sort of talk to people about anything, have a chat to people engage with people”*

IMHA (Focus group)

The availability of IMHA services in this way means that the initial approach can be informal and that an individual can explore the opportunity, without commitment:

*“Having a presence, we’ve got constant presence on the wards people can ask to see us but we’re on the wards anyway, we can sit down and people*



*tend to approach us. And then once other patients see us working with one patient they realise that we are independent and then they come to us."*

*IMHA (Focus group)*

*"What I'm saying is I'm glad there's something like this for patients here who can ... you know who don't know much, you know not very well spoken and what I think, I feel is that there needs to be more Advocates to talk to most of the patients here and let them know there's help if they need it, not necessarily by phoning them but if they come to see them at least one to two times a week every week and talk to them and new patients every time so they know they've got help available, that's what they need, they do need that but whether they take the help or not that's a different matter but at least they know it's their options."*

*IMHA partner (Acute ward)*

It was evident that qualifying patients used this opportunity to weigh the IMHA up and decide whether or not the person had something to offer, often based on an assessment of their personal characteristics and stance in relation to mental health services.

One service described how having a specialist advocate for African Caribbean men, who adopted such an approach, paid dividends:

*"It's his job to make sure that he sees every single one of them who ends up on the wards and makes sure that he sees them again, again and again so it's like to ensure if there are any issues that they want taken up because we have found that those are people who have not taken up services as much in the past."*

*IMHA (Focus group)*

One of the other advantages of IMHAs regularly going onto wards was that they might identify people who would be unable to instruct them and potentially miss out:

*"We have come across people in hospital, whilst visiting someone else, whom we believe, from what we witness, would really benefit from some advocacy support. However, if we introduce ourselves and explain what we do, the person may not be able to give clear consent that they would like our help. In these cases we need to have a third party referral to give us a legitimate mandate to act on the persons behalf. We have certainly encouraged mental health staff to make referrals in such cases."*

*IMHA Manager*



Alternately, qualifying patients might also conclude that the IMHA service may not be as independent from mental health services as it claims and this tension is explored later on.

Further, it was more complex to consider how such an approach would work with those on CTOs:

*"I work on a ward and I know that I pick up all the patients who are detained in my area but what I don't know is... who's in the community on a CTO. You can't be everywhere in the community picking up those people."*

*IMHA (Focus group)*

Some IMHAs made sure that they regularly visited community facilities that people might be using. However, in some, participants, particularly commissioners, indicated unease with this type of arrangement, expressing concern about the time, and thus resource implications and the potential to foster dependency.

### **Access to interpreters**

Ideally IMHA provision for qualifying patients will be provided by bilingual advocates, who may also have an understanding of the potential cultural issues. However, there may also be occasions when an interpreter will be required to enable the person to access and work with the IMHA service. Participants identified easy access to interpreters for people for whom English is not their first language or who are deaf as essential. IMHAs need to be able to work effectively alongside interpreters as well as playing a role in ensuring that they are available.

*"Recently I had somebody who was Polish on the ward and it was a case of her English wasn't bad but what I had to say to the ward was, "You need to get a Polish translator in because this is about her liberty and she's detained under the Act and I don't believe that her English is good enough and she would accept that her English wasn't good enough to understand the legal subtleties of the Act. So I had to say to the staff, "listen," but they were saying to me, "But she can speak English," "It doesn't matter, you need to actually make sure that you're getting somebody who will translate word for word into Polish for her so she understands what it means."*

*IMHA (Focus group)*

This raises the issue about access to interpreters for mental health professionals and their capacity to understand the need for interpreting services and be able to work alongside them. We interviewed an African refugee, via an interpreter, who was clearly uncertain about whether he had accessed IMHA services and seemed to have no knowledge of his rights under the MH Act, nor what section he had been detained on. He showed us several appointment letters, all in English, which meant

he was likely to default on any appointments, and implied that he may not have received appropriate information about IMHA services.

IMHA services reported working with interpreters but raised the issue about a lack of clarity as to responsibility for the costs, with this being met by the mental health service in some instances whereas in others the expectation was that they would be met by the advocacy service. Some IMHAs mentioned using Language Line, a telephone interpreting service, but the available languages were often limited and there was a concern that they may not understand the IMHA role and therefore not accurately capture the meaning of what was being discussed.

Access to interpreters is not solely an issue in relation to access but also in terms of the provision of ongoing support. Furthermore, we are not trying to suggest that providing interpreters will necessarily mean that the IMHA service is culturally appropriate nor that people will want to use it, and we discuss this in Chapter 9.

### Peer promotion

Some qualifying patients learnt about IMHA services from their peers, i.e. other service users and this is clearly helped if the IMHA is visible and there is the opportunity for the individual to approach them informally, as above:

*"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 (Low secure unit)*

*"When I had my second stay, there were actually people talking about advocacy, they'd come in to talk about it, it actually struck a chord with me in terms of thinking it would just suit me in this particular situation because it wasn't working so well for me before, maybe I could make it work better for me if I had an advocate."*

*IMHA partner (PICU)*

*"I think because we're more visible on the wards I think and obviously the issue around confidentiality but I think it's fair to say that when we go on the wards that they all recognise us now going on the wards, so if one person's got an Advocate `why can't I have an Advocate as well?"*

*IMHA Manager*

Whilst peers are a trusted source of information about the role and quality of IMHAs, we found that the links between service user involvement activities and advocacy tended to be weak. The most common method of linking with service user involvement activities was for IMHAs to attend patients' meetings or service user meetings to describe their service.

## Existing knowledge of advocacy

Knowledge of advocacy from previous experience, specifically experience of using generic mental health advocacy services, involvement in a patient's forum or working in health or social care services, clearly gives those patients an advantage.

This raises questions about the general promotion of advocacy and links between forums and staff that promote service user involvement and their potential role in terms of promoting rights, safeguards under the MHA and access to IMHAs. The relationship between IMHAs and these types of activity is considered later but did not appear to be as well-developed as it could be.

### 5.3.2 Timing

The provision of information in a timely manner was clearly important and the fact that this is vital for people on Section 2, who have a limited window of opportunity to appeal, was brought to our attention.

Although qualifying patients may have been given information on detention or seen the IMHA on the ward, there were clearly issues about when it felt appropriate to take up the IMHA offer. In some instances it was only when the person was faced with a pressing issue and could clearly see the need:

*"I was detained under the section 2 but I saw her later on 'cos when my section 2 was due to expire I was assessed again by the Psychiatrist and they said that they wanted to detain me for up to another six months and then I freaked and said 'right I want to see the IMHA now' so they called her and she came across and spoke to me."*

*IMHA partner (Acute ward)*

In other instances, the vulnerability of people at the point of detention, and thus the receptiveness of the qualifying patient to information on detention, was identified as a barrier to access. This was highlighted by mental health professionals, IMHAs, qualifying patients and carers:

*"Yeah, it's hard isn't it if you're ill yourself to actually ask for help, it's like trying to sort of diagnose yourself, it's hard enough to know which direction to turn when you're well, I find it quite amazingly complicated when you haven't got the concentration and you can't follow half a sentence really properly without asking the person to repeat themselves, it's pretty difficult to ask."*

*Service user (Focus group)*

*"Those that are sectioned are probably iller than they would've been when*

*sectioned two or three years ago. Many are so ill that they cannot, or indeed they will not use advocacy services at their own choice."*

*Carer (Focus group)*

*"You know they say well you're entitled to this, and they say 'well I don't want that, what do I want that for?' and that's their attitude and she said especially with older people and you could perhaps say to them, 'well look you're entitled to an advocate or do this' and things, and they'll say, 'oh I don't want that, what do I want that for?'"*

*Mental health professional (Focus group)*

Thus, the timing of the advocacy offer and the need for an assertive and repeated approach to qualifying patients was considered important:

*"As soon as section is applied and we do it every week, especially because some people don't always retain the information so they're told the first day then they're told like every day for up to 72 hours and then we go every week."*

*Ward Manager (Older persons' ward)*

Carers also emphasised the important role that they and nearest relatives can play in reinforcing the advocacy offer subsequent to detention and thus it is essential that mental health professionals bring access to IMHA services to their attention too.

#### **5.4 Making contact with IMHA services**

Having found out about the service, the individual could make a direct approach to the IMHA, if the IMHA regularly visited the ward, ask staff to contact the service on their behalf or contact the service by telephone. It was evident that some service users were unhappy with asking staff to follow up on their behalf or would choose the member of staff judiciously:

*"She came with these sets of opinions and values, you know, she wasn't warm, she wasn't friendly, and she didn't appear to know what she was doing anyway."*

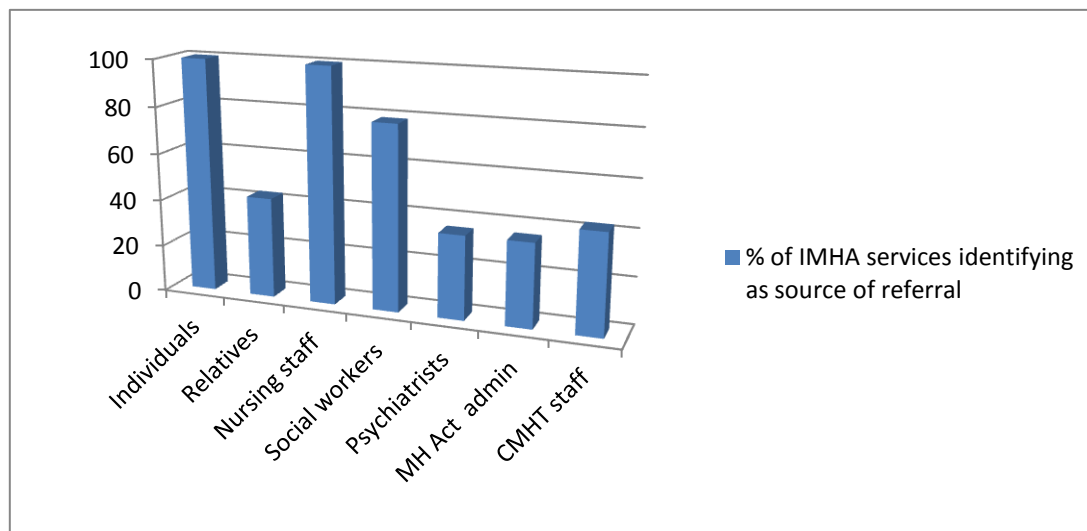
*IMHA partner*

However, a more frequent cause of concern was the issue of contacting the service by phone as often the individual had to ask a member of staff to use the phone; the phone was located in a public place or in the nursing office or there was no-one in the advocacy office to speak to and so the person had to leave a message with no easy way for the IMHA service to make direct contact. In one of the secure services, qualifying patients had to use phone cards but these had to be bought from a shop, with limited opening hours and were often in short supply.

## 5.5 Referral to IMHA services

### 5.5.1 Source of referrals

As might be expected, individuals (self-referral) and nursing staff account for the majority of referrals to the IMHA services. Figure 6 indicates the referral sources identified by the IMHA services, with all of the services that responded to this item indicating that they received referrals from individuals themselves and nursing staff on inpatient units.



**Figure 6: Sources of referrals to IMHA services**

From the interviews with nursing staff on inpatient units, attitudes to referring individuals varied. In two of the case study areas, referrals were happening automatically on detention on specific units, although in one instance this practice did not appear to be taking place across the organisation. Several members of nursing staff expressed the view that it was important and consistent with the spirit of advocacy for the person to self-refer and that they would support this rather than making the referral directly:

*"It's usually down to whether the individual wants that. There are some times when we actually ask formally for somebody to become involved because we believe maybe the person, there might be some capacity issues. But yeah, by and large we like it to be a, we like the patient or the service user to sort of agree that they want one; it's not something that we would go out and get for them. It's about what they want."*

*Specialist Nurse*

However, the limitations to this approach were also highlighted:

*"I don't recall any self-referrals in my recent history, that's not to say that they haven't happened but by and large they tend to be generated through*

*the patient saying you know 'I'd like an Advocate' or coming as a result of the Primary Nurse having a one-to-one with the patient who then identifies you know say 'well you might benefit from having someone independent to represent you' and that's particularly the case where patient's sort of mental state functioning isn't quite what it should be because of the nature of their condition at that particular time".*

*Ward manager*

The staff role in referring qualifying patients is viewed as crucial by IMHAs:

*"A lot of it depends on the engagement of other people working at the units we support. You know a lot of our work is down to them referring the person on to us."*

*IMHA*

Mental health professionals can also be involved in ensuring that service users' requests to see an advocate are followed up:

*"If a patient requested an Advocate we'll check that the ward staff have actually arranged one and if they haven't we'll follow that up as well."*

*Mental Health Legislation Lead*

In some instances a lack of understanding can lead to inappropriate referrals:

*"We still have the odd occasion where ... and this is mainly down to lack of understanding about Advocacy, that perhaps people make a referral to us that isn't appropriate for us to work with, you know it could be a sort of family issue or a mediation type issue."*

*IMHA Manager*

Mental health professionals can sometimes become aggravated by their involvement in the referral process. For instance, experiencing difficulties around the information requirements:

*"Another sort of bone of contention in a way, is the information that we give when we make the referral, you know, because for us we give minimal information because it's up to the patient what they want to disclose to the advocate or not ... They've [the advocates] complained and, you know, I've seen them again and, you know, I had a lot of conversations with ... the contracts manager, trying to pick my way through and clarify, and to be honest I'm not even that sure to this day what the process is .... We just let them know that a Section patient is here, we don't give any further information. And so that's sort of landed us in hot water a little bit."*

*Practice Development Nurse*

Some staff expressed resentment at the advocacy service's demands for time to be spent supporting the referral process. In other instances, it was evident that mental health professionals would refer but were exercising judgment as to who to refer based on idiosyncratic criteria. These included:

- ⌘ Patients with particular concerns for example in relation to the care plan
- ⌘ Patients who wanted to make a complaint about an aspect of their care and treatment
- ⌘ Patients judged as lacking capacity or having difficulty communicating
- ⌘ Patients who were assessed as having the capacity to benefit:

*"When it's relevant and the patient's in the right sort of frame of mind, sometimes I'll suggest that they contact the advocate."*

*Psychiatrist (Secure service)*

This could be interpreted as mental health services gatekeeping access to IMHA services and reflects a fundamental lack of understanding of the duty on them to promote information about the IMHA service to qualifying patients and the patient's rights in terms of accessing the service. However, it was also evident that some staff respected the qualifying patient's right to decline the service but nonetheless would continue to promote it as an option.

### **5.5.2 Reasons for referral**

The reasons for referral given are summarised in Table 6 in order of frequency for each referral source. Of note is the difference in the reasons given by qualifying patients and mental health professionals. The majority of service users who were asked why they self-referred to the IMHA service said that it was to have a voice in the process and/or to enable them to come off their section.

Referral Source		
Self	Mental Health Professionals	IMHAs
(1) To have a voice	(1) Rights under the MH Act	(1) Ward rounds. CPA/Tribunals
(1) Coming off section	(2) No family or in conflict with the family	(2) Leave or being discharged
(2) Negative experiences of care and treatment	(2) Complaints/ disagreement with care plan	(3) Rights under the MH Act
(3) Tribunal, manager's meetings, CPA and ward rounds	(3) Person not well enough to self-advocate/lacking capacity	(4) Medication
(4) Information and support	(3) Determine appropriate care to facilitate recovery	(5) Safeguarding/ Vulnerability
(5) Medication	(4) Move to a different service or accommodation	(6) Individual specific needs
(6) Missing property	(5) Lack of trust in staff	(7) To obtain information from professionals
(7) Accommodation	(5) Safeguarding or protection because of vulnerability	(8) Move to a different service or accommodation
(8) Leave	(6) Being placed on a CTO	(9) Person not well enough to self-advocate
(9) Access to notes	(7) All referred/determined by the patient	(10) To access a solicitor
(10) To access a solicitor	(8) Tribunals/CPA	(11) Smoking
(11) Specific needs	(9) Other: medication/negotiate the mental health system	

**Table 6: Reasons for referral rank ordered by referral source**

Often this reflected a sense of powerlessness in relation to the system, as this IMHA partner, who was in a medium secure unit, explains why he got in touch with the IMHA:

*"I didn't really know where I stood because one person was saying this, one person was saying that, I mean staff wise and I didn't know where I stood."*



*One person was saying 'oh you do the course you go into the community' another person was saying 'you do the course you go into low secure' another person was saying 'you do the course then you can always return back to jail with a good report' you know all saying different things and then you know I was confused."*

*IMHA partner (Medium secure unit)*

The most common reason given by IMHAs for referrals to their services was support in ward rounds, CPAs and Tribunals to enable a person to have a voice and so is broadly similar to that given by service users. Mental health professionals cited the role of IMHAs in promoting a person's rights under the MH Act as the main reason for referral. Of note is the second most common reason given by mental health professionals, and that is the absence of family contact or conflict with family members, which was not identified by service users or IMHAs. Issues were raised by both mental health professional and IMHAs about the potential vulnerability of service users, often in the context of older peoples' services, and this raises a question about the relationship between IMHA provision and safeguarding in the context of the Safeguarding Vulnerable Groups Act 2006.

### **5.5.3 Timing of referral and speed of response**

It was not surprising that service users considered it highly important that IMHA services are easy to contact and that there is a response when the individual calls:

*"It's difficult sometimes to get access via the telephone, that's the only difficulty that I've had, sometimes the Advocate hasn't got the message and two days later when I've not heard from them I've phoned up and they've had to send another message, so if you want help immediately it's not always possible to get that help these days because of the phone system that exists."*

*IMHA partner (Focus group)*

This was not always the case and several people identified delays in getting a response from the IMHA service and reported that this discouraged them from using the service.

From the limited data available from the case note analysis, the average speed of response was two days for the IMHA to make contact with the person and slightly longer before the person was seen; although typically this was within a week. A small number of qualifying patients commented on delays in the speed of the response, remarking that they had found this difficult and in one instance the man had given up.

## 5.6 Reasons for not using IMHA services

Mental health professionals in particular reported that although they may promote the service through providing information, some qualifying patients did not necessarily want to use the service. As one commissioner commented about the response to his queries about service uptake:

*"The answer tends to come back along the lines of 'the staff are fully aware of the procedure, they are advising patients, patients are choosing not to use the service' and that may well be the case."*

*PCT Commissioner*

Twenty-nine qualifying patients were interviewed (16 men and 13 women) as to whether they were aware of IMHA services and why they had chosen not to use them. Two thirds (67%) were unaware of IMHA services or were unsure whether they had used the service and it proved difficult to confirm whether or not they had. For example, one man thought he may have seen an IMHA briefly and the IMHA service had no record of the person using the service but thought he might have used another advocacy service, which had subsequently closed down. For those that were unaware of the service, their understanding was poorly developed with several making it clear that they did not know what an IMHA was for or asking for an explanation. Other participants expressed a vague idea.

Whilst others thought that the role was to help with complaints, as was also the case for a couple of participants who were aware of the service. Lack of awareness was the main reason given for not using it by service users who had not used IMHA services. Mental health status was also cited as a reason; with one woman saying that she had not used it because at the time she was refusing any form of support.

For the third who were non users but aware of IMHA services, they recalled being informed by staff or meeting the IMHA on the ward. However, several of those did not necessarily understand its purpose. We therefore categorized the reasons for not using the services as a positive choice (i.e. aware of its purpose and choosing not to use the service) or a negative reason (i.e. non-use arising out of lack of information or difficulties in access). The basis for positive choices included:

- Not having the need for the service, although in some instances this was because the service was seen as responding to complaints and the person did not have any.
- Receiving support from a service user group.
- Wanting to sort things out themselves or to be independent. As one man commented:

*"I didn't feel IMHA was necessary for me. I can make my own decisions. I didn't need it. I understand fully that I have a right to an IMHA. I could see how it would be useful but not in my case".*

*Non-IMHA user (Recovery service)*

However, not using the service does not mean that it is not valued or that the service user might not choose to use it in the future. As one young man observed:

*"Even if no-one uses an IMHA, it is good to have it. Like if you go into war with a gun, I'd rather have it and not need it than need it and not have it"*

*Non-IMHA user (CAMHS service)*

The negative reasons were problems with making contact with the service or, in the instance of one woman who had been in contact with the IMHA service, losing contact when discharged on a CTO, being unclear how the service can help or confusing it with the complaints service:

*"I knew that I had a right to have one but I didn't understand why I would need one. Somebody had said that I had a right to have one if I wanted one and I remember a lady coming in with a clip board saying she was for Advocacy but I didn't understand who she was or why I would need one."*

*Non-IMHA user (Acute ward)*

There was some evidence from the case study interviews that certain service users who declined to make use of advocacy did so because they saw the advocacy function as part of a pacification process, steering people away from pursuing legitimate complaints or grievances with the system.

Few alternatives to IMHAs were mentioned by those who did not use the service, with only four people identifying an alternative and these were family, friends, a service user group and a solicitor, with IMHA being seen as second best to the solicitor.

## **5.7 Missed opportunities**

An analysis of a subsample of mental health case notes for qualifying patients who did not access IMHA services revealed a number of opportunities when access to an IMHA could have helped strengthen participation in the decision-making process and effective communication with mental health services.

Figure 7 provides an illustration of the issues that one man, initially on a CTO faced. Overall, it was not clear from mental health notes whether a referral to an IMHA had been considered or discussed. A number of issues were recorded in his notes where an opportunity to access IMHA services would have upheld his rights and enabled him to participate more fully in decision-making. However, it was not clear whether he declined this offer or whether it was ever made.

For one man on a CTO, his mental health case notes record that staff were to present MH Act rights as set out in Section 132. Subsequently the CTO was revoked and he returned to the ward on a Section 3. He was informed he could appeal but there is no mention in his notes that he could have an IMHA.

He was unhappy to be back on the ward as he did not see himself as unwell and said he did not need medication and does not have schizophrenia. He wanted a change of consultant as he felt the doctor was being unfair and that a consultant of similar ethnic origin (White British) would understand him better. The case notes recorded that he was frustrated at being in hospital and would prefer to be discharged from the current ward and go back to another ward. He was also complaining that high doses of clozapine were making him tired all the time and sleepy.

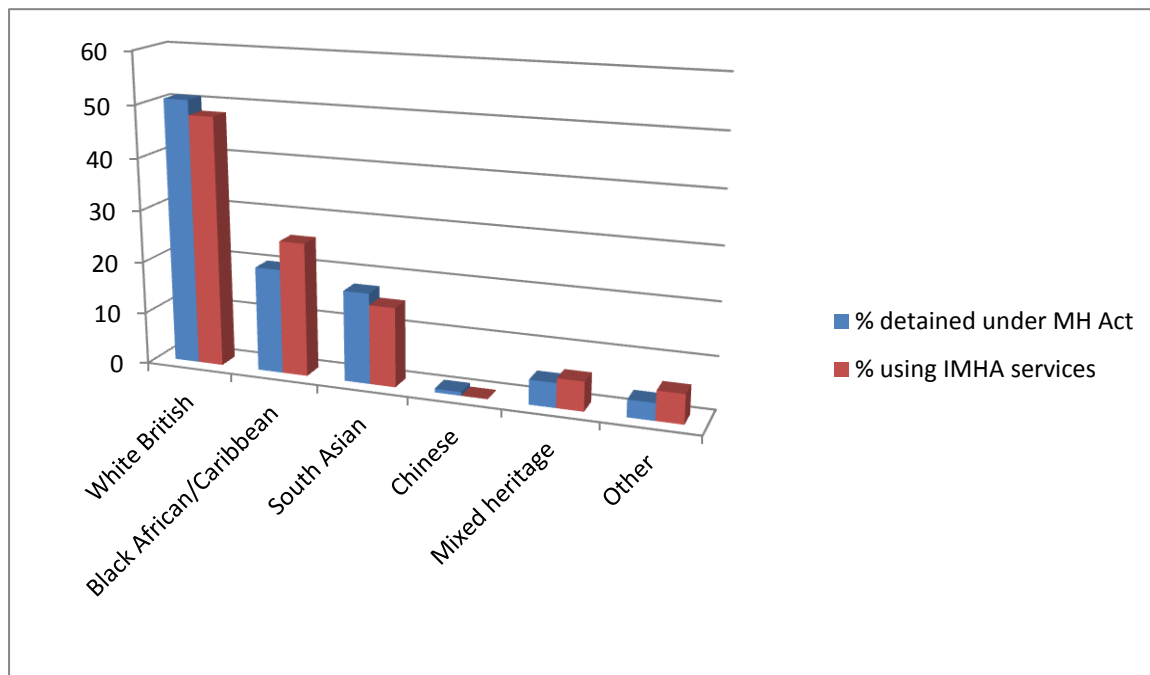
**Figure 7: Missed opportunities for referral to IMHA services from mental health case note analysis**

## 5.8 Equity of access

As noted earlier, concerns were raised during the focus groups and interviews about particular groups of people accessing IMHA services. Our data on the use of IMHA services confirm that the gap between demand and actual use is greater in urban areas. This is likely to disadvantage people from BME communities because these populations will be denser in urban areas, the admission rates higher and thus the proportion of people from specific BME communities detained under the MH Act will be higher. However, the data provided by the IMHA organisations in the case study sites generally indicate that people from BME communities represent a reasonable proportion of the case load, with the exception of the two sites in B and H where the uptake was low.

Figure 8 considers the data for Site A in relation to ethnicity and compares the data on the number of detentions and use of IMHA services by the main ethnic groups for 2010-2011. This suggests that in this site people do not appear to be significantly disadvantaged on the basis of ethnicity, although slightly fewer people from South Asian communities were accessing the IMHA service than expected. This does not take into account the added vulnerability of people from these communities may experience in their relationship with mental health services, particularly racism that has been documented elsewhere. This also needs to be considered in the context of approximately one in five qualifying patients accessing the IMHA services. So overall there is a significant gap in provision for all ethnic groups confirming the local perception of unmet need. Furthermore, the IMHA service was part of an organisation that had originally developed to provide support to BME communities

and thus may have been particularly good at engaging with these communities. Unfortunately, we do not have comparable data for the other sites, as this would have allowed us to investigate these issues in more depth.



**Figure 8: Comparison of expected and actual uptake of IMHA services by qualifying patients from BME communities in Site A for 2010-2011**

It is worth noting that two of the sites were not able to provide this data. Furthermore, the data has not been validated; there appear to be gaps in the data and it does not pick up differences in the extent of the use by different ethnic groups nor their satisfaction with the service.

We found that the proportion of children and young people accessing IMHA services was poor in two of the sites; there was no data on this provided for two of the sites and children and young people were not admitted to secure facilities in two sites (D and E) and so this was not relevant. There was variation in whether IMHA services were being commissioned for children and young people. The uptake of IMHA services was higher in the two sites that had developed dedicated provision for children and young people (A and F).

The data on uptake and use also indicates a lower than expected uptake for older people and for example, in Site A 6% of people using the IMHA service were over 65 but made up 16% of the total number of people detained under the MH Act.

The capacity of IMHA services to provide appropriate and tailored support to the diverse range of qualifying patients is a key indicator of quality. We consider this in more detail and in relation to other groups including people with disabilities, learning difficulties and LGBT people in Chapter 9.

## 5.9 People placed out of their area of residence

Concerns about the confusion for arrangements for people placed away from their area of residence was highlighted during the focus groups by IMHAs and influenced our decision to include an independent sector provider as a case study and to undertake a brief survey of independent sector providers as to the arrangements for access to IMHA services. It is worth noting that people can also be placed out of area in specialist NHS facilities, particularly secure services and also, for example, in units for people with eating disorders or deaf people with mental health issues. This issue is considered in more detail in Chapter 12.

### 5.10 Informal patients

By definition, people who are not detained under the MH Act are not eligible for IMHA services, unless being considered for treatment that requires consent or a second opinion (see 2.2.2). However, concern was expressed about the potential vulnerability of two groups of informal patients in particular and the question was raised as to whether the safeguard afforded by IMHA services should also be available to them. The first group and most commonly identified were 'de facto' detained patients, i.e. people who are not under Section but are liable to be detained if they decide to leave. For this group, the issue is less significant if generic mental health advocacy is available and signposts or refers on to the IMHA as appropriate. In the instances where this had happened, it did not appear to present a particular difficulty.

The second such group are people detained under emergency sections for example Section 4, 5 and 136, who may go on to be detained under Section 2. We spoke to a small number of people for whom this had happened and a number expressed confusion as to what was happening to them and also concerns about treatment by the police. They were usually unaware of advocacy at this time but thought it could have been useful.

### 5.11 Factors influencing uptake of IMHA services

Although statutory advocacy was not universally welcomed, framing access to IMHA as a right and the responsibility on mental health services to provide information as routine was identified as key to facilitating better access. Reflecting across all the findings, we identified the following five main factors that influence access to, and uptake of, IMHA services:

- Understanding of the purpose of IMHA services and the role.
- Availability of IMHA services.
- Promotion by mental health services.

- Receptiveness of qualifying patients including trust in and familiarity with the service.
- Demonstrable commitment to equality of access.

### **5.11.1 Understanding of the purpose of IMHA services and the role**

Understanding of IMHA services and the role emerged as a critical factor in promoting access. We found that some qualifying patients are not using IMHA services because of a lack of understanding or confusion about the role or that mental health professionals are not bringing IMHA services to the attention of qualifying patients because they view themselves as the patient's advocate and cannot see what added value they bring. This is explored in depth in the next chapter, which reports the different accounts that participants gave of the purpose of IMHA, as well as their lack of understanding and points of confusion.

### **5.11.2 Availability of IMHA services**

The availability of IMHA services obviously influences access and uptake and the capacity and caseload sizes of IMHA services is considered in a subsequent chapter. IMHA participants commented that their organisation's capacity will influence the extent to which IMHA services are able to promote the service and be available to provide outreach to specific settings and impact on availability for involvement in multidisciplinary meetings. We found that the difficulties of negotiating access, as referred to above by qualifying patients, was seriously compounded if the service was not available or was slow to respond when a service user initiated contact. We heard about the difficulties that some IMHA services have experienced in covering unexpected staff absences due to sickness. It was also evident that demand in urban areas is higher and that the capacity of IMHA services in these areas poorly matched to the potential demand, as shown in section 5.2. This is discussed in more detail in Chapter 12 in relation to commissioning.

### **5.11.3 Promotion by mental health services**

Whilst many mental health professionals reported that they did mention it to qualifying patients, some observed that this often felt like a paper exercise. It was evident that the response to the offer is dependent on the quality of information, the timing of the offer and the options in terms of establishing contact with the service as well as the individual service user's disposition towards advocacy services. It is thus a concern that we have identified such a degree of confusion and misunderstanding about the role, which will invariably influence the attitude towards IMHA services. This is explored in further detail in Chapter 10. The organisational culture was identified as contributing to this and the extent to which general information about rights under the MH Act are promoted.



#### 5.11.4 Receptiveness of qualifying patients

The receptiveness of qualifying patients to the offer of IMHA services is a critical issue in relation to access and this is influenced by understanding the role and remit of IMHA support, as discussed earlier, and also by experience of mental health services:

*"The client group itself, because they don't tend to be very engaged in services by the very nature of the fact that they would come to our service, they're difficult to engage people on the whole, so they wouldn't perhaps choose to access that service themselves you know, so the people that we have that have used it have been tended to be supported or encouraged or talked it through with you know and staff have kind of like suggested that to them."*

*Manager (Rehab unit)*

The ability to understand and retain information when admitted to hospital, often in distressing circumstances, has already been highlighted and this may influence how and when the offer is made:

*"The other argument is when do you offer the service because if you offer it when somebody first comes in and they're quite ill you're obviously trying not to upset them and that but if people have been in for a couple of days and they're more settled then that's the right time to offer the service, when people actually make that informed choice about whether they want the service or not."*

*IMHA Manager*

It points to the need for the offer to be repeated and the understanding of IMHA services to be explored as well as using a range of methods to promote the service.

*"What we've got is a good working relationship so you walk onto a ward and a member of staff will say you might want to go and see Johnny in the corner over there, we're concerned about him. If you're not on the ward and you don't have access to the ward you're not gonna get that nature of referral and sometimes the people who ask the most need the least. So we need, there needs to be a system where you can engage with the hard to reach groups."*

*IMHA Manager*

Having trust and confidence in the service was identified by qualifying patients as important in influencing access and underpins the preference for an informal approach to the service. This provides an opportunity to understand the relationship to mental health services and the contribution that IMHA services can make to changing the reality of their detention:



*"I suppose familiarity that brings down the barriers for people to want to trust him because it's a big step, even if a man is desperate to want to go to a stranger, whether he is independent or not, so you know you need that sort of like that's the fact that goes with this name, so him sort of coming on the unit quite regularly has brought down them barriers and people now respond to him, talk to him, chat about various issues and problems so in that respect that's very good."*

*IMHA partner*

This illustrates that qualifying patients want to make decisions about using IMHA services, if provided with information and the opportunity to assess the contribution for themselves. Peer support networks and service user initiatives have a role to play here in relating information about the experience of using IMHA services. Furthermore, ensuring that families and carers are well informed about the purpose of and access to IMHA services will also make an important contribution to promoting uptake.

#### **5.11.5 A tangible commitment to equality of access**

The belief expressed by several mental health professionals that those who need IMHA services the least are making the most use of them clearly needs further investigation. This is reliant on monitoring uptake not just in terms of who is using the service but also in terms of the profile of qualifying patients locally and the potential barriers to access that they face. One of the findings of our research is the poor quality of the information on uptake and access and the lack of evidence that this is being used to inform the service design or delivery.

However, a real commitment to equality and diversity goes well beyond data monitoring to understanding the specific issues that diverse groups of qualifying patients have, and an equality analysis may help with this. Our data points to the need to work in partnership with organisations with specific expertise and networks that are well placed to facilitate uptake. It was also evident a dedicated approach might be needed for qualifying patients who face additional barriers in terms of access as a consequence of specific needs for example not speaking English or requiring a different style of service, for example for children and young people, people from BME communities and deaf people or persons more likely to require a specific form of advocacy, for example non-instructed advocacy for older people with dementia. There may be issues to do with previous experience of mental health services, including racism, detention under the MH Act or knowledge of other people's experience that act as barriers. Our study did not focus on this specifically but we know from our previous research that a lack of trust and familiarity with an advocacy service can act as a powerful barrier to access (Newbigging, McKeown and Hunkins-Hutchison et al, 2007). Provision for people from diverse groups is considered in more detail in Chapter 9.

### **Access to IMHA services – Key findings**

1. There are variations in the access to and uptake of IMHA services, particularly between qualifying patients in urban and rural sites, and between those in secure services, acute inpatient care and in the community on CTOs.
2. There is a strong consensus that those who need the IMHA service the most access it the least.
3. Specific groups of people may be under-served by IMHA services. These include:
  - People from BME communities
  - People with learning disabilities
  - Older people, with dementia
  - People who are hearing impaired or deaf
  - Children and young people
  - People on CTOs
  - People placed out of area
4. Reasons given by qualifying patients for not using IMHA services largely reflect a lack of awareness or understanding of the service and thus how it can help. This is contrary to the views of staff who emphasised that qualifying patients exercised choice about using IMHA services.
5. Access and uptake of IMHA services is influenced by:
  - Understanding of the purpose of IMHA services and the role.
  - Availability of IMHA services, based on adequate resources matched to local need.
  - Promotion by mental health services.
  - Receptiveness of qualifying patients including trust and familiarity in the service.
  - Tangible commitment to equality of access, e.g. through working in partnership with community organisations and making sure interpreting services are readily available.
6. Leaflets or posters can be useful but it was clear that relying on promotional materials only is inadequate. Efforts to increase access and uptake need to address the main factors identified above.

## 6. UNDERSTANDING OF IMHA SERVICES

### 6.1 Introduction

The purpose of IMHA described by participants reflected the conception of advocacy as voice, often framed as protection of individual rights. Thus, it was often described as a safeguard by statutory services with the vulnerability of people experiencing mental distress detained under the MH Act. Its purpose was also defined as empowerment with an explicit reference to the imbalance of power arising from detention under the MH Act and the relationship with statutory services. IMHAs and commissioners in particular provided definitions of purpose that reflected these elements and also reflected the normative definitions provided by the legislation and guidance.

Other participants referred to more covert meanings. From the perspective of mental health professionals this included providing a direct challenge to them and to services. Whilst a small number of service users considered that its main purpose was to maintain the status quo by smoothing over the situation, a small number of participants identified a broader purpose in terms of contributing to an individual's overall recovery. Each of these is explored in more detail below and they are not mutually exclusive, more often a matter of emphasis with many participants identifying more than one purpose (for example, voice and protection of rights).

### 6.2 The purpose of IMHA

Regardless of whether or not an IMHA partner, qualifying patients understood the purpose of IMHA as giving them a voice:

*"They're there to help people to actually be their voice sometimes as well because when somebody is poorly it's very, very difficult to sort of speak out or to even see beyond the confusion sometimes. They're there to look after their interest and their basic human rights yeah; to sort of... to see that there's no abuse of power and to advocate their interest. "*

*IMHA partner (Acute ward)*

As this individual implies, the IMHA is construed as an ally who holds the partner's interest in focus. As well as identifying difficulties in speaking up for oneself as a consequence of mental health status, many referred to the difficulties of expressing themselves in the context of multidisciplinary meetings:

*"An Advocate speaks up for you and puts your points forward for you. They're pushing for you, they're pushing on your behalf where the doctor's trying to fiddle faffle and get off the subject."*

*IMHA partner (Acute ward)*

*"So you've got more of an opinion in your ward round with the doctor, with the Psychiatric Doctor who I personally think ... it's the Psychiatric Doctor who sits over there while I sit round here and he's got like a Secretary over there with a computer taking notes and they do it like that and it's just so I have more of an opinion at the ward round without him just rubbishing you and telling you 'no, no you can't do that, no, no you can't do that'."*

*IMHA partner (Acute ward)*

Other service users felt the purpose was both to enable them to understand what was going on, the MH Act process and to enable them as individuals to be taken more seriously by mental health professionals. The importance of expressing what the service user wanted **without judgment or opinion** was highlighted by IMHAs as fundamental:

*"Because we are truly independent, we are saying what they want, whereas the Community Mental Health Team would say that they're saying what the service user wants but they're not, they're working in best interest and our job is to make sure that they're being listened to regardless of what they're asking and I do get asked for some bizarre... to say some bizarre things in CPA's you know."*

*IMHA*

The purpose of IMHAs in relation to communication was identified by mental health professionals and attention drawn to two aspects in particular. First, the difficulties some service users had in expressing themselves in general because they lacked confidence or were more withdrawn:

*"It is a totally independent service that hopefully would give the service user the confidence to raise issues that they might feel we would ignore or that they would be a little wary of raising with us, some people aren't very good at expressing themselves either verbally or written and it does give them you know that support."*

*AMHP*

Second, the difficulty of expressing views in multidisciplinary meetings was also identified by mental health professionals and the purpose of IMHAs usually described in terms of providing moral support to qualifying patients in these situations. This was particularly true in relation to MH Review Tribunals with the distinction being drawn between the IMHA role and that of solicitors, who provide the legal representation. However, a small number of staff expressed concerns that the purpose of IMHA services was to replace the role of solicitors as a consequence of reductions in the availability of legal advice.

The purpose of IMHA services was stressed by some mental health professionals as being more pertinent for those qualifying patients who did not have support or were in conflict with family members.

As well as providing moral support, mental health professionals generally framed the purpose of IMHA services in terms of protecting rights. This had two aspects; first, enabling an individual to understand their rights and what they were entitled to and, second, to enable them to exercise their rights.

*"Well it's to safeguard the person really and to ensure that they understand what's happening to them, make sure they understand their rights, make sure they understand that they do have the right to appeal, make sure that they have the opportunity to get heard in the meetings, a bit of moral support."*

*IMHA Manager*

IMHA partners also understood the IMHA role in terms of protecting rights, often in the context of overall recovery:

*"They act on your behalf and sometimes they explain things when things happen or you're not happy with things, to give you your rights and you know to push you a bit forward to give you hope at least, to make you understand the medication at least what's happening to you and why you're held in a hospital..."*

*IMHA partner (Acute ward)*

Some mental health professionals had a limited view of what protecting rights meant and their conception was limited to enabling qualifying patients to understand their situation and the process of the MH Act. Little mention was made of supporting qualifying patients to actively participate in decision-making. However, some mental health professionals did refer to the purpose of IMHAs in terms of addressing the imbalance of power, in the context of the MH Act:

*"Once we start to remove all of the safeguards from the system we then fail to be a democracy anymore and we become a totalitarian system. I am pleased that our system does allow for people to be given the opportunity to try and regain liberty from any sort of detention really, even though fundamentally it may in essence fail in the end at least they had the opportunity to try."*

*Ward Manager (Acute ward)*

Some mental health professionals developed the theme of protecting rights in terms of IMHAs providing "checks and balances" in the system:

*"To me it adds more checks and balances and improves the service user's role and also as well it improves service user experience."*

*Ward Manager (Medium secure unit)*

Other staff construed the purpose of IMHA services in terms of being oppositional rather than providing a safeguard, largely reflecting an understanding of the purpose of advocacy as promoting the 'best interests' of qualifying patients:

*"I think it comes down to a rather unpleasant position where if by the very nature of advocacy services you're inferring that the nurses and doctors are not the patients' advocates and are not doing everything in their power to ensure that the primacy of their work is to ensure the good mental and physical health of the patients. So I think your question [what is the purpose of independent mental health advocacy?] reflects a very difficult position which is, in which there's an inferred criticism."*

*Psychiatrist*

The issue of the mental health professional role in respect of advocacy is explored further in Section 6.5.

IMHAs were more likely than other stakeholders to frame IMHA as empowering the service user in the context of having an on-going relationship with health and social services, their journey as a service user and the broader context of the difficulties that they face. They were much more likely to see IMHA as either similar to generic mental health advocacy or as one element of what it means to be advocating for a person experiencing mental distress:

*"They don't want to know about that (what being on a Section 3 means), what they want to know is what are you going to do about the fact that they've got a bill for fifteen hundred pounds of arrears in housing benefit, that's what they want to do. And actually they are right because that bill is one of the significant things that impacted on their mental health that brought them into hospital."*

*IMHA Manager*

BME advocacy providers described how some BME organisations would frame advocacy as befriending, support or mentoring and how this could have far-reaching implications in terms of commissioning and providing IMHA services:

*"They (BME organisations) wouldn't recognise it as advocacy, they would recognise it as supporting someone from their community end of, so they wouldn't look at an advocacy tender and say 'oh that's what we do' they wouldn't know that that's what they do, they just get on with the business of supporting the community where they set themselves up to support. So for example as a member of the African Caribbean Society, we do quite a lot of*

*support and I would call it Advocacy but whether they know what Advocacy is."*

*BME advocacy provider (Focus group participant)*

However, other participants were deeply sceptical about the purpose of IMHA services. Both service users and mental health professionals articulated a concern that the purpose of IMHA services was to maintain the status quo and implicitly excuse the MH Act:

*"It's the same argument that people use with soup kitchens, while you just you know you just... the continuing the homeless, you're feeding them, you know you're providing the soup kitchens but you're just perpetuating the homelessness and I think there's a level of that argument can be applied to the Advocacy Service."*

*IMHA partner (Acute ward)*

For some service users this view was confirmed by their experience of IMHAs reinforcing what they had previously heard from mental health professionals, for example in relation to detention under the MH Act.

### **6.3 Understanding the role and remit of IMHA services**

Some IMHAs felt there was increased acceptance and understanding of the role of advocates. However, this could also come with an expectation that they behave as part of the mental health services team, and thus potentially compromise their independence. Others pointed out that advocacy services had always been funded by the statutory services but were able to maintain their independence and that:

*"If any time a care worker, psychologist tries it on with us we make it very clear that we are totally independent."*

*IMHA (Focus group)*

Table 7 summarises the understanding of mental health professionals in the case study sites of the IMHA role. In general, just over half of the professionals in all the sites were able to recall the name of the service or an advocate. There were two exceptions to this: one site where only one out of seven members of staff asked this question was able to name the service and another site where all of the staff asked were able to recall the name of the service or the advocate.



<b>% of mental health staff asked who were able to recall name of IMHA or of the service</b>	<b>Confusion with IMCA</b>	<b>% of mental health staff interviewed understand that it is an obligation</b>	<b>% of mental health staff interviewed that knew IMHAs can access records</b>
Median = 55% (Range = 15% -100%) but was influenced by organisational changes	Median = 30% (Range = 18%-45%) but usually by community staff with little contact	Median = 60% (Range =20%-86%) understand it is an obligation	Median =27% (10%-30%)

**Table 7: Understanding of mental health staff in the case study sites of the IMHA role**

In some sites, the difficulty in naming the service reflected recent organisational changes or the configuration of advocacy services, with several providers.

We found confusion between the IMHA and the IMCA role and this was particularly apparent amongst community staff who often had a poorly developed understanding of the difference and, indeed, limited experience of IMHA services, and this will be explored in greater detail in the next section.

Further, the extent to which mental health professionals understood that their service had an obligation to promote the service varied. Some staff had a clear understanding and a good grasp of their role in relation to promoting IMHA services:

*"So I believe my obligation is to ensure that people know that there is this service available, that these are the benefits of using the service and that, you know, it's not even something that they have to pay for, but just to ensure that they understand about the service, about the fact that they can access the service and about the fact that the person is independent of mental health services."*

*Specialist Nurse*

For others, their understanding of their obligations in relation to IMHA services was unclear or couched in very general terms. As Table 7 illustrates there was variation between the sites in terms of the percentage of staff that we interviewed in understanding their obligations, ranging from 20% of those interviewed in one site to 86% in another. However, it was also clear that this understanding of obligations varied between service locations within the case study sites. In some instances, the professional understood it was an obligation but thought it rested with somebody else, typically the IMHA service or ward staff at the time of admission.



The understanding of the IMHA role in relation to access to qualifying patients' notes was particularly poor with less than a third of those interviewed overall being knowledgeable about this aspect of the IMHA role and there was significant confusion about what to do if an IMHA made this request. Furthermore, little reference was made to the potential for IMHAs to promote participation in decision-making. The involvement of IMHAs in multidisciplinary meetings was typically framed in terms of providing moral support or voicing a person's wishes and rarely as enabling better decision-making through an improved understanding of a person's hopes and journey to recovery.

These results partly reflect the level of contact and experience that professionals have had of the IMHA role. Some professionals had a theoretical understanding but little practical experience of the IMHA role, and this was particularly, but not exclusively, the case for community staff:

*"I can't say that we've had much to do with IMHA's to be honest. What I mean by that is I can't say that I've had enough experience to say whether it's a good service or it's not a good service. I think, in theory, it's excellent but I think that in reality..."*

*Nurse Prescriber*

The findings also reflect the extent of training that the majority of staff recalled having undertaken. Some had no recollection of any training but the majority indicated that they had received limited training, often as part of MH Act training. This training was often provided in-house and it rarely involved the IMHA service, qualifying patients or service users more generally. Service users in one of the focus groups commented that it would be helpful if doctors had training so that they had greater understanding and thus respect for advocates and their role.

The professionals most likely to have received thorough training on the IMHA role were AMHPs who were also more likely to receive refresher training or discuss the role at network meetings. One of the sites had made considerable efforts in terms of training, although this was not reflected in the knowledge of the staff that we interviewed. However, there is a responsibility on mental health professionals to keep up to date with changes that affect their practice. Thus, improved post-qualification training is not the only solution and indicates that the issue of working with IMHAs needs to be supported through supervision and discussion in team meetings and could be facilitated by location within a recovery-focused approach.

#### **6.4 Confusion about IMHA services, their purpose and role**

We met qualifying patients who had not heard about IMHA services until they had been invited to take part in this study and were often vague as to what this referred to, with some believing that it was part of the mental health system or the process of detention.

This lack of understanding is a major barrier to access for qualifying patients, as reported in Chapter 5. The purpose of IMHAs can be confused with that of solicitors, generic mental health advocates and the Independent Complaints Advocacy Services (ICAS) by qualifying patients in particular. Not surprisingly then, the understanding of the IMHA role can be poor or non-existent with qualifying patients assuming that IMHAs are able to support them in a range of areas, not just in relation to the MH Act or that their role is to provide support with complaints:

*"Independent Mental Health Advocacy is to help you write letters and send letters of complaint or compliments to the authority or the management wherever you're residing at the time."*

*IMHA partner (CTO)*

The independence of the relationship between IMHA service and mental health services may also be poorly understood by potential users and alongside the experience of being detained can act as a barrier to access and also impact on the relationship:

*"The reason you're being sectioned is you are outside the remit of being capable of looking after yourself, so straight away, even though you are unwell, you are in fear before the arrival of the Section. The Section is the imprint of dominance on this fear of authority; it sets you off on a bad footing with the Advocates."*

*IMHA partner (Focus group)*

This was compounded by the assumption that the IMHAs are employed by the mental health provider or the local authority.

Similarly, carers were not always aware of what this new form of advocacy meant but thought that they could play an important role in promoting it. This was echoed by voluntary sector providers who drew attention to the potential confusion with IMCA. Some also said that they found the acronym IMHA confusing and did not always recognise the term or realise that it referred to advocacy:

*"(If you said) 'Do you know who the Advocate here is?' and straight away they would say it was me but if you went back a few days later 'oh do you know who the IMHA is?' and they'll go 'no, no what's one of them?'"*

*IMHA (For children and young people)*

As illustrated earlier a number confused IMHAs with IMCAs; sometimes this appeared to be a slip of the tongue, although in many instances a deeper misunderstanding was revealed on further exploration. This is illustrated by a psychiatrist who makes an interesting point about a general need for advocacy:

*"We're not aware of IMCAs and IMHAs, we just call them independent advocates, I don't sort of say IMCA, IMHA, even that can make a difference"*

*and in terms of improving, I try to keep things simple is that shall we just offer it to everybody, and that's the concern we started off with, the patient's right or their voices are not being heard then, you know should we just offer it to everyone."*

*Psychiatrist*

And also by this community team manager, who not only confuses IMHA and IMCA but misunderstands the purpose of advocacy and frames it in terms of best interests:

*"I haven't got that much experience but when that's discussed on the shop floor you think 'oh hang on a minute' you know there's this person you know they say maybe has no capacity but somebody needs to come up for their interests and particularly I think people who are alone etc., because there is nobody who they can check that with and if you have difficulty decision making as well."*

*Community Team Manager*

Construing advocacy as best interests leads to misunderstandings between mental health professionals and IMHA services, although this may not be clearly articulated. However, some had also had experience of best interest assessments being undertaken by the IMHA in a different role and this can compound the confusion and uncertainty.

Further, there were instances when mental health professionals thought the purpose of the IMHA was to specifically help with communication or consent to treatment:

*"So the IMHA role I see it as somebody who comes in with higher, I wouldn't say skill level, a better understanding of communicating with people who for whatever reason can't consent or have difficulties in consenting or working with the general advocacy service."*

*Occupational Therapist*

Some people will have both an IMCA and an IMHA and thus it is important for mental health professionals to understand their respective roles, as one IMHA recounted in relation to a woman detained on a MH Act section who was refusing treatment for cancer:

*"The issue with this particular lady was that she had cancer and was in total denial of it and they're asking me to talk to her and I'm saying 'it's not my role to get her point of view across, my role isn't to convince her to go (for treatment), you need an IMCA to ...'. They wanted Advocacy, I don't think they were very clear on what my role was and what the IMCA role was and it was me that said around the cancer 'if she lacks capacity and you're saying ... then you need an IMCA to do the report'."*

*IMHA*

We also encountered a lack of understanding in relation to the eligibility for IMHA services of people on CTOs. We found a small number of staff who had no understanding. For example one nurse who thought it would be useful if the advocate could be involved in carers' assessments. Others viewed the IMHA as an additional member of the team:

*"I had somebody the other week who had been evicted. They had had no money and I just ... I had so much work; I couldn't see them for a week. Now their anxiety level goes up, their mood goes down and all because I can't get to see them and it's not that ... and that makes me feel very unhappy, as a worker, knowing that I can't ... I haven't got the time to do it and if they had an advocate that would be able to, not harass me, but actually go away and do something practical, then that would be very helpful."*

AMHP

The confusion was explained in terms of lack of experience, particularly by community staff, the development of IMHA service from generic mental health advocacy and a lack of clarity as to their respective roles and remit. Further, the limited training that most mental health professionals had received was not addressing this. Most people could either not recall the training or indicated that they had a slot in the MH Act training; rarely did this provide an opportunity to meet with the IMHA service and discuss the detail of what they do and the implications for mental health services (see Chapter 7 on Landscape of IMHA services).

## 6.5 The mental health professional role and advocacy

The interviews with mental health professionals raised some fundamental questions about the nature and purpose of advocacy. Many, particularly nurses and social workers, saw themselves as clearly having an advocacy role, saying that this aspect of their professional role was encouraged during their original training and reinforced by professional codes of conduct.

*"It's integral as the role of the nurses to advocate for our patients and I regularly do when we're in meetings. We do ward rounds and CPA's and I'll regularly put the point across that the patient might want to ask, you know having discussed the various issues and we quite often try and also bring in the point of view of the patient as well because I think that's absolutely essential."*

Ward Manager (Learning difficulties ward)

*"I mean I'd see myself as being an advocate and I have done on many occasions, like, you know, especially around complaints. If patients make complaints I'd seek to rectify the complaints in the first instance if they were, you know, locally resolvable."*

Modern Matron (Secure services)

Some professionals, particularly nurses, felt that they also had an advocacy role by virtue of their position, being a key worker or care coordinator, which involves getting to know the person well, spending time with them and taking a holistic view of their needs.

*"A relationship between a nurse and a patient is quite close, that's what we try to make it therapeutic. We try and really understand their emotions and their needs. Sometimes it's difficult to separate other things from that because you become close with that person, now an Advocate doesn't have that emotional bond with the patient because they don't spend that length of time and they're not trained to do that."*

*Staff Nurse (Acute ward)*

The staff nurse here was reflecting on the quality of the relationship she tries to build with service users over the longer term and in an intensive living environment. This was similarly referred to by other nurses, who described working to build a relationship so that patients could discuss their concerns with them.

In describing the advocacy element of their own role, mental health professionals identified:

- Giving information about detention under the MH Act.
- Helping someone to understand other information or letters from services.
- Pursuing complaints.
- Identifying and voicing the needs of the person usually in multidisciplinary meetings when the person was not confident or able to do that for themselves.
- Supporting decision-making.
- Challenging the medical opinion or that of other disciplines.
- Signposting or referring to other services.
- Safeguarding the interest of an individual, vis a vis family members.

There was the sense for nurses in particular, that claiming an advocacy role reflected their relationship with some service users, who might bring difficulties about other members of the team to them, or be reluctant to approach an IMHA. They also saw themselves as exercising an advocacy role in challenging the decisions or views of other team members, particularly doctors:

*"I would expect the nurse to be taking the role of an Advocate, even if it's against the doctor, you know a medical decision or whatever, and if they think that the patient needs one, if they don't think the family member is suitable then they should find one for them because I mean sometimes you know say you get a patient who will come in who is severely depressed, but*

*they have made it plain that they don't particularly wish to have some form of treatment but the Consultant is pushing at it and they're not giving them the full information, then you need to step in."*

*Ward Manager (Older adults ward)*

This form of advocacy was about giving voice to the service user's wishes if the mental health professional judged that this was in the person's interest:

*"I think as nurses mainly you know we are there to safeguard their interest or safeguard them against any abuse or anything so we do advocate, maybe when you attend ward rounds and you know that your patient is requesting for leave so you have to advocate on their behalf that they have been very settled in their behaviour."*

*Team Leader (Secure services)*

Thus the conception of advocacy provided by mental health professionals often emerged as a best interests one; balancing the patient's wishes with ascertaining what is in their best interests and protection. This was expressed as reflecting the mental health professionals' duty of care and it is this which distinguishes it from the IMHA role:

**Interviewee:** *"In that way the role can be compromised as a nurse really because I might know that as a patient this is what you're saying but I also might know that, a) it's not the best thing and b) it's outside of my remit, or certainly outside of my professional, you know, role."*

**Interviewer:** *To say not to take medication?*

**Interviewee:** *Yeah, or to say, do you know, 'I fully appreciate that that's your preference not to take medication' but, you know, I would also be saying 'but when you're well you do recognise you need to take it.' Do you know, whereas an advocate or an IMHA wouldn't necessarily have to talk about that side of it really."*

*Specialist Nurse*

For some mental health professionals, the values underpinning advocacy and the rights of people were keenly felt:

*"I'm constantly getting myself into trouble for advocating too loudly for my patients, and I do that. You know, across my career, I left my last job because of unacceptable clinical practices. You know I resigned, I'm very principled. So I constantly advocate for my patients full stop."*

*Occupational Therapist*

The extent to which mental health professionals recognised the inherent conflict of interests between them assuming an advocacy role and their broader role varied. A

relatively small number of mental health professionals appeared not to understand why independent advocates were needed and this was variously expressed as hurt, irritation with IMHAs perceived as “an interference” or scepticism about the need for this new role:

*“I think that the team here are cracking and I think that they advocate for their patients and I think that sometimes the implication that nurses don’t advocate is unfounded.”*

*Practice Development Nurse*

However, for others independent advocacy sat alongside the professional role as an enhancement:

*“I think that’s a big part of being a nurse that we do act as an advocate to our patients ourselves, but the fact that it’s an independent service, it’s not... you know that is not provided by the nursing team is a good thing as well...”*

*Staff Nurse (Acute ward)*

Many professionals, however, whilst viewing their profession as having a definite advocacy role also recognised the limits to this or the potential conflict of interest and thus the need for independent advocacy:

*“So it just gives patients that extra support because although I try to carry the advocacy role, they see me here and I think at times they doubt whether I’m here for them or not because I’m part and parcel of management, I’m employed here. It makes a difference to hear it from the outside world.”*

*Social Work Manager*

As is reported in the next chapter, very few of the service users who did not use IMHA services identified support from mental health professionals as a viable alternative to IMHA services. However, this understanding of advocacy and the professional role can influence the attitude and relationship with IMHA services, as explored in Chapter 10.



**Understanding of IMHA services – Key findings**

1. Service users and carers do not always understand the purpose or role of IMHA services and can confuse it with Independent Complaints Advocacy (ICAS) or a support worker role.
2. Although some service users have a well developed understanding of the purpose and role of IMHA, there was also scepticism about whether it exists to maintain the status quo.
3. We found that in all of the case study sites just over half of the mental health professionals were unable to name the service or an advocate, reflecting limited experience, complex advocacy provider configurations and recent organisational changes. This was particularly marked for community staff.
4. Areas of misunderstanding and confusion for mental health professionals included:
  - Confusion with the IMCA role.
  - Assuming that IMHA services are only for people detained under the MH Act who lack capacity.
  - The difference between IMHA and other forms of advocacy, particularly generic mental health advocacy.
  - The scope of the role in relation to a broader range of practical and social issues facing service users.
  - A substantial number of staff interviewed did not fully understand that they had an obligation to promote the service and knowledge about the IMHA's right to access notes, and to support participation in decision-making was generally poorly developed.
5. The training that the majority of staff had received was generally cursory, usually as part of a general overview of the MH Act. The exception to this was the systematic approach to training in the High Secure service and that delivered for AMHPs.
6. The view of mental health professionals, particularly nurses, that they have an advocacy role is widespread. This is usually framed as best interests advocacy linked to their duty of care and some mental health professionals have well developed understanding of how this differs and can co-exist with the IMHA role. But other staff view that the IMHA role is superfluous and this shapes their attitudes and relationships to IMHA services.



## 7. IMHA SERVICE LANDSCAPE

### 7.1 Introduction

Recent research (Hakim & Pollard, 2011), together with the focus group findings, indicates that there is uneven provision of IMHA across the country, and that the organisations providing this form of advocacy vary significantly. Drawing on information gathered from the survey questionnaire of IMHA providers and interviews with different stakeholders, this chapter paints a more in depth picture of the IMHA service landscape than has been possible so far. It begins by outlining the nature, scope and size of IMHA service providers in the eight case study areas, their aims and ethos, and the composition, skills and training of the IMHA workforce. Next, it identifies what methods of case allocation were used by these services and considers how IMHA services were attempting to meet the diverse needs of qualifying patients including developing links with other specialist services, for example, translation and interpreting services and with other advocacy services. Finally, we reflect on current monitoring and review mechanisms adopted by both IMHA providers and commissioners to ensure provision of a quality service.

### 7.2 Profile of IMHA providers

#### 7.2.1 Provider type

Across the eight case study sites a total of 22 IMHA providers were identified. Just over three fifths of the 18 providers who responded to the questionnaire survey were well-established advocacy organisations that had been in operation since the mid to late 1990s, and two had been in existence from the 1980s. A third of these were more recently created, that is, in the past five years. Just two stated that the advocacy service had been set up in 2009, that is, when IMHA was enforced. Most also stated that they had been providing advocacy support to people under compulsion pre-IMHA, and had been commissioned to provide IMHA on the “*basis of our reputation*” or because of “*having skilled advocates*”, as the following quotations illustrate:

*“We’ve provided mental health advocacy ... since we’ve been up and running practically, since about 2001, on the wards at a local Mental Health Unit...that included working with people who were detained under the Mental Health Act. So we had provided that service historically and then our commissioners approached us and asked us to put in a bid to provide the IMHA Service in March 2009.”*

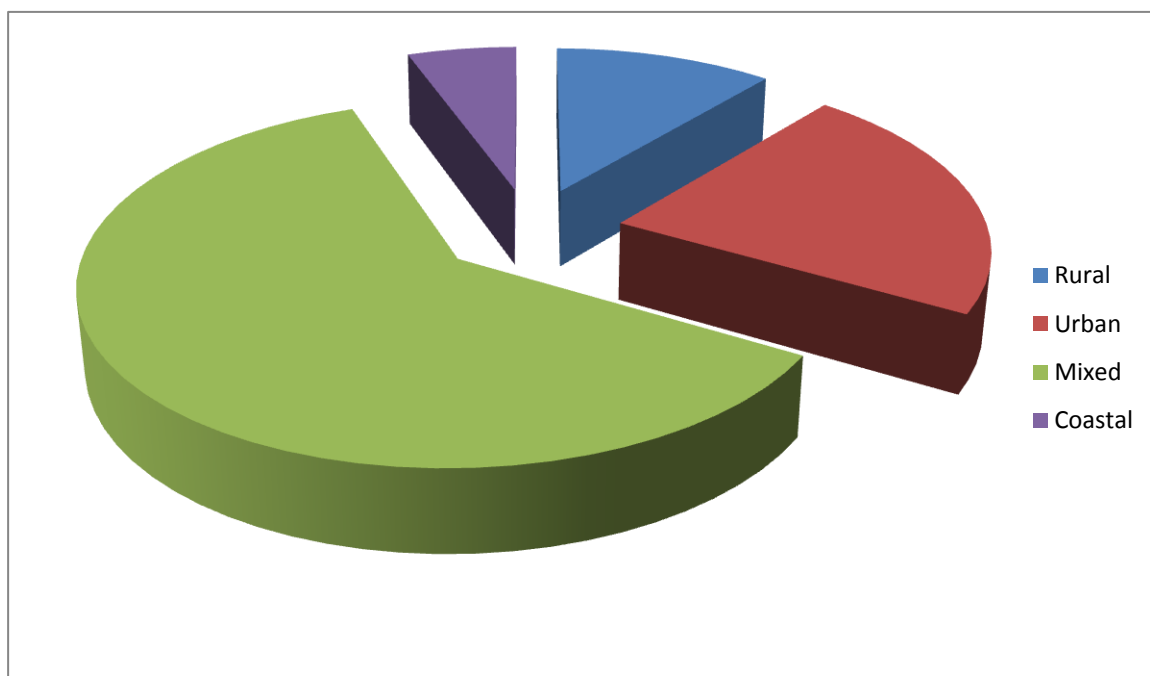
IMHA

*“In April 2006 we were in a contract with the mental health NHS Trust to provide mental health advocacy...to people who were accessing secondary mental health services, both in the community but also on inpatient wards. The criteria for accessing the service for people who were inpatients is...*

*exactly the same in terms of the qualifying criteria for IMHA. So when IMHA kind of started in April 2009 well actually we'd been providing a very similar service beforehand."*

IMHA

The 18 participating IMHA providers were a mix of small local charities run by boards of trustees or directors, and local branches of larger regional and national charitable organisations, and one freelance advocate commissioned by the independent sector to provide services to specific secure units. IMHA services operated within complex geographical boundaries: responses to the survey questionnaire indicated that while advocacy services in two of the case study sites were operating in large inner city areas, the majority of IMHA services were operating within areas they defined as mixed urban/rural (see Figure 9 below).



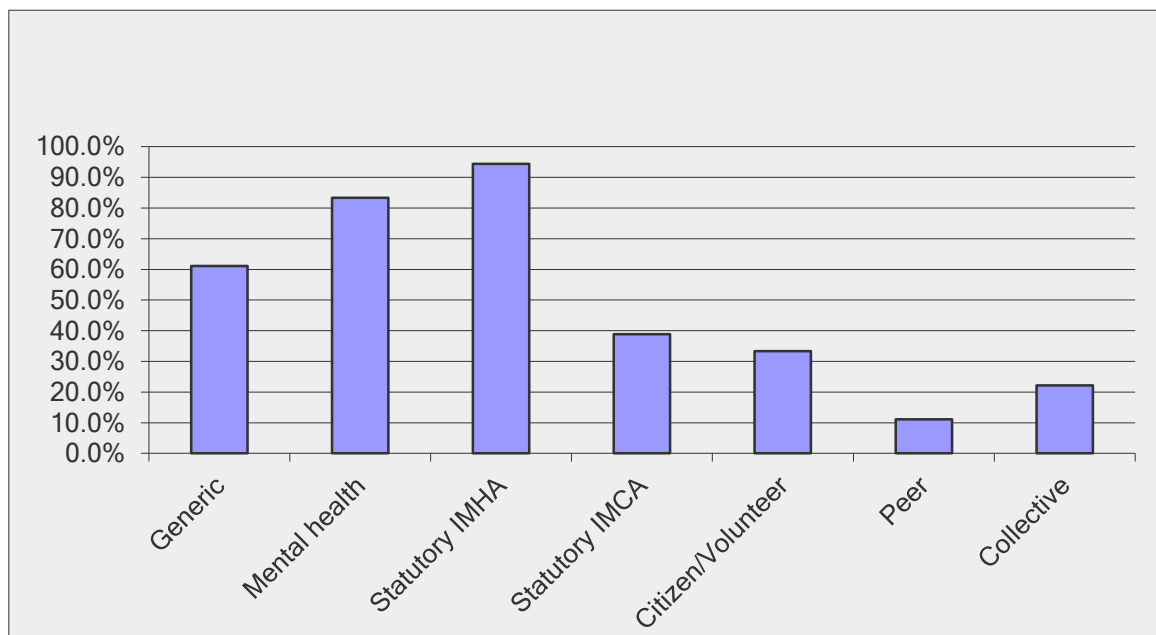
**Figure 9: Type of area where IMHA providers operated**

### 7.2.2 Type of advocacy service provided

Those IMHA providers who responded to the questionnaire survey were involved in a wide range of advocacy provision, not solely the delivery of IMHA. In particular, they offered a menu of advocacy support to mental health service users. As the following chart shows, in addition to IMHA they offered statutory IMCA, mental health, generic, citizen or volunteer advocacy and a range of peer and self-advocacy support to meet a variety of individual needs.

The majority (61%) indicated they provided IMHA support to children and young people under 18 years, mainly in specialist CAMHS units. Although, as shown earlier (See Chapter 5), the number of individuals under 18 years old who had accessed

IMHA support was extremely small, which partly reflects the relatively small number of children and young people detained under the MH Act. One national organisation specialising in advocacy support for children and young people, was commissioned to support young people aged 16-17 years in two districts of one of the case study sites, as well as in other parts of the country. Furthermore, two thirds of IMHA providers stated they were specifically commissioned to provide advocacy to older people and to people with learning disabilities. Even though all IMHA services are expected to meet the needs of ethnically diverse populations, only a small proportion (44%) of services stated they were commissioned to provide advocacy to BME groups.



**Figure 10: Range of advocacy provided by advocacy services providing IMHA**

### 7.2.3 Number of services providing IMHA

Across the eight case study sites there was wide variation in numbers of IMHA providers operating, their size and the type of organisation providing IMHA. For example, in two sites (G and H) five different advocacy services provided the IMHA service across at least seven PCTs. Similarly, in another site (B), four different providers were commissioned by five PCTs. In contrast, just one IMHA provider, commissioned by a single PCT, operated in two of the sites (C and F). Another site (E) had two IMHA providers, one a local service and the other located 150 miles away. All sites commissioned IMHA provision for secure settings, and to provide IMHA in independent/private hospital settings.

Case Study Site	A	B	C	D	E	F	G	H
Number of IMHA providers	3	4	1	2	2	1	5	5

**Table 8: Number of IMHA providers identified in each case study site**

Not only was it the number of IMHA providers in an area that differed across the study sites, but the type of advocacy organisations also varied. For instance, three of the five IMHA providers in site H were local branches of large national organisations, one was a regional charity, and another was a national specialist children and young people's organisation. In contrast, all four IMHA services in Site B were delivered by local advocacy bodies serving distinct geographical patches.

The interface between advocacy and mental health services is therefore more complex in some areas than others because there are multiple providers covering diverse populations, which is likely to have a bearing on service users' and professionals' knowledge of relevant IMHA providers and consequently, on the frequency of referral and access. In the focus group discussions, mental health professionals raised the existence of multiple providers as an issue that could have a negative effect on quality, advising that staff and service users were sometimes confused about which organisation provided IMHA.

In a number of sites with multiple IMHA providers, advocacy services had engaged in area forums to enable sharing of information and discussion of best practice issues. On the whole, relationships between advocacy providers were reported to be collaborative but there was an indication that the competition for IMHA contracts engendered between small advocacy services had caused some difficulties, for example:

*"Having different providers pitched against each other is very difficult. In our patient experience meeting the old providers didn't turn up, the new providers were there, there were two other community advocacy services there who had lost considerable grants this year, one of whom is losing half his job and it was a bit tense."*

*Patient Involvement Lead*

In one site, three of the four advocacy services providing IMHA worked together as a consortium to provide the IMCA and generic mental health advocacy services for the area, and had aligned their paperwork and database systems to ensure people received comparable levels of service even if dealing with different advocacy services, and to streamline reporting to commissioners. Close working between the services also meant it was easier to deal with out of area referrals. In another site, a providers' forum had been useful, though it did not remove competition between agencies:

*"We're all in the same boat, we don't know what's going to happen and we've taken it upon ourselves to say well, you know, the only practical way to continue is to accept that we are still competitors and that we have to be careful about how we go about things but there are merits in saying right, we've all got to know what we mean by the terminology that we use and the terminology that the Commissioners are using. I mean I think the best example of that was the standard of measurement of time in the face-to-face contact - we sat down and discovered that everybody actually defined face-to-face contact as something different."*

IMHA

#### 7.2.4 IMHA team sizes

Variability in size of IMHA teams and services had been highlighted earlier in the research by IMHA staff participating in focus groups. These participants had themselves come from teams of varying sizes, and thus questioned whether, for instance, an appropriate and effective service could realistically be provided by one part-time IMHA covering as many as 18 wards compared to a team of 10 or more IMHAs. These research participants had suggested that having too few IMHAs negatively affects services' capacity to provide quality IMHA on account of *"not being able to spend enough quality time with clients."* Information gathered from the case study sites confirmed this assertion. It also meant that there was less time available on the wards or in other settings to provide information about IMHA services and stimulate referrals, as discussed in relation to access in Chapter 5.

Across the eight case study sites, the size of advocacy services and teams providing IMHA varied hugely: the average number of IMHAs per advocacy service was four. In some, the number of paid advocates was as few as two while in others there were 14 advocates (though not all these were IMHAs). Similarly, the number of volunteer advocates engaged by these services varied from zero to 20, with no clear relationship between the number of paid and volunteer advocates: some services with few paid advocates also had no or few volunteer advocates, and those with more paid advocates had the highest number of volunteers. Not one of these services, however, deployed volunteer advocates as IMHAs. The number of full-time equivalent (FTE) IMHAs per advocacy service was on average three, although this varied from one to seven FTE IMHAs in the different services. The following table illustrates this variability of provision across the sites.

Case Study Site	A	B	C	D	E	F	G	H
Number of paid advocates	3 services with 6-13	4 services with 6-14	9 in one service	2 services with 2-5	5 in one service	2 services with 6-10	One service with 6	5 services with 2-11
Range in Number of IMHAs	5-6	1-6	3	1-5	2	4	2	1-5
Number of FTE IMHAs	5 in one service (ICA)	Between 1- 5	7	Between 1-4	2	2	2	Between 1-2

**Table 9: Numbers of paid advocates and IMHAs in the case study sites**

### 7.2.5 IMHA and IMCA

Very few of the advocacy services identified had paid advocates who worked as both IMHA and IMCA; this was the case in only two of the study sites (B and E). This is perhaps not surprising given that just seven (39%) survey respondents indicated that their organisation provided IMCA (see Table 9 above), and that on average just 1.5 paid advocates in their services were IMCAs. In some services it was the stated vision to have “highly trained advocates who can pick up and do different types of work” (Site E), whereas others considered these as separate specialisms. In a minority of services, there was mention of advocates taking up DOLS advocacy as well as statutory IMHA and IMCA. One explanation for the separation of IMHA and IMCA roles may lie in the different funding and commissioning mechanisms, which will change in 2013 when local authorities become responsible for commissioning IMHA provision.

### 7.2.6 IMHA and generic advocacy

It was common in several services, though not all, for IMHAs to operate as generic mental health advocates with 61% of survey respondents stating their advocacy service provided generic advocacy. Across the 18 agencies, around three out of four IMHAs were also generic advocates. A strong argument was put by some interviewees, and also earlier by IMHA focus group participants, that having advocates able to alternate between these roles enabled them to more easily adopt an holistic approach to meeting people’s needs, and that it increased the overall flexibility of the service:

*“You have to have one package including being IMHA as well as the generic you see because they will have asked you more, to do more things just to tell*

*their rights about, when they're detained. They will also want to know their rights, information about mental health... and once a client comes with one problem they will have many more to sort out."*

IMHA

An IMHA from one area highlighted the benefits to be gained from advocates being able to move seamlessly from one type of advocacy to another:

*"I think it's an advantage to the patients that I can do both because I don't then have cut off points where I say 'oh well you're voluntary now so I'm not advocating for you anymore'... because we do community ... if I'm doing something for somebody and they're discharged or they leave the unit, I will continue advocating for them until their issues are resolved or they're happy and satisfied..."*

IMHA

Another focus group participant had moved from an agency providing broad based advocacy to one that was purely an IMHA service commenting:

*"It's very difficult to say no to patients ...you want to go in there and take on everyone's human rights and work with everybody and that's something we can't do because of the statutory obligations."*

IMHA

Other IMHAs and managers argued that such flexibility could be achieved within larger advocacy services employing different types of advocate, or having advocates with more narrowly defined roles developing close working relationships with other advocacy organisations thus complementing each other's provision. Some initially separated IMHA and generic mental health advocacy roles, only to integrate the two in light of experience to both capitalise on the wider staff resource this allowed and to assist with addressing diverse client needs:

*"It worked well at the start because it was a new service and obviously we need to focus on a lot of the development elements... but after about six months we felt that it would be more beneficial... if I was off ill when I was providing that role, really there wouldn't have been anybody else that could pick up that work...Means that we have that flexibility and also it supports the development of the advocates...and in terms of diversity as well and being able to provide an Advocate who can support that person..."*

IMHA Manager

An opposite viewpoint held by a minority of IMHAs and mental health professionals was that this could lead to role confusion and lack of understanding about the IMHA role. As one IMHA staff member observed, *"Sometimes there can be confusion for the staff on the wards...which hat is the advocate wearing on which day?"* The actual



pattern of separate or mixed roles differed from service to service, and within areas: for instance, in one site with two advocacy services, one service had five IMHA/generic advocates, while advocates in the other service acted purely as IMHAs. Although common, therefore, it was not consistently the case in any one site that IMHAs always acted as generic advocates.

### 7.3 Ethos of IMHA services

The ethos or philosophy underpinning advocacy services providing IMHA was highly consistent across study sites and providers. Repeatedly, interviewees and survey respondents emphasised how the same values and beliefs should, and do, underpin all types of advocacy. Across all data sources we found emphasis was placed on the following key aspects:

- IMHA services upholding individuals' rights in "all aspects of their detention".
- Support being "person-centred" and "holistic".
- IMHA services and advocates being "impartial" or "independent".
- Advocacy services being free of charge.

and, centrally, that

- The purpose of IMHA advocacy was "giving voice" to disempowered people.

Some examples of stated aims of IMHA were as follows:

*"To provide free and independent advocacy to help people understand their rights and to support them in exercising those rights; to help people access information, put their views across and be part of assessments and decisions about the health or social care they need."*

*IMHA provider (questionnaire)*

*"All of our advocacy services are based on the same values and the IMHA Service is no different...all of our services are free, we're independent from other services, we're there to empower people to speak up for themselves whenever possible and supporting people to do that for themselves but to be there to do it for them if they really want us to...we're inclusive and... we're confidential. So all of those values go across all of our advocacy services."*

*IMHA Manager*

*"...independent of the ward culture. I think if you're working on the same ward day in day out it can be very easy to become either internally yourself a part of that culture, or to be seen as part of that by the people on the ward. So I think to always mentally step away is really, really important."*

*IMHA (Focus group)*



In addition, one advocacy organisation specifically stated that a vital aspect of its service was tailoring the support to local needs:

*"The [organisation] holds dear, the whole kind of citizen's advocacy routes, they want to retain that. They don't want to become a big national you know streamlined service. We want to be able to respond to local need for local people locally."*

IMHA

A critical point highlighted by IMHA staff in particular, was about the need for IMHA to address *"the issues people are bringing to us"*. In other words, as many IMHA staff involved in this research stated, IMHA should be a *"patient-led service"*. Those involved in focus groups frequently linked being client or person-centred with a quality IMHA service. IMHA staff referred to advocacy as being the person's choice (except of course, when non-instructed), a point that was supported by service users:

*"I'm the client and I'm always right. I feel that is the main issue."*

IMHA partner (Focus group)

From IMHA staff's perspective being person-centred meant accepting an individual's understanding and representing his/her interests, which was in contrast to what has been described elsewhere as acting in the person's 'best interest', for example:

*"It's about people, their views, their opinions, their voice. It's not about my views and opinions, it's about their views and opinions, it's as simple as that."*

IMHA Manager

*"You represent the views of the client, you never represent your own views."*

IMHA

However, the potential for tension in operationalising this concept was expressed by an IMHA focus group participant who talked about *"the client's needs being the leader"* and went on to say:

*"It doesn't work unless there's a relationship, unless there is some degree of trust, unless you develop that kind of partnership agreement. So I think what you're really talking about is a relationship with that person rather than that person necessarily leading you and but I think it's about the client's needs being the leader as opposed to the client being the leader."*

IMHA

Furthermore, while IMHA is unanimously felt by advocates to be about working to *"champion rights"* and *"offer people more control"* in a situation when control has been removed in an extreme way i.e. the person is under compulsion, there are

clearly challenges in working within current mental health legislation and services. Such strains were hinted at by IMHAs:

*"Fundamentally we are a patient-led service. However, I think one has to be realistic to say that we have a number of criteria that our commissioners of service expect us to fulfill and perhaps their priorities are not necessarily in total alignment with the majority of the patients' priorities."*

IMHA

Thus, the extent to which IMHA services were truly person- or client-centred, and the implications for the advocacy relationship (between advocate and partner), and between advocate and mental health professionals, were common themes running throughout this research, and are ones to which we will return in the final discussion.

## 7.4 IMHA staff

A number of key personal qualities, as well as skills and training were expected of IMHAs, and those with direct experience of IMHAs (i.e. IMHA partners) suggested that the quality of IMHA staff does vary, even between IMHAs in the same service. Across the stakeholder groups there was general consensus about the personal qualities of IMHAs, as well as of the training and skills they require to deliver a quality service.

### 7.4.1 Individual characteristics of IMHAs

Issues that might impact on the quality of the relationship between the IMHA and the advocacy partner potentially include characteristics such as gender, ethnicity and shared cultural identity. A minority highlighted that impairment and disability were also factors that might impinge on the quality of the relationship and thus the effectiveness of IMHA, as the following professional from a specialist mental health setting observed:

*"If you have a qualified person and you know the IMHA who's deaf, who's signing is then so much better you know deaf people get frustrated at having to clarify to hearing people what they've just said...If [IMHA] is a deaf person and they're culturally similar you know the relationships are much better, much closer."*

Ward Manager (Deaf services)

Nevertheless, little specific reference was made to the impact of the IMHA's gender, ethnicity or disability per se, even though the experience of abuse, particularly sexual abuse, was identified as having a potential impact on relational quality. This was usually in relation to female service users wanting to relate to a female IMHA, which in a female dominated service was rarely an issue. Gender, ethnicity and disability factors were of far less importance to service users than the training and general personal qualities of IMHAs that will be discussed below, as the following asserted:

*"It's nothing to do with their ethnic background, because I love all people, White, Black, Chinese, Pakistani, English, I'm not a racist and I never will be."*

*IMHA partner (African Caribbean woman)*

*"It was okay because I got on right well with J."*

*IMHA partner (Acute ward)*

There was also the understanding among service users that in a few services there was only one advocate providing IMHA so offering choice of any kind was impracticable. It was further suggested that it is the short term nature of the IMHA relationship that makes this less important an issue than would be the case in longer term advocacy relationships:

*"Why do I need a choice because...If they do their job professionally then it doesn't matter whether you get on with them or not... So only if you use the services an awful lot do you need to have choices. And in an emergency situation when you need someone, you need someone quickly they just need to be professional and know their job. If at a later date you don't get on with that person then you could be offered choices."*

*IMHA partner*

This perspective was confirmed in the following reflection by an IMHA:

*"I did once make the mistake of asking somebody whether they would prefer..., but at the time we had two ethnic minority staff who could have seen this particular guy... I did say to him 'would you prefer to see somebody from your own ethnicity?' And he said as long as you get me what I want I don't care if you're white, black or pink with purple stripes."*

*IMHA*

Nonetheless, that the IMHA workforce in the sites was predominantly White and female is noteworthy as this clearly offered limited opportunity for meeting specific service user preferences, particularly in terms of cultural and ethnic diversity. The vast majority (73%) of IMHAs across all the advocacy services were female. In some individual advocacy services all IMHAs were female, and in others, where gender was mixed, just one out of four IMHAs was male. When this was the case, there was evidence that service users had been offered some choice:

*"I was asked if I would prefer a man or a woman to be interviewed by and I said I wasn't really bothered. It doesn't bother us, a man or a woman you know it makes nae difference."*

*IMHA partner*

The lack of flexibility in terms of offering choice of gender of IMHA was not raised as problematic by any of the service users interviewed. In circumstances where one or more advocates were male, cases were sometimes allocated along gender lines – "I'm

a male advocate so I generally get males". In another situation, the mixed gender of IMHAs had enabled case re-allocation:

*"I've had to change clients once from being female more than anything because I felt that I wasn't sure if they wanted the IMHA support from what they were saying and it was quite graphic...so I asked one of my male colleagues to take that case because I was uncomfortable with it and they did that and things completely changed...For safety reasons, I've had to change because it came about that there was a significant risk to females with one particular person and again I did highlight that to my Manager."*

IMHA

An IMHA in one service was, however, more critical of the gender imbalance:

*"I think, given our relatively small numbers, we could actually do with having another male member of staff available simply because of the high proportion of patients we have who have a sex offending history and therefore, you know, if I'm not around and we've only got female staff remaining they can't be seen unless the manager goes out, which he's quite happy to do and will do. But it's a less than ideal situation."*

IMHA

In terms of ethnicity, the IMHA workforce was even less diverse with 84% of IMHAs across the 18 advocacy services being of White ethnicity. This was equally the case in sites where the population was known to be more ethnically diverse as in those where this was not the case. Unusually in one advocacy service, two out of its four IMHAs were of BME or dual heritage background in an area with a significant BME population. While a rare occurrence, there was evidence that service users in some areas had been able to express ethnic and cultural preferences in relation to IMHA:

**Interviewer:** "And were you able to choose your IMHA advocate?"

**IMHA partner:** "Yes I was. Because the first one wasn't very good, she wasn't very in tune with my needs so I asked for a replacement and they sent me this Black girl, she was very good."

An IMHA provider in an area with an ethnically diverse population had made specific efforts to reflect this diversity in the employment of advocates:

*"I've been concentrating on Asian language speaking advocates, Polish, because we have a large Polish community and Kurdish. I've got a Kurdish speaker because there's quite a large Kurdish population. And I'm actively looking at the moment for somebody Portuguese because there's a large Portuguese population in [name of area]. So these people are helping us just*

*as and when required because they've been in for training...I can rely on them and they are on our books..."*

IMHA

There was infrequent mention of translation and interpreting services by IMHA providers, no mention by mental health professionals and very limited mention by a couple of IMHA partners whose first language was not English. In just four out of the eight sites was there any mention of the relationship between IMHA providers and interpreting and translation services. This was in respect of accessing these services through the NHS Trust, and occasionally through Language Line as this was said to be expensive to access. IMHA staff had sometimes drawn on other colleagues within the wider advocacy service who could speak the service user's language but were not trained as IMHA.

#### 7.4.2 Personal qualities

Across stakeholder groups in this research, the following personal qualities of IMHAs were identified as essential:

- Personable, friendly, and approachable personality – *"she's kind", "caring, considerate, and compassionate"*.
- An ability to relate well to a broad range of qualifying patients and to understand the individual's perspective.
- Perseverance or sticking power and following through – *"she doesn't give up"*.
- Non-judgmental approach.
- Clear and honest in communication.
- Dependable, turning up as expected and doing what they say they will.

The friendliness and approachability of the IMHA, their perseverance in seeing an issue or task through, the clarity and honesty of their communication and dependability were of critical importance to IMHA partners. Underpinning the key qualities of IMHAs identified by service users was the advocate's capacity for empathy – *"to get inside someone-else's shoes and to get alongside them"*. Another stressed the requirement for IMHAs to be sensitive to the person's advocacy needs and to adjust how they implement the advocacy tasks agreed according to each individual:

*"A good advocate gives all the information out and then sits for a minute and lets the person think and then ask questions."*

IMHA partner

*"She lets you lead if you can lead; if you can't lead she interjects and suggests things and helps you."*

IMHA partner

*"He was good at talking to the doctor the way he worded things and he'd always say what I wanted to say for me... and he'd always say it how I wanted it said. He'd never write it in his own way or anything."*

*IMHA partner (Acute ward)*

While IMHAs were expected to, and did identify with their advocacy partners, all types of stakeholders emphasised the importance of acting in what they referred to as a *"professional"* manner. This was framed in terms of reliability (including being on time), dependability, being user-focused and being respectful. It was also about the perceived competency of the advocate to act appropriately on behalf of the individual, and his/her ability to understand the issues from the partner's perspective:

*"She has insight into what they've come to see you about. Answers when they first come to see you what they're going to be able to do from the start, clear about what they are going to be able to do."*

*IMHA partner*

*"They've always come really prepared and any reports or any paperwork that they've sent or provided, if they haven't been able to come for whatever reason to the meetings, they always seem to be of a really high level... they tend to be really very professional."*

*Ward manager (Medium secure unit)*

#### **7.4.3 IMHA training and knowledge**

Different stakeholder groups expected IMHAs to be knowledgeable and trained in a number of areas, which, on the whole, was supported by people's experiences. They felt IMHAs needed to be knowledgeable about:

- Mental health law and the Code of Practice.
- Mental health difficulties, including of older adults with mental health difficulties and people with learning difficulties.
- How the mental health services system works and how to navigate through.

Overall, the IMHA services had met the expectation in the Code of Practice (Department of Health, 2008a) and as stated in most service specifications, that IMHAs will be trained within 12 months of becoming an IMHA. On average, three out of four IMHAs in these services had completed the IMHA module of the National Advocacy qualification, and others were in the process of completing this mandatory course. As advocates are required to use their experience of delivering IMHA when they undertake this module, there is inevitably a delay in starting for new IMHAs, which would explain why not all IMHA staff were qualified. Even so, there was wide variation between the research sites. In two sites, for example, all IMHAs had completed this training, in contrast to one area with one advocacy service where just a third of IMHAs had completed, and another with just a quarter of IMHA staff

completing the module in one service. In all other sites, the vast majority of IMHAs had completed the course.

Additionally, advocates had participated in induction and other training programmes run by the advocacy services as well as NHS Trusts on topics such as equal opportunities and diversity; non-instructed advocacy; and personality disorders. Some had received training on Tribunal procedures from solicitors. Clearly, the vast majority of IMHAs were experienced advocates who had worked in mental health settings for a number of years, and some had social work, law and other professional backgrounds. It was this professional training that some said had better equipped them to do IMHA as it was in more depth:

*"I did the module because I had to, and I certainly didn't find it difficult. I think the social work training enables me to do a better job as an IMHA."*

IMHA

In terms of professional development, there did not appear to be a clear career path for IMHAs other than becoming a manager or co-ordinator. Some IMHA staff interviewed had at one stage been volunteer advocates and had moved into paid advocacy as generic mental health advocates prior to becoming an IMHA. Others had trained as social workers or lawyers and had then chosen to become IMHAs, some following on from student placements in advocacy services.

Mental health professionals generally had little knowledge of the training requirements for IMHAs. Some health professionals were of the opinion that IMHAs needed more training on mental health problems/distress:

*"Training is critically important because the last thing you want is someone dashing in, bull in a china shop, making things worse....learning the boundaries absolutely crucial....partly in the relationship is what it's about and the same with the clinical team, a good understanding of confidentiality."*

Psychiatrist

IMHAs in one site highlighted an issue to do with the cost of training. While there are a number of national and regional training events, local advocacy services often struggled to afford to pay for courses and associated travel costs out of the limited resources for IMHA as although most if not all contracts include an element for staff training, this had rarely been sufficient to fund training other than the specialist IMHA module.

#### **7.4.4 IMHA skills**

All types of stakeholders, but especially IMHA partners, highlighted the importance of the skill of listening:



*"A good listener, that's all you really need. Half the time all you need is someone to listen to you, you know and not going 'yeah, yeah, yeah no bother' you know, all you need is someone that will listen to you..."*

*IMHA partner (Secure services)*

*"Not the gift of the gab. The ability to speak lucidly and with empathy not just sympathetic but to put yourself in the, not the mind because we're supposed to be so ill, but to put yourself in the feelings of the patient and speak accordingly for the patient."*

*IMHA partner (Acute ward)*

Linked to listening skills were of course, other good communication skills. In support of this, many IMHAs explained how they had made efforts to ensure the advocacy partner understood, for example, information on the Section – *"I'll put it into simple English for myself to understand and then relay it in the best terms I can..."* The value of this type of approach was confirmed by IMHA partners' experience:

*"He knows how to talk plain speech, not gobblydegook English....Has person to person skills, articulation, able to speak to people at different levels like doctors on one level, nurses at another level, management at another level and then the patient."*

*IMHA partner*

*"Not intimidating ... communicative is a big thing because there isn't a lot of communication between staff and patients generally, there are exceptions but as regards to your treatment there isn't much at all."*

*IMHA partner*

*"Skilled in bringing people back to the point... most of us can't concentrate for long periods and as a result he'll be able to re-focus your attention and he does it with some skill. He does it with me because I digress on the story and he'll sort of bring me back round again."*

*IMHA partner*

The importance of being a skilled communicator was considered essential by all stakeholders; though the complexity of pinning down exactly what is meant by this was acknowledged. Mental health professionals argued that the task was made complicated both by the needs of people with advocates and by the mental health service system:

*"IMHA needs to be somebody who is also aware because we work with vulnerable adults, somebody who is aware of the professional boundaries that they give as an advocate so that they don't overstep the mark and make*



*the promises that will maybe affect somebody's mental state that they say 'oh you will be discharged tomorrow' and then it doesn't happen like that."*

*Team leader (Medium secure unit)*

*"They have got to be able to tread that line between being sufficiently assertive with the service if there's something that's not right but not, not stepping over into being abrasive or approaching things in the wrong way so that even if there's, even if they've got a very good point they're presenting it in such a way that the service is going to feel under attack and isn't going to listen properly. So that's quite skilled isn't it being able to do that?"*

*Commissioner*

Some mental health professionals suggested that at times some IMHAs were not sufficiently knowledgeable about mental health conditions, which they suggested sometimes had an impact on the appropriateness of their interventions:

*"They could benefit from a better understanding of some of the mental illnesses and mental health conditions we have on the ward because sometimes that is one of the problems. Somebody will come in and they're presenting as quite delusional and... I think the advocate sometimes finds it difficult to understand if this ... what's the delusion and what's the reality and sometimes we have complaints and they don't quite understand that this is part of that person's condition... but that's only happened a few times. They're normally really, really good and do show a good understanding."*

*Nurse (Acute ward)*

The importance of IMHAs having a sound understanding of mental health problems/distress was afforded similar priority by some service users, and while most assessed them as being good at communicating with people with mental health problems (in contrast to some mental health professionals), a minority suggested IMHAs needed more specialist mental health training to increase their effectiveness:

*"I'm very medically aware of the terminology used and the doctors are aware of it. Obviously the advocate isn't. I'm not saying they need to know because I'm an aware patient where that's concerned, but she does need to know the difference between anti-psychotics and mood stabilisers and anti-depressants and some of the basic terminology. I think there are gaps in her knowledge base that should be filled..."*

*IMHA partner (Rehab unit)*

## **7.5 Caseload size and allocation**

The average caseload size of individual IMHAs in these services was around 25 cases, but this masked wide variation between different IMHA services. In some advocacy services, IMHAs were reported to have a caseload of eight while others reported a

caseload of 55. In the absence of further contextual information from the services this anomaly is difficult to interpret accurately. Caseload size did not appear to be associated with either the number of IMHAs in a service, the make-up of advocates' caseloads (i.e. % of caseload that was IMHA), or whether or not cases remained live for a fixed or open period. On average, IMHA cases were around 65% of the caseload of those IMHAs who were also generic advocates.

Commonly across the sites (62% of respondents), it was reported that IMHA cases were kept open for a relatively short period of time, i.e., one to three months. However, respondents queried what a 'typical IMHA case' is. One advocacy service kept cases open on average for four to six months, while two others in two different sites, kept cases open for an average of seven to twelve months. Nonetheless, the majority (87%) of cases were open ended as opposed to individuals receiving a fixed number of visits. In one service where the IMHA input was fixed this was set at four hours for involvement in CPA and six hours for Tribunal work. Another reported that each ward has a minimum of two visits per week but all clients were seen pre-CPA meetings for six monthly reviews.

Interviews with IMHAs and managers confirmed that normally, on receipt of a referral, managers allocate individual cases to those IMHAs who they considered had the capacity to take on new cases. At the same time they attempted to achieve "balanced caseloads" for IMHAs, in that they aimed to ensure the caseload of any one IMHA was not dominated by overly complex or difficult issues:

*"I have an overview of the cases that people are currently working on, what their caseload is like, what their split is like between the different sorts of advocacy that we provide and then I would allocate that to the most appropriate person...We don't want any of them to be too heavily leant towards one particular service, especially with the IMHA Service and this is actually another pro of them doing all the different advocacy, is that they can have the distinction but, for example, they're not spending you know five days out of five on the mental health ward because that can be quite oppressing, especially when working with people who are particularly unwell, so we like to sort of balance that out across the team."*

*IMHA Manager*

However, if there were particular specialisms within the team, such as working with individuals with hearing impairment or with cases where the advocacy is non-instructed and that advocate was available, referrals were matched as far as possible. This was obviously limited by the small pool of available IMHAs within advocacy services. One reason why a case might be reallocated was in local services where individuals may be known to the IMHAs and there would be a potential conflict of interest.

*"We've had a couple ... sometimes it's if you recognise the name you say 'oh I can't take that'...Someone else takes it and doesn't discuss it when you're around. I know I've been to one meeting and it's turned out that I've actually known them through being a relative of someone I know."*

IMHA

## 7.6 Monitoring and review

At a basic level, professionals and IMHA staff reported that health services recorded whether or not an advocate (and in rare cases, whether an IMHA) had been offered as part of Section 132 rights under the MH Act. Though recording of which service users had enlisted the support of an IMHA was practically non-existent. Monitoring requirements were part of contractual arrangements with PCTs. Advocacy services were obliged to compile at least quarterly reports, and some also provided monthly audit reports. The detail required was subject to ongoing negotiation with PCTs. Such statistical or activity data reports generally collated information on, for instance, referral sources, the number of cases, the characteristics of IMHA partners, time cases kept open, number of hours spent per case, advocacy issues dealt with, etc.

The quality of monitoring systems was variable and at least one provider did not separate its IMHA cases from generic mental health cases in reporting to the PCT. In terms of equality monitoring information there was some variability among the advocacy services; while 100% of services stated they collected information on partners' gender, ethnicity and age, fewer routinely collected information on disability (64%), religion/faith (43%) and sexuality (29%).

Some commissioners had been more specific about what information they expected to be collected and how they expected this to help development of the service:

*"The monitoring is going to show where the hot spots are and the service development and improvement plan which we need to agree within the first six months of signing the contract, what are the issues and what are we going to focus on."*

Commissioner

Different requirements from multiple commissioners when services were provided across wide geographical areas could be challenging. Even among commissioners, there was sometimes limited understanding of the level of uptake by qualifying patients, and some advocacy services reported difficulties with accessing information from the PCTs and NHS Trusts about numbers of qualifying patients, which made it hard for them to assess whether or not they were providing an appropriate level of service.

Advocacy services had their own internal mechanisms for quality control as this Manager explains:

*"I do case file audits sort of randomly, about four a month. I'll go and I'll pick out a few cases and go through the case notes but as well as that we also have like I said these one to one meetings and every so often I'll ask for the advocates to bring all of the case files so that I can have a read through of them..."*

*IMHA Manager*

A handful of IMHA partners across the sites recalled having been asked to complete feedback and/or satisfaction forms, often at the end of IMHA support, although many others could not remember ever having been asked to feedback. IMHA services confirmed that feedback forms were only completed by a minority of people. Some IMHA partners commented that they had not completed a form but they had been asked by their IMHA what they thought:

*"It's verbal feedback – 'have I been of help to you?' 'Is there anything else I could do that I haven't done?'"*

*IMHA partner*

Outcome measures of different kinds appeared to be used as a before and after tool in many cases, with IMHA services going through an outcomes monitoring form in the early and final stages of the advocacy. The primary aim was not the provision of information to commissioners, but offering a tool for self-evaluation to service users:

*"We ask people to rate themselves on 1 to 10 in certain elements of how much choice and control do you think you have, and then we do it again at the end of working with them and hopefully there's been some improvement there. It's good for them to be able to see that as well."*

*IMHA*

*"Basically what we've tried to do is to get the patients to self-assess over a certain number of criteria, we're looking at reading skills, writing skills, decision-making skills, organisational skills and understanding of technical terms and jargon, where they see themselves. And the idea is that we ask them to continue to reassess themselves on a 12 month basis against a set of, basically it's a set of multiple-choice questions, you know, how do you score yourself against this set of questions and we would hope that their score increased as some kind of indicator of greater ability to self-advocate."*

*IMHA*

Advocacy services had used monitoring information to some extent as an ongoing tool to assess the quality and appropriateness of the service. For instance, some had considered what the information told them about why some people did not use the service as much as why some people did. The information generated from the different monitoring activities was used internally, for sharing with other advocacy services through forums, and as a way of highlighting service user-led concerns

about mental health services. Some IMHA service managers were invited to regular strategic or operational meetings with senior mental health professionals, which provided an opportunity for the service to input information about collective issues raised through advocacy, and this was confirmed by one ward manager who commented:

*"If something occurs with advocacy that maybe that we've not done something as well as we can do then obviously we do get feedback on those sorts of things...if there is something significant that's gone amiss then we will get feedback."*

*Ward Manager (Acute services)*

Communication and information exchange between advocacy and mental health services also took place informally in the interactions between IMHAs and ward personnel on a day to day basis. This was not restricted to information exchange but involved problem solving or negotiating change at ward level:

*"The advocacy workers themselves will, if they've got an issue, they'll ring me up directly and say 'can we meet?' So I think we have quite a fairly good working relationship in that way, you know I'm quite receptive to any issues they've got likewise they've always been with me with anything."*

*Ward Manager (Acute services)*

IMHA services frequently compiled anonymised case studies to demonstrate the detail and process of IMHA activity and sometimes to demonstrate outcomes for individuals – *"telling a story can really bring it to life"*. This was perceived positively by commissioners. However, one commissioner made the observation that the selected cases were likely to be the ones where there had been a good outcome and they might therefore not be representative – *"so it's useful but only to a certain point."* Chapter 11 discusses further this issue of measuring the impact of IMHA.

### **Landscape of IMHA services – Key findings**

- Provision varied greatly according to - type of organisation providing IMHA; the menu of advocacy services provided; number of IMHA providers in an area; and number of IMHAs within the service.
- The interface between mental health services and advocacy was clearly more complex in some parts of the country – some related to multiple IMHA providers covering diverse populations, while others related to just one provider.
- Few advocacy services or advocates offered both IMHA and IMCA, but it was common for IMHAs to also operate as generic mental health advocates enabling a holistic and flexible approach.
- The underlying ethos of IMHA is that it upholds individuals' rights, support is person-centred, independent, free of charge, and, centrally, that its purpose is to give qualifying patients a voice.
- The IMHA workforce was predominantly female and white, which meant services were generally limited in the extent of choice they offered, although this was not raised as an issue by service users.
- The gender, ethnicity and disability of IMHAs were of far less importance to IMHA partners than the training and general personal qualities of IMHAs.
- On the whole IMHAs were considered to be highly skilled, experienced advocates, and it was the minority who felt they should be more knowledgeable about diagnostic labels and treatment.
- On average three out of four IMHAs had completed the IMHA module of the National Advocacy qualification, but in one service just a third of IMHAs were trained and in another just a quarter were.
- There were major discrepancies in IMHAs' caseloads - from eight to 55 cases, with no clear reason as to why this would be so, other than available resources.
- Commonly, IMHA cases were kept open for between one to three months, and the majority were not time limited.

## 8. PROVISION OF IMHA SUPPORT

### 8.1 Introduction

In this chapter we explore the relationship between IMHAs and their IMHA partners, reflect on the complexities of the IMHA role, the main activities IMHAs were engaged in, and examine the practice of non-instructed IMHA. We look at the extent to which IMHAs had helped their partners to exercise their rights under the MH Act, and had enabled them to participate in decisions about their care and treatment. We focus in particular on the direct experiences of IMHA partners and the mental health professionals working with them to assess their satisfactions.

### 8.2 The IMHA and partner relationship

On the whole, IMHA partners interviewed in the case study sites were positive about the relationship with their IMHA. Some mental health professionals, however, were more reserved and even cynical about the value of this relationship:

*"I may have patients who are so manipulative, you know, it's ... they try to, quite frequently, to manipulate mental health professionals and they find advocates quite easy to manipulate, probably a little bit more easy to because they don't have the background, a lot of the time."*

AMHP

This relationship was judged by IMHA partners to be effective when it was either productive (i.e. the IMHA did as asked and/or a desired outcome was achieved), or the IMHA displayed certain personable qualities. Key to this was that the partner felt the IMHA was *"on my side"*, that they understood the situation from the partner's perspective, they showed respect for the individual and their point of view, and ultimately, that the advocacy was person-centred:

*"When she spoke I just knew that she wanted the best for me... I just had to be nice to her, I couldn't be horrible and she was nice back to me and when she'd seen that I waited the second week or so, last week, she was glad for me and I was happy because she never, she never lied or nothing like that, she told the truth..."*

IMHA partner (Acute ward)

*"I found her very professional... They're very down to earth and they don't come out with all the mumbo jumbo speak, you know they talk in plain English.... I think they're quite friendly, open and friendly. It didn't appear officious because you can be put off by people who talk with all this new jargon and yeah, and people don't understand it."*

IMHA partner (PICU)



Good relationships between IMHAs and their advocacy partners were understood to take time to build. In particular, this was facilitated by continuity of advocate who was able to switch roles from IMHA to generic advocate and back again when the person's change of situation called for this, as in the following example given by one IMHA. It was argued that if the same advocate could be involved throughout there was a better quality of relationship:

*"It's a continuum, I see this person in the community, they've got an issue, I help them resolve it. The next time I see them they're an informal patient. They still see me because they're on our database as having been referred to me before so they automatically see me... Six months, a year goes by they're actually admitted on Section. I'm the IMHA who sees them because they've already been referred to me. Now that is not always going to be true of course because people leave, people retire and all the rest of it but I stand a much better chance with a local supplier of it being the same person and... I'm much more likely to get the client on my side telling me what is really bothering them and being able to do something about it than I will, having to have three or four visits to build up the right relationship."*

IMHA

Having the opportunity for building trust in the advocate over time was felt by IMHAs, IMHA partners and mental health professionals alike to be a key aspect of the quality of the relationship:

*"To be an inpatient wanting to receive IMHA service, as soon as you're an inpatient under section it's almost like time has stood still for you... your reality has shifted to another domain so that patient or that client will see the IMHA probably not as an ally but as a threat until the relationship is built up that they are an ally to assist them and to help them, but again that takes time."*

BME advocate (Focus group)

*"I think this patient's been on a section for about a year now, so M has sort of developed some sort of rapport with this particular patient, can understand that person's way of reacting to things."*

Team Leader

*"I cannot over emphasise as a user how important is trust and consistency when...especially with seeing services from outside organisations that want to help you, because by the time you've got into hospital your relationship with the world is one of distrust..."*

IMHA partner (Focus group)



### 8.3 A complex role

In order to ensure service users exercise their rights and that their voice is heard, IMHAs undertake a plurality of roles, and are involved in a wide range of activities to differing degrees in both hospital and community settings. Furthermore, as noted previously, this role is conducted within challenging legal and service contexts.

Partners often talked about what the IMHA did in terms of how they supported them particularly in meetings, emphasising the importance of having someone who was *"on my side"* at ward rounds, CPA meetings, and Tribunals. They tended to emphasise the IMHA's role in ensuring they were aware of, and were able to exercise, their rights, which included the right to legal representation. Some partners said it was the IMHA who had helped them access a solicitor and had informed them of their right to appeal through the Tribunal system.

From the service user perspective, therefore, IMHAs played an invaluable role in ensuring the service user's voice was heard in the system. Across the case study sites, IMHAs were variously described in an active role of *"godmotherly person"*, a *"lever"* or a *"hammer"* because they made something happen. Others described them more in a negotiating, smoothing role as for instance *"diplomat"* or *"bridge"* between service users and professionals, even being the *"WD40"* in the system:

*"They're kind of like bridges. The gap can sometimes exist between patients and Healthcare professionals."*

*Ward Manager (Acute ward)*

*"That's why I've described her as WD40...it's been necessary for me to have her to almost smooth over some of this disjointed problems that occur from me being shoved around."*

*IMHA partner*

For another person the IMHA provided a useful safeguard in the role of *"witness"* to the poor treatment she experienced from mental health professionals, and similarly, other partners referred to the important safeguarding role played by the IMHA:

*"It's nice to have somebody like N or one of her associates to be there as a witness to it all and see what they get up to, and put a stop to certain events that they could get up to."*

*IMHA partner (CTO)*

In fulfilling complex and diverse roles, IMHAs engaged in certain key activities that were nonetheless tailored to the individuals they worked with, and these will be discussed in detail below. First, however, we turn to the many dilemmas and tensions within the role highlighted from our data.

## 8.4 Dilemmas with IMHA role

IMHAs evidently felt that aspects of the statutory role, such as being able to speak to staff without the person being present and accessing patient notes, went against the basic ethos of advocacy even though advocates went to great lengths to ensure the full participation of the person at all times. The fact that such advocacy could take place without the person being present was, in a way, a threat to the fundamental values of advocacy and to some, was a sign of creeping professionalisation, turning advocates into yet another professional.

The IMHA role was commonly framed as empowering and safeguarding individuals' rights, as well as being essentially person-centred. However, there was tension between these dimensions and IMHAs themselves sometimes felt "*fettered*" by the role. IMHAs were somewhat divided in their assessment, some emphasising the importance of having a bounded role while others saw little difference with how they had previously practised mental health advocacy:

*"Because the role is a statutory one, it's got boundaries, we've got these aims of you know helping people to understand their rights and the legislation they're being held under which is... a big change from generic advocacy where you don't have that kind of rights emphasis quite so much. But it's supporting people through that you know and the remit is open to interpretation."*

IMHA

In particular, IMHAs' opinions differed about the extent to which an IMHA could become involved in issues that were broader concerns for the individual than his/her rights in relation to the MH Act. IMHAs may signpost to other forms of advocacy support when previously they would have continued providing that support. Further, the focus of the role meant that as soon as someone no longer qualified for IMHA services (i.e. they were no longer detained under the MH Act), often at the point of discharge, they may not have access to advocacy unless the advocacy service had a strategy for ensuring continuity of access. Many advocates found this difficult to accept and at odds with the foundational principles of advocacy, i.e. to be client-centred, and ultimately for the individual to self-advocate, which may or may not have been achieved by the time they no longer qualify for IMHA services.

In those services where the IMHA role is seen more as a function and advocates able to take on generic mental health advocacy and possibly also the IMCA role, there was arguably less of a conflict around the limitations of the role. There also was a view that access to IMHA should be widened and that this would reduce some of the role conflict experienced so far:

*"Why should we differentiate between informal and formal because somebody who is informal could quite easily actually meet the criteria for*

*being sectioned and so just the fact that they've gone in as an informal patient means they're not entitled to an IMHA and I think everybody should."*

IMHA

The legislative requirements in relation to the IMHA role however, were generally viewed as having raised the profile of mental health advocacy and, to some extent, broadened understanding of advocacy and thus had strengthened involvement in key aspects of the process of detention. For example, the role encouraged a clear expectation of advocates' involvement in key meetings whereas this was less so in the past. Particular aspects of the role were, however, debated and differing views were expressed as to whether the new elements were problematic or not.

### 8.5 Key role in providing information

Providing accessible information about aspects of compulsory treatment under the MH Act was a central role performed by IMHAs in all sites. Data from all stakeholders highlighted the importance of this role in relation to:

- Providing information about detention and rights under the MH Act such as the right to appeal and the right to legal representation.
- Explaining what Tribunals and other systems are and how they work.
- Signposting to other services including benefits and housing advice.
- Facilitating access to information, for example, on the effects of drug or other treatments when requested by patients.

Providing information lay at the heart of the IMHA role in ensuring access to rights under the MH Act, and promoting participation in care and treatment. IMHAs gave advice in terms of rights specific to the Section. For some, they were hearing about these rights for the first time from the IMHA:

*"She explained to me I could go with a ... I never knew I could go through with the tribunal, do you understand, that was like kryptonite in my ears."*

IMHA partner (Acute ward)

One partner explained how the IMHA providing information had helped her *"to play the game and get the best outcome from a dreadful situation."* Another commented that the IMHA had helped her to come to terms with the situation she was in:

*"She helped me understand why I was here and why I couldn't just walk out...she helped me understand that the things that were going on in my life I wasn't able to be out there."*

IMHA partner (Medium secure unit)

In addition to simply providing a list of available solicitors, IMHAs could use their knowledge of how individual solicitors had represented others at Tribunals to advise on which were the best.

A key aspect of what IMHAs did was to make information for service users/patients jargon free so that it became more accessible and understandable:

*"They write it down, information, what the people in the interview say and write it down on a basic language so I understand, easy language to understand..."*

*IMHA partner*

IMHAs could ask professionals for clarification if they felt the individual did not understand what was being said. They worked to ensure the person had understood the decision-making process by being involved after meetings. Interestingly, a clinician observed that while the same information might be conveyed by health services staff it was the independence of the IMHA and the nature of the relationship they had with service users that ensured they were listened to more than staff:

*"Everything will be explained to them by the staff, however, from what I've saw, sometimes these are not really registered by the patient but my patients seem to listen to what the IMHA say, even if though they are conveying the same message. In that sense though somebody who is outside the team is useful and they could also tell them additional things which we don't necessarily do."*

*Psychiatrist*

## **8.6 IMHA role at meetings**

There was firm evidence from both the interviews with IMHA partners and mental health professionals that IMHAs were regularly involved in supporting qualifying patients at various official meetings (such as CPAs, Tribunals, Hospital Managers' Hearings, ward rounds and other multi-disciplinary meetings) often helping them to prepare for these meeting, sometimes attending, and debriefing after the meetings to ensure understanding of decisions taken at the meetings. There was however, a difference in their involvement and presence at the varying types of meetings, which we now look at in turn.

### **8.6.1 Care Programme Approach (CPA) Meetings**

There was involvement of IMHAs in CPA meetings, but this was not consistently the case across all the sites. In some sites, mental health professionals and IMHA partners reported numerous examples of IMHAs supporting them in preparing for, and engaging in CPA meetings, while there seemed to have been little or no involvement by IMHAs at these meetings at other sites. IMHAs themselves tended to emphasise the importance of their presence at these meetings as providing moral support for

the person and as a key opportunity to check that the person had understood decisions about their care plan. IMHAs stated they had encouraged service users to use CPA meetings as formal opportunities to raise issues or concerns they had raised with them regarding their care and treatment or to query aspects of their compulsory order.

One of the key issues to be mentioned by IMHAs regarding CPA meetings in two sites in particular, was the lack of consideration of the IMHA in the scheduling of these meetings, and secondly the frequent late running of CPA meetings:

*"The meetings are booked without considering us, they're not booked ... you know it's not kind of 'we'll check that the IMHA can do this and if they can't we'll move it' it's 'this is the date, if the IMHA can be there fine'. Then the problem you face, if somebody's been waiting for a CPA for four weeks and you say 'well actually I can't come on that date but this is when it is', they tend to want to go ahead with it because they've been waiting such a long time and then the people ... a lot of the time they've confused, I say to them 'what happened?' 'Well I don't know'"*

IMHA

The organisation of key meetings such as CPA can be a litmus test of the health of working relationships. Failure to consider advocacy thoroughly in the planning and invitations to meetings can expose problems in staff-advocacy relations. Lack of effective communication makes the advocacy role more difficult and places strain on the relationship with care teams. Arrangements for booking CPA meetings can overlook the advocate, or key information like time of the meeting can fail to be passed on. But some advocates appear to be able to navigate this system by knowing who the best person is to contact:

*"Well I've overcome some of that because I actually directly contact the patients Consultant's Secretary."*

IMHA Manager

In one area where there were concerns that IMHAs were not being informed of CPA meeting dates in time to schedule their attendance, the support given by IMHAs was predominantly around preparation rather than attending on the day. One IMHA suggested the issue was that the responsibility for letting the IMHA know about CPA meetings rested with the patient but when the person was unwell they did not always contact the IMHA to let them know. Arrangements made with MH Act Administrators and ward staff only sometimes worked to alert them to set CPA meeting dates.

IMHAs listened to what the service user wanted to raise about their care and treatment at the CPA meeting, usually made a written record and came to an agreement with the individual about how they wanted these points to be raised.

IMHA partners highlighted the added benefits of having their IMHA at the CPA meeting:

*"Well I had a CPA coming up and... I wanted to have the support from the advocacy, I wanted to have a presence to kind of ask questions which I thought that if she asked, might have had more ... carried more weight, if you know what I mean, if she asked the questions because I've asked questions in the past and they tend to kind of answer a question with a question. So I thought if I had the advocacy present maybe I'd get a straight answer, and she asked the questions and she done a good job and we got answers to certain questions, and it went well because not too long after that I got my leave, so I think it went well really."*

*IMHA partner (Medium secure unit)*

### 8.6.2 Mental Health Review Tribunals

Views were mixed about whether IMHAs had a role at Tribunals, and what that role should be, and, indeed, whether or not they should be present at these meetings. Some IMHAs referred to the additional guidance in relation to Tribunals issued during 2011 (Ministry of Justice, 2011). There were stark differences between sites in terms of the frequency with which IMHAs reported being involved in Tribunal meetings, which was confirmed by the mental health professionals in these sites. From professionals' comments regarding their awareness of IMHAs at Tribunals, it seemed that attendance not only differed between sites but also within the same site. Mental health professionals from some hospitals reported never having witnessed IMHAs at Tribunals with some even going so far as to say that *"they don't have a role at Tribunals"*, while others remarked positively on the support role IMHAs played at Tribunals. A consultant psychiatrist in one of the sites asserted that he would *"like the advocate to be there as the rule rather than the exception"*. However, this was not a consistent viewpoint held across the sites.

Some IMHAs attended more Tribunals than Managers' Hearings, while for others, attending Tribunals was rare, if at all. IMHAs who did attend Tribunals reported mixed experiences, highlighting uncertainty about their role:

*"In my experience, not all Tribunal Panels understand the IMHA role. So I've had varying experiences of... I've been to one Tribunal who have acknowledged my attendance, have asked me after the meeting if I've had anything to add. I've had the complete opposite experience, where the Tribunal Panel just thought I was there as a support for the person, didn't acknowledge me, didn't ask me if I wanted to say anything. When I put my hand up to speak to the Tribunal Panel it was dismissed."*

*IMHA*

An IMHA from another site confirmed this type of experience:

*"It depends very much on the Tribunal or the Chair and who's managing the Tribunal. Some are more kind of engaging and some of them you know, 'what are you doing here?' really."*

IMHA

This uncertainty was echoed in the reflections of the IMHA role by some partners who were unconvinced of the value of IMHAs at Tribunals, especially when compared to the solicitor's role:

*"I don't think there's much point an advocate attending my Tribunal because they [Panel] just, they only really listen to the lawyers really."*

IMHA partner

*"They do have a certain role to play in a Tribunal but you know at the end of the day everything is up to the judge and the doctors. "*

IMHA partner (Acute ward)

At Mental Health Review Tribunals, the IMHA role was most often described as an important *"support"* role, during what some mental health professionals and IMHA partners described as an *"intimidating"* and *"awe inspiring"* situation. Confirming this view, IMHAs stated that their role at Tribunals was to *"sit and support"* and not to be actively involved in the proceedings. This was clearly frustrating for some IMHAs who found it difficult when witnessing less than effective legal representation. A ward manager of a PICU highlighted the *"quality support"* provided by IMHAs throughout the whole process, and, indeed IMHAs in several sites reported being involved prior, during and after Tribunals, and how this ensured they were aware of the proposed care plan. As one IMHA partner explained:

*"She kept saying to me 'ssh don't butt in, it's not your turn yet, sshh you're okay' and she was you know there for me asking if I was alright and I kept saying 'yeah, yeah'...and you know she was very supportive to me and I'm just glad I had someone friendly there to help me on that day...She was like backing me up all the way. She was my like crutch and the solicitor was like a crutch so I had two crutches on both sides."*

IMHA partner (Acute ward)

The role of the IMHA in ensuring the service user voice is heard by the Panel was not to be underestimated, whether or not they were present at the Tribunal Hearing. When mental health professionals and partners referred to their experience of IMHAs at Tribunals it was overwhelmingly in positive terms. Prior to the Tribunal, these advocates spent time supporting individuals to prepare what they wanted to say. In some cases, the IMHA articulated what the individual wanted the Tribunal to hear:

*"We had a young Chinese boy who had a bit of a language difficulty and some learning disability and he'd written everything down on paper that he*



*wanted to say and the Advocate actually read that out for him, which I thought was really good, a really good idea because people can gather their thoughts maybe a week or so beforehand, put it down on paper because they could find going into a room with a number of people there quite intimidating..."*

*MH Act Administrator*

An AMHP described how he consulted with IMHAs in conjunction with service users when compiling his professional reports for Tribunals. IMHAs had provided service users with information about how to apply to a Tribunal as well as helping to demystify the process – explaining how the Tribunal works, how the panel is made up and what happens at the meetings. Importantly, IMHAs explained that the key purpose of the Tribunal was for staff to explain and justify the need for detention, thus increasing accountability.

### **8.6.3 Managers' Meetings/Hearings**

IMHAs were reported as less likely to support patients at Managers Hearings than at ward rounds and CPA meetings, but were more likely to be involved in these meetings than Tribunals as solicitors were often not present. The IMHA role at these meetings varied according to whether or not the individual had legal representation, and according to the panel's understanding of the IMHA's role:

*"I helped the person write down what they wanted to raise in it and put across their point of view and when the solicitor is there, the solicitor does all that obviously but when I'm involved and there's no solicitor I'll put across that to the panel and if it's suitable, if the client wants, which they don't always with Managers appeals, I'll make some notes as well just so that they know what's happening following ... and it does depend on the panel if they're happy with that."*

*IMHA*

A MH Act Administrator perceived the IMHA role at Managers' Hearings to be vital especially in light of the financial disincentive for solicitors to attend such meetings:

*"When we have a Hospital Managers meeting they have a checklist and part of the checklist is to ask if an advocate is actually attending, so they do look for that more and more now because a lot of our people are quite vulnerable and with solicitors they may support somebody with a Tribunal because they're going to get some money out of it, whereas a hospital managers meeting they probably wouldn't support them, so the advocate this is the only person, if they haven't got any relatives or friends, who can support them through that particular process."*

*MH Act Administrator*



At one site, Hospital Managers' Meetings were reported to be run to a "high order": Hospital Managers received training and it was recognised that solicitors had an important role at these meetings. Elsewhere, however, IMHAs were more likely to be operating by default in a quasi-legal role, which was not always viewed as a positive development:

*"... IMHA's are now coming through on a route which I don't believe they were ever designed for to becoming representatives in situations that was never envisaged....The thrust of what an IMHA is doing, from what I'm told, is really helping to support that patient to express their views rather than challenging ( which is the whole point of a Managers meeting) the detention criteria, because it's cross examining the doctor, challenging their views, accepting that there may be a mental disorder and the need for treatment but why do you have to be detained in hospital for it is the crucial point in most arguments about detention. That is not something that in my experience, IMHA's are focused on, it is what Mental Health Solicitors are focused on."*

*Solicitor*

There was an indication from other professionals however, that when IMHAs adopted a more representational role in lieu of solicitors that this was not entirely welcomed:

*"We had a Manager's Meeting where an advocate made a comment about a patient's mental state and quite rightly the Chair of the hearing said that shouldn't really be happening because I think also sometimes the patients get confused as to what's happening, and if you've got somebody saying one thing and somebody saying another, quite rightly patients are unwell and it leads to confusion, it leads to deterioration."*

*Psychiatrist*

It was unclear from the data whether the irregular presence of IMHAs at Managers' Hearings in general was because service users did not want IMHAs there or because staff encouraged them to request the solicitor be present as they perceived this as more appropriate. In some sites, only when the solicitor was not present were IMHAs encouraged to attend.

#### **8.6.4 Ward rounds/MDT meetings**

Although this did not apply to all IMHAs, some reported being more likely to be asked to support their partner at ward rounds and multi-disciplinary team (MDT) meetings than at either Tribunals or Manager's Hearings. At ward rounds and other MDT meetings they played an important role ensuring that the service user's views were aired. Mental health professionals recognised that it was not easy for service users to put their point across to a room full of professionals and that having "someone on your side" was valuable and empowering. Similarly IMHAs suggested

that such meetings can be daunting and intimidating for anyone, including staff. This viewpoint was supported by IMHA partners' experience:

*"I asked him if he'd come into the ward round with me, which he did, and just him being there in that ward round was enough to give me the confidence to give over what I wanted to say you know, it was just him being there."*

*IMHA partner (Acute ward)*

*"I can't manage on my own at the meetings; he can say 'hang on a minute'..."*

*IMHA partner (Forensic learning disability)*

As with other types of meetings, IMHAs spent time before the meetings clarifying what issues and concerns service users had, played a part in the meetings by supporting the person to voice their concerns or delivering a pre-prepared statement on their behalf, and de-briefing after the meeting. IMHAs in some sites though did report problems regarding the scheduling of these meetings similar to their experience with CPA meetings, in some cases not receiving sufficient notice to attend.

The role IMHAs took in relation to these meetings was about ensuring the agenda was grounded in the concerns of the service user and ensuring their voice was heard:

*"I'd see her maybe 20 minutes, half an hour before the ward round, before I was due to see the doctor and sit with me and find out how I am, what's been happening with me and what my issues were, what problems I may have encountered."*

*IMHA partner (Acute ward)*

*"I said to them you know, I mean I don't want you to do everything for me, I want to go into the review and this is me and I want to start speaking but I realise, you know that I might probably have a problem with me stuttering you know or I might suddenly you know choke up or clam up or whatever and forget something, so you know we have the list of questions, and they made sure that we covered all the points and came in as and when."*

*IMHA partner (PICU)*

IMHAs reported positive experiences and encouragement from the clinical team for them to attend these meetings, and mental health professionals, including consultant psychiatrists from some sites, confirmed that they encouraged advocates to attend their ward rounds. As a consultant psychiatrist from one site commented:

*"They are good bridge so and especially in some of the cases ... where we need you know that somebody had talked with the patient and expressed the views, they find advocacy to be very helpful and very useful. Where we*

*find a patient is not able to, or is not going to, or is reluctant to, or is shy to express their views in the team meeting, or where he is or she is going to find it difficult to ask for certain things, or as I said you know where the patient has been explained something to be a reinforcement, so there is a good role of advocate."*

*Psychiatrist*

Service users in particular emphasised the benefits of IMHA involvement in ward rounds, reviews and MDT meetings:

*"I mean there was two in this morning going in with somebody who on their own would be very, very frightened, they wouldn't be very good at advocating their own interests do you know what I mean, so they do a really, really good job you know..."*

*IMHA partner (Acute ward)*

One way in which the role of the IMHA was contrasted with the role of a general advocate was in the statutory role enabling an IMHA to remain in the room at meetings with professionals should the service user/patient decide to leave:

*"When you're supporting a person in an advocacy role at a meeting, if that person becomes overwhelmed, upset, angry, demonstrates hostile behaviour in the meeting and they decide to leave the meeting, as an advocate I have to leave the meeting with them, because I am there supporting that patient...As an IMHA, because it's a statutory right for the patients, if that exact same scenario happens, and I've very often got the consent of the patient, sometimes I will say to them if anything happens and you don't feel as though you want to stay until the end of the meeting and if you choose to leave, one of your options is for me to stay in the meeting to gain the outcomes to enable me to feed them back to you after the meeting, and I would say 100% have always said yes."*

*IMHA*

## **8.7 Accessing patient records**

Plainly, there was some uncertainty, even initial resistance, from mental health professionals around the right of IMHAs to access patient records. Across the sites, knowledge of this right among mental health professionals was variable. As one IMHA commented, professionals questioned this right in light of their experience of the past advocacy role – *"when we started asking it was like 'but you didn't before'"*. A ward manager expressed concerns around confidentiality – *"obviously records are very closely sort of guarded situations"*, finding it hard to envisage a time when this right should be exercised.

A psychiatrist in one site referred to a service user who wanted an IMHA but did not want them to access his/her records because there were things he/she did not want the advocate to know. While some IMHA partners from this same site did not have an issue with IMHAs accessing their notes, there were those who confirmed that this would be detrimental to the relationship:

*"There's a lot of my psychiatric history there that I wish to remain private and I don't necessarily want it going to somebody who's not involved in my permanent care package. And, because if she would have access to my notes I'm very, I would probably not have given permission. I'd ask whether, can you not access my notes; I would have put a barrier up and disengaged from the service. Because I don't particularly want her to know about my past and my reasons."*

*IMHA partner (Rehab ward)*

In general, it was rare for IMHAs to request access to patient records. In many IMHAs experience it had happened *"only once"*, or never at all. As one IMHA reflected, *"I've never needed to look at anybody's notes"*. This was a common response across all sites. Professionals' comments also confirmed this experience: an AMHP in a community team stated, *"They've never needed to"*. It was invariably the case that professionals in most sites were unaware of the right of IMHAs to access patient records. Given this was only an occasional occurrence; it tended to be considered a non-issue by many research participants. As an AMHP in another site reflected, it was not the norm and professionals' fears about being inundated with requests to see patients' notes had far from materialised with implementation of IMHA.

Accessing the notes posed a dilemma for some advocates:

*"I've avoided that, looking at the records because of the clause that we can't share everything. If there is something we can't share with the service user... and as a passionate advocate I suppose I wouldn't ever want to be in that position where I know something about the service user that I couldn't share with them and that is I think where ... and common from the IMHA forum that people have ... as IMHA's we've avoided using that right because of that but I'm trying to think of I suppose creative ways that I can use it to benefit the service user instead of being scared of it."*

*IMHA*

Any access to notes/records was implemented on a controlled basis. Professionals expressed concerns about third party information, which they would not release to service users and therefore to IMHAs either. Where this right had been exercised, the process was suggested to have been *"drawn out"* in some areas while in others, clear protocols between the NHS Trusts and advocacy services existed including controlled access to NHS databases, which facilitated ease of access:

*"If we do need access to it, it depends on which ward it is, sometimes if it's paper records and they've got them there, they're happy for us to see the bits that we want if they've got them there, if not then we'll just get in touch with the Mental Health Act Administrator and they'll get it sorted for us..."*

*Generally if we do want access to someone's records then we will try and do with them there..."*

IMHA

In other areas, there was uncertainty among some professionals about how the process for IMHAs accessing service users records would work, and whether this was the same process as for solicitors.

Mental health professionals especially those managing wards queried what information IMHAs should be able to access, which tended to arise from lack of awareness that this was indeed a right. Where the right had been exercised, it had been a valuable check of whether and how opinions had been recorded, and what follow on actions had been formalised, for example:

*"What I was aiming to do, and well he said to me 'I've filled in the form asking them to find me a solicitor'. So I said 'is it okay with you if I ask the staff that allows me to see that?' And he said, 'yeah of course it is'. So I then went to the member of staff, saw the record, I saw it for myself, nobody had done anything about it. Shocking. Because that's a person's life."*

IMHA

## 8.8 Advance Directives

As IMHA services provide a safeguard and their purpose is to enable participation in decision-making, we were interested in ways in which self-determination may have been promoted and the relationship of this with IMHA services. We therefore asked qualifying patients whether they had used an Advance Directive or Advance Statement. Nearly all of the service user participants had not, nor did they understand what one was, with several expressing interest when it was explained and asking for further information. Only one of the IMHAs interviewed had had any involvement in supporting Advance Directives:

*"[The person said] I have an Advanced Directive' and I'm like 'great okay then', and I said you know 'do you know who's got copies?' and they reeled off a long list so actually the team should have had a copy of that Advanced Directive for admission and yeah we managed to action that because you know they'd stated very, very clearly why they didn't want this and they didn't want that and they didn't want the other because of side effects which is actually been supported by a Clinician at the time, so that was a very positive outcome."*

IMHA

However, this IMHA also pointed to the potential for mental health services to override an advance directive, if it was judged not to be in the person's best interests.

### 8.9 Non-instructed advocacy

IMHA can be either instructed or non-instructed advocacy. Non-instructed advocacy was needed when individuals under the MH Act lacked capacity, or did not recognise the potential benefits of advocacy. The preference of advocates was clearly for instructed IMHA, and in pursuit of this we were given numerous examples of IMHAs establishing communication with the individual before adopting a non-instructed position. IMHAs were keen to establish capacity, and to ensure that involving an advocate was what the person wanted:

*"We always, even when working with people on a non-instructed basis, we will always still try and gain their views and wishes if we can, so the first thing that we would do is still approach them and try and communicate with them and try and sort of open up that communication, if we can't then obviously we'd need to take a step back, but we always do that prior to anything else because we want to keep that person at the centre of the decision."*

IMHA

The focus group discussions indicated that advocates viewed non-instructed advocacy as potentially problematic and as a fundamental shift in role for mental health advocates. This was confirmed by the case study interviews with IMHAs.

Non-instructed advocacy appeared to many to go against the central ethos of advocacy being not just person-centred but also person-driven; values that were at the heart of how IMHA providers defined their services (see previous chapter). As one IMHA engaged in non-instructed advocacy remarked *"it does feel quite unnatural at first"*, contrasting this with generic advocacy when the advocate would not be asking questions of staff or family if the person had not asked them to. In one site, the IMHA reported categorically never using non-instructed IMHA. Several IMHAs in other sites reported only using non-instructed IMHA as a last resort, if at all - *"I've not needed to use it"* or that there were *"very few cases of non-instructed"*. This was almost always followed by a description of the work they had undertaken to establish the person's viewpoint because they had been unwilling to accept the professional's assessment of non-capacity without question:

*"You don't want it to be that the professionals have made that decision that that person should have an advocate without including that person as far as possible in the discussion."*

IMHA

In another site, the IMHA described the practice of “watchful waiting”, i.e. waiting to see how the situation unfolded, if he was undecided about an individual’s capacity to instruct him as an advocate.

Where non-capacity was subsequently established, some IMHAs had referred on to the IMCA service, which was particularly so in those organisations with different types of advocate including IMHA and IMCA. In other cases, IMHAs did carry out non-instructed IMHA, sometimes in conjunction with an IMCA, at other times separately. Some of those who felt most comfortable with this form of advocacy had received specialist training, and some of these acted in an IMCA capacity as well as IMHA – *“the advocates we use for our non-instructed are also IMCA trained”*.

The complexity of undertaking advocacy in a non-instructed capacity was described by an IMHA who contrasted what non-instructed meant with two individuals he/she worked with:

*“I’ve got two cases where they’re non-instructed, in some ways they’ve not obviously given me consent. One is completely non instructive because I can only get a yes or a no out of him. The other, actually he ... what I do with him it’s around where he’s going to live when he’s discharged and I’ve just asked him the same questions and he always gives me the same answers, he’s not yes or no, I can have a conversation with him, he wants to go to be near his mum and he wants to live in a certain area where he used to live and I just... again I’ve known him quite a long time and so you know I would ask the questions that the team are sort of ... I would go to the CPAs and ask him the questions and if it’s consistent then I would take that as that’s what his opinion is, whereas the other gentleman, he just doesn’t speak to me at all...”*

IMHA

One IMHA made the point that those who were referred for non-instructed IMHA were likely to be the most vulnerable, and therefore most in need of an advocate:

*“Historically a lot of advocacy organisations wouldn’t actually do it, but in [name of organisation] there’s always been the ethos that they’re the people that probably needed it the most and therefore we always have.”*

IMHA

The advantages of being able to access non-instructed IMHA were highlighted by different mental health professionals. For instance, at one site, an AMHP described a situation where it had been vital to the team to ensure that the service user’s viewpoint was represented when a decision was needed about ECT treatment. At the same site, a unit manager of a rehab unit had found it helpful to speak to IMHAs about non-instructed advocacy for a person who the clinical team felt should appeal his Section and have his voice heard in the decision making processes. In this



instance, the individual was not lacking in capacity and despite several visits, an IMHA service was eventually declined. More often than not, the issues facing an individual for whom non-instructed IMHA was suggested concerned a proposed change of accommodation for instance on leaving hospital, or key decisions around treatment as in the example above.

Professionals indicated that there could be conflict with carers/family members especially, but not solely, when an IMHA was working in a non-instructed capacity. As a professional in a community setting commented:

*"If the person hasn't got the capacity to make that decision, they're working alongside them on their behalf and I think family members sometimes do struggle with that because they don't know the processes or the reason behind what you're doing."*

AMHP

In order for the IMHA to represent the individual's wishes (as much as they are known) and ensure that his or her rights are respected, IMHAs made repeated visits to them and those involved in their care. This was confirmed by mental health professionals, who said if a service user was not engaging with the IMHA they came back repeatedly to try to establish communication. In respect of someone with advanced dementia, ward staff had been especially concerned that he had a voice through advocacy:

*"We're now going down the guardianship order for this gentleman, he's going to be placed in a nursing home and he'll be put on a DOLS so there's a lot of restrictions. I mean we've been through the appeals and everything, they've kept him on the Section 3 but still you know even though he's difficult to engage with he still needs a voice, we thought it was only right that the advocate be involved. Well she's been back, I think it's the fifth time she's been back and he still won't engage."*

Ward Manager (Older people's ward)

In some sites, IMHAs using non-instructed advocacy followed a policy or procedure, which they outlined, comprising several stages that typically included:

- Establishing whether or not the person lacks capacity or is able to communicate their wishes in some way.
- Speaking with ward or community based staff to find out about what the person communicates on a day-to-day basis and to establish any preferences.
- Looking at case notes relating to the particular issue and at what has happened during their stay in hospital for instance, and if any preferences expressed in any way.
- Observation of the person in their surroundings.



- Speaking to family and/or friends to gain a picture of the person's life, how they came to be detained, what their previous living situation was like, how suitable etc.
- Feeding the results of all information gathering into decision making meetings such as CPA meeting.

IMHAs were also keen to ensure that despite being non-instructed, they were not acting in a 'best interest' way. As one IMHA explained:

*"Obviously the other challenge is to be very careful and clear and particularly with myself that I'm not putting in my own point of view you know, so where I've done that I usually ... always run that by my Line Manager what I'm doing at every stage to make sure that he can be challenged."*

IMHA

An IMHA from another site explained this approach as adopting a "watching brief", finding out what information was available to establish what the person's wishes and feelings would have been if they could express them to ensure that these are taken into account in the decision making process.

### 8.10 Relationship with Safeguarding

Advocacy has been identified as a potential mechanism to prevent abuse and safeguard the welfare of vulnerable people, through enabling people at risk to express themselves in potentially abusive, or actually abusive situations (Faulkner & Sweeney, 2011). In the context of IMHA provision, this may be particularly relevant for qualifying patients lacking capacity or on guardianship orders in residential care but may also be relevant to people detained in hospital or on CTOs. In order to explore this, we approached two professionals with the lead responsibility for safeguarding within two mental health provider organisations. One declined to be interviewed because, although he had heard of IMHA, he did not have any real experience of it. The other person was interviewed and recognised the potential contribution of IMHA to the Safeguarding process:

*"Providing some support to service users who are going through that [the safeguarding] process can be extremely helpful and if somebody hasn't got a relative or a friend or a partner to do that, you know advocacy can be really, really important and really helpful."*

Safeguarding Lead

Although we have limited data on this relationship, we gathered the impression that IMHA and Safeguarding can exist in parallel worlds. This lack of connection between the two was confirmed by the Safeguarding Lead that we interviewed, but explained in terms of the different type of issues that Safeguarding teams get involved with:

*"The cases that we do deal with we wouldn't necessarily know whether it was someone detained under the Mental Health Act. It might actually be a very key piece of information, but most of the time if we're looking at abuse and neglect, we're probably looking at issues when someone goes home, so if it's an elderly person, about, you know ensuring that issues about their financial abuse, with their families, it's very rare that we get issues about inpatients."*

*Safeguarding Lead*

The role of IMHAs in relation to the Safeguarding process clearly needs further investigation and guidance.

### **Provision of IMHA – Key Findings**

- IMHAs undertake a plurality of roles, which are complex and conducted within challenging legal and service contexts.
- The IMHA role was commonly framed as empowering and safeguarding individuals' rights, as well as being essentially person-centred. However, there was tension between these dimensions.
- Some IMHAs felt the boundaries of the role can get in the way of acting holistically.
- IMHA had raised the profile of mental health advocacy and, to some extent, broadened understanding and had thus strengthened advocates' involvement in key aspects of the process of detention.
- IMHA partners perceived IMHAs as "godmotherly", "a hammer", "a lever"; and in a negotiating role as "a diplomat", "a bridge" and as "WD40" in the system.
- Key aspects of the IMHA role were: providing information; supporting service users at Tribunals, CPA, managers' hearings and ward rounds; and accessing patients' notes/records.
- The right to access patient notes/records had rarely been exercised at any site.
- Very few service users had an Advance Directive and none of the IMHAs interviewed affirmed any involvement in supporting service users with drawing one up.
- Non-instructed IMHA was fairly uncommon, and several IMHAs felt uncomfortable acting in a non-instructed way. They would do all they could to establish the person's wishes and preferences, and to ensure that non-instructed advocacy did not become 'best interest' work.

IMHA and Safeguarding appear to exist in parallel worlds and the role of IMHAs in relation to Safeguarding procedures needs further investigation and guidance.

## 9. IMHA SERVICES AND THE DIVERSITY OF QUALIFYING PATIENTS

### 9.1 Introduction

As previously discussed, the ethos underpinning IMHA services includes the notion of being person-centred. In this context this means being sensitive and able to respond to the diverse range of qualifying patients, who come from a variety of backgrounds and have a range of different needs. The capacity of IMHA services to provide accessible and appropriate services to the diverse range of qualifying patients relies on effective commissioning, based on adequate intelligence about the local population, and the differing needs in relation to IMHA services. As we discuss in Chapter 12, there was little evidence in our case study sites that this had been undertaken. In this Chapter, we build on the previous findings in relation to access and provision (See Chapters 5 and 8 in particular) to consider the issues relating to provision for specific groups in respect of access to, appropriateness and acceptability of IMHA provision. This raises questions about the design of IMHA services and the involvement of diverse service users so that the services live up to the aspiration of being person-centred.

### 9.2 Provision for children and young people

Children and young people detained under the MH Act 1983 are eligible for IMHA services, irrespective of age. They also qualify as a voluntary patient if their clinician is considering giving them Electro Convulsive Therapy (ECT). The majority of young people under the age of 18 who qualify will be in specialist units, typically forensic units, with the majority aged between 15 and 18. Whilst the numbers may be relatively small compared with adults, Young Minds reported that young people under the age of 18 spent a total of 84,501 days on mental health wards in the first half of 2009-2010 (Young Minds, 2010). Children and young people with mental health issues are vulnerable; they risk not receiving appropriate care and prior to amendments of the in the MH Act 2007, may have been placed in unsafe settings where they might experience physical or sexual abuse (Children's Commissioner for England, 2007). Further, they may face instability and upheaval associated with having been in care (Chase, 2008) or being placed in a specialist unit some distance away from their family. Access to independent advocacy has been identified as a safeguard for children and young people with mental health problems (11 Million & Young Minds, 2008).

Overall, we found that the proportion of children and young people accessing IMHA services was relatively low and the variation reflected differences in commissioning and whether specific provision had been developed. In three sites (A,F and H), children and young people had a dedicated IMHA service and in two instances, this was provided separately from the service for adults of working age while in one this was provided by the same service. In one of these sites (H), the national children's

service commissioned to provide IMHA reported no uptake. In three other sites with no specialist service, but who had been commissioned to provide IMHA services to children and young people, there had been almost no uptake in the previous year.

This points to the importance of IMHA services developing specific provision for children and young people. The majority of children and young people we spoke to had experience of the IMHA service. However, there are a number of barriers that children and young people may face in accessing IMHA services. From a scoping exercise to map general advocacy provision for children and young people in England, Brady (2011) identifies a number of barriers that children and young people can face in accessing advocacy services. Those that are particularly relevant to accessing IMHA provision are:

- ✎ Lack of knowledge about advocacy.
- ✎ Physical barriers, such as staffing levels and the type of telephone used by the service provider.
- ✎ Communication barriers, particularly for younger children.
- ✎ Language barriers for children and young people who speak limited English.
- ✎ Confidentiality barriers and the dilemma between safeguarding rights and protecting children.
- ✎ Emotional barriers, reflecting young people's lack of confidence in themselves.

The power differential that exists in relation to age may also serve as a barrier in settings where all staff will be adults. Thus, the profile and visibility (in order to build up familiarity and trust in the advocacy service) will go some way to addressing these issues. Indeed, one 18 year old young man that we interviewed who had not used the services, clearly understood the concept of advocacy, was pleased it was available, knew how to access it and thought he would use it if the need arose. The appearance of the IMHA and representation of youth culture can be appealing to young people. One service had gone out of its way to develop a different style of advocacy for children and young people, including specially designed leaflets and a resource pack to promote self-advocacy. This sort of approach is to be commended.

The issues that IMHA services supported children and young people with were broadly similar to other groups and getting off a Section was a major theme. The importance of having a voice in the process was expressed by this 16 year old young woman who had been detained under the MH Act in different units since the age of 14:

*"Like if people don't ask me questions I just sit there till the person asks me a question but after when they ask me I answer to them but like with my*

*Social Worker there speaking up for me, the IMHA came in that day and she was speaking up for me and that but it was quite cool."*

*IMHA partner (CAMHS unit)*

Maintaining the involvement of advocacy as young people move from CAMHS services into adult services will be important and measures will need to be in place to ensure that this happens smoothly. As young people may be in care and moving into specific accommodation on discharge, the interface and relationship with other advocacy provision for young people, particularly for care leavers, will be important.

### **9.3 Provision for older adults**

Older adults detained under the MH Act may be particularly vulnerable and, as a high proportion may have an organic disease, lack the capacity to instruct an advocate. Further, there may be particular issues in relation to safeguarding as older people can be vulnerable to abuse and exploitation.

The use of IMHA services for older people varied across sites and was identified as a major gap during the focus groups, and confirmed by the case study interviews and questionnaire returns. This gap was attributed to the development of IMHA services from generic mental health advocacy services. This has shaped their development in two ways. First, prior to the introduction of IMHAs, advocacy services were typically funded to support adults of working age. Second, the services provided instructed advocacy and may be less familiar or comfortable with non-instructed advocacy. Thus, some older adults qualifying for IMHA services without the capacity to instruct an IMHA may therefore miss out:

*"I think that's a historical thing that up until the IMHA Service came in we weren't able to work with those people, we weren't funded to work with those people because we had to work with people that could instruct us and tell us what they want and quite often the older adults who were detained especially aren't able to do that, so that's been again quite a struggle and they do refer, they tend to refer the quite complex cases and perhaps people that don't have friends or family who can support them but I'm well aware that there are people there that aren't being referred to us, especially for the Older Adults Units."*

*Advocacy Manager*

Only one IMHA provider in one case study site had developed its provision for older people with dementia. In addition, one of the services that we shadowed had also developed its provision and regularly visited wards for older people with dementia. Nursing staff on wards for older people were interviewed in three of the case study sites and were familiar with both IMHA and IMCA services. These staff had responsibilities for older people with a broad range of mental health issues, including dementia, and so were more familiar with non-instructed advocacy. Overall, the

uptake of IMHA services on these wards was reported as relatively low, which was in part attributed to close involvement of family members and a reluctance by the older people to seek external help. However, as IMHAs may not be regular visitors to such wards or reluctant to use non-instructed advocacy, older people may be disadvantaged. As one IMHA partner pointed out, many of the other people on the ward that she was on would not have been in a position to initiate referral to the services:

*"A lot of the patients here are very, very poorly you know they wouldn't be able to know what was going on even if they knew about the Advocacy, they're so poorly."*

*IMHA partner (Ward for older people with dementia)*

These findings indicate that either staff need to routinely refer all qualifying patients and/or IMHA services need to visit older people's wards and be ready to provide non-instructed advocacy. Engaging with families and carers, as in other contexts, could increase the uptake of IMHA services.

#### **9.4 Provision for people from BME communities**

People from BME communities may experience specific forms of disadvantage, including racism, in relation to the mental health system. People from African and Caribbean communities are two to six times more likely to occupy a bed in hospital and have higher rates of detention under the MH Act (CQC, 2011), more likely to be readmitted within a year of their first involuntary admission (Priebe, Katsakou, Amos et al, 2009), more likely to be placed in seclusion, with people from Caribbean communities also more likely to stay in hospital longer (CQC, 2011a). Furthermore, the emergent findings from the AESOP study confirm a picture of poor outcomes and negative experiences of people from Black Caribbean and Black African communities (Morgan, 2012). The higher occupancy rates for certain BME groups are reflected in the disproportionately high numbers on CTOs (CQC, 2011a; NHS Information Centre, 2011c).

All this points to the need to tailor IMHA provision for specific communities in order to address these issues and advocacy has been highlighted as a mechanism to potentially change this experience. Several reports have pointed to an urgent need for advocacy for BME communities, particularly for people from African and Caribbean communities, reflecting concerns about over-representation in inpatient wards, overuse of medication and low use of psychological therapies and inquiries into the deaths of African and Caribbean men in mental health services (Keating, Robertson, McCulloch et al., 2002; Department of Health, 2005; Centre for Social Justice, 2011).

Our data on uptake by BME individuals indicates considerable variation, although not all sites provided this information. As noted earlier, even in the sites where access for



BME communities was consistent with demographic data, the local perception was of significant unmet need. When the issue of access for patients from BME communities was raised with IMHA services in our study, the majority said that anyone could access their services and that ethnicity was not an issue:

*"I don't think we've ever had an issue or a challenge in terms of that, I think really because ... you know we recruit Advocates with the values of sensitivity and most of the people we have worked with, well pretty much all of them, are able to understand those principles and understand that our Advocates will work with anybody to the best of their abilities and then if there are any issues we, like I said, we would use other services and we have links with sort of other services as well in the community so the Chinese Society is one so we're able to kind of access those as well and get support from them if necessary, so there are ways round it."*

IMHA Manager

This IMHA manager worked in an area where the BME population was relatively low, and in reality there were few BME organisations locally to work with to provide the sort of partnership working he described. The value placed by mainstream IMHA services on their own capacity to respond appropriately by framing the issue in terms of language differences was evident in the responses from other organisations. This is illustrated by services, with a staffing profile of predominantly White workers, in an area with a large South Asian population:

*"We don't come across people who can't speak English that often but it does happen. We do have people who maybe speak a different language but we'll try... if we don't have someone who speaks it in the office, we'll try and get the translator in, maybe even any method possible, whether it's a ward member, ideally someone independent and just try and work around it."*

IMHA

We also interviewed a number of advocates, including IMHAs from BME communities, either working in mainstream advocacy organisations or as in two instances, a BME service. One Asian advocate working in a mainstream advocacy organisation, but not as an IMHA, described the very poor access to IMHA services for the local Asian communities. He felt that this reflected the absence of culturally sensitive provision coupled with negative experiences of mental health services acting as barriers to access.

Overall, we found a relatively limited awareness across the mainstream IMHA providers and commissioners as to the specific needs of local BME communities and few efforts appeared to have been made to establish these. For example, we did not find any evidence that data from the Count Me In census cited above (CQC, 2011a),



had been considered, or that consultation with specific community groups had taken place.

The specific needs of people from BME communities in relation to IMHA services was most often construed by IMHA providers in terms of language issues, with access to interpreters being critical, as reported in 5.3.1. This is clearly important and if they were not readily available other patients may be expected to interpret, as described by this young woman of South Asian heritage:

*"There's one woman I'm having to translate for them, they don't even have an interpreter here. It's just, I don't know... I don't know what I'm doing here because I'm helping people more than I'm helping myself here..."*

*IMHA partner (Acute ward)*

Advocates from a BME background, not necessarily employed as IMHAs, might also be asked to interpret but sometimes felt that this was not appropriate, and were concerned that they would end up providing a service to BME clients by default rather than design. However, the issues to do with access and appropriate provision are more profound than language and the BME advocacy providers, some of which were providing IMHA services and some which were not, gave a more nuanced account of the needs and response to qualifying patients from BME communities. They described how an understanding of the history of marginalisation of people from BME communities and their experience of mainstream British society and of mental health services could influence their understanding and decision whether or not to use IMHA services, and how a shared understanding can help:

*"I'm not saying, I'm Black so I understand what you're facing and my colleague doesn't because she's not Black, that's not the way, but I think the other part of it is historically the understanding of what has been, what has happened and the reason for this place to be set up and how people have been treated in the past, how it affects people, how medication can be over-used, the side effects of that to people, how it's disabling in certain things."*

*BME Advocate*

This advocate refers to how the advocacy organisation that he worked for had been established as a grass roots organisation in response to the BME communities' concerns about people's negative experiences of mental health services and the lack of appropriate provision for people from BME communities.

An individual's assessment of an organisation or the capacity of either the IMHA or a mental health professional to understand these issues, can play a role in determining whether an approach may be made. In this instance, this woman was asked whether she would ask her keyworker to help her access the IMHA service:

*"I don't trust... I don't trust her enough for that. No, I don't... I've known my key worker for nearly twenty years, I don't trust her enough for that. I would ask someone like... do you know the African girl in the office, I'd ask her."*

*Non-IMHA user (African Caribbean woman)*

An IMHA highlighted the importance of being clear of the IMHA's stance in relation to the mental health system, because of his experience of coercive mental health services:

*"You can always tell which side of the fence they're on... I can. So if this Advocacy came to see me and they seem to be leaning towards the side of the mental health team then I probably wouldn't get involved with them because you can be treated in the community, you don't need to be locked up to be treated."*

*IMHA partner (Medium secure service (African Caribbean man)*

It was not clear from this whether a shared identity would have helped or was not as important as the capacity of the IMHA to stand alongside this man. However, the majority of IMHA partners from BME communities reported being satisfied with the IMHA and reinforced the qualities mentioned by other IMHA partners. This needs further investigation as this was not the main focus for our study but an earlier study of advocacy indicated that this was important, particularly in determining understanding of, access to, and the nature of advocacy provision (Newbigging, McKeown, Hunkins-Hutchison et al, 2007).

Cultural competence rests on a good understanding of a person's background and cultural expectations. Here, an advocate of South Asian heritage discusses why a qualifying patient chose him to advocate instead of a non-Asian IMHA:

**Advocate:** *"I could understand, I could understand their culture and even their language to a certain extent. How they live, I know their joint family system because I come from a joint family as well. I know how they live together and how their two houses join together. One his brother's house, one his and they were still, the father was still the head."*

**Interviewer:** *Why do you think that understanding of a culture is important for people in relation to IMHA?"*

**Advocate:** *Whether the same or just generic advocacy... the culture is different isn't it? Entirely different than Western culture. It's understanding, you know of the people, you are talking to, it's quite important, they come to me... 'oh yes it's nice to see somebody who understands us. There is a stereotyping and there is a lack of understanding as well of Asian cultures."*

Not making assumptions on the basis of a person's ethnicity, being open-minded and having the capacity and confidence to explore potentially difficult issues were viewed as important dimensions of cultural competence:

*"It is just about asking those extra questions and just you know treating the person as an individual and not assuming that because you know somebody has coloured skin that they are a certain way or they'll have certain needs but it's about asking the questions and asking them in a sensitive way."*

*IMHA (BME advocacy organisation)*

However, sharing an identity with qualifying patients can mean that there are concerns about confidentiality and these have to be faced. The boundaries of confidentiality, both in relation to their own community and also the mental health professionals have to be made absolutely clear:

*"I know from my community they have mental health issues, sometimes I see them on the ward. When they speak I know that they are from my type of community and I know that they need that service. As soon as they see me they recognise me, we recognise each other, but because we are from the same community they say 'oh, I'm fine I don't' need this service.' But give it two or three days down the line, when they see me attending to other clients."*

*IMHA (BME advocacy organisation)*

The issues that IMHAs may need to respond to for BME clients may be broader than for the majority community, reflecting specific cultural issues as commented on by these two advocates:

*"I met with a lady yesterday who's been on the ward for nearly a week and it's quite, she's quite clearly a Somali and she's not been offered Halal meals. She's been eating vegetarian meals for a week so it's about asking those questions and just... and when I asked her she sort of said, 'it's okay, I don't want to be a trouble', but it's about letting her know it's not a trouble, that's her needs and that's something that needs to be taken care of."*

*IMHA (BME advocacy service)*

*"Because the demands from the Asian community, it's not only, make them understand what mental health is and how, because it is different, perceived differently by the Asian community, about what depression is, you know."*

*BME advocate (Mainstream advocacy service)*

Consequently, BME advocates approach the task with an understanding of the potential disadvantage faced by people from BME communities:

*"We're picking up the trends, we're picking up what's going wrong generally on the ward and we're also building up an experience of the kind of issues"*

*that can go wrong and I think we're looking for it, do you know what I mean rather than it being an add on, it's something that's at the forefront of your mind rather than, 'oh that person's got coloured skin perhaps I should ask them about...', do you know what I mean?"*

*IMHA (BME advocacy service)*

The picture that emerged from this and our previous research (Newbigging, McKeown, Hunkins-Hutchison et al, 2007) is that mainstream advocacy organisations may receive the funding for IMHA provision but not be attractive to, or have the skills and knowledge to provide culturally competent services for qualifying patients from BME communities. There are two possible solutions to this. First, IMHA providers working in partnership with BME community organisations. However, we found little evidence of this in practice, despite guidance that promotes this as a way of enabling access to IMHA services and ensuring that the services are culturally appropriate (NIMHE, 2009; Newbigging, McKeown, Habte-Mariam, et al, 2008). This is illustrated by this advocate from a mainstream IMHA provider:

**IMHA:** *"If we can support another advocate to do their role but if an advocate say a Vietnamese advocate had a working relationship with a client but the person becomes IMHA qualified then there's no reason why the IMHA and the advocate, they should try and work together."*

**Interviewer:** *"Yeah okay, and does that happen then on your patch?"*

**IMHA:** *"Very rarely, very rarely but there's no reason why it shouldn't happen."*

Another IMHA described the climate of competition as a potential barrier to partnership working. Where BME organisations co-existed with mainstream IMHA providers, they might be providing advocacy for qualifying patients although not being funded to do so.

The second solution, suggested by one of our peer reviewers is to invest in capacity building and upskilling grass roots community groups to help to fill this very evident gap in the service, specifically in terms of supporting service providers to develop a clear understanding of the need to offer a choice of culturally appropriate advocacy where this is lacking. Again, we found little evidence of this in practice. However, the recent report from the Centre for Social Justice (2011) picks up this theme and recommends that the number of advocates available is increased sharply and explores the ways in which community-based organisations could contribute to strengthening mental health advocacy, in its broadest sense, for BME communities, and access further training to become IMHAs.

## 9.5 Gender sensitive provision

Two main issues emerged in relation to the gender sensitivity of services. First, the staffing profile of IMHA services – predominantly female- may limit choice on the basis of gender. It was not clear how significant this was for the men in our study, although in general gender was not identified as important. Women were more likely to identify wanting female IMHA, usually reflecting cultural issues or the need for relational security, as a consequence of experiences of abuse. The predominance of female staff, however, does not guarantee that cultural sensitivity or an awareness and understanding of issues in relation to a history of abuse. Thus, both the training and supervision of IMHAs needs to take this into account and support IMHAs to understand the issues presented by service users:

*"I think it's vital, I mean we deal with things that counsellors don't deal with and yet they get [supervision] but they wouldn't deal with what we deal with, when people are constantly talking about self-harm, talking about their experience."*

IMHA

Also, further discussion within IMHA networks of potential development needs in relation to gender sensitive services would be useful.

## 9.6 Provision for Lesbian Gay Bisexual and Transgender (LGBT) people

No specific provision was identified in any of the case study sites for LGBT people nor was this raised by any of the participants, although the sample included people who identified as gay or bisexual. It was notable that IMHA services are less likely to record an individual's sexual orientation and therefore it was harder to evaluate the uptake or issues for this population. A couple of the IMHA services and focus group participants indicated that IMHAs in their service felt uncomfortable about asking for this information, which is why it was not routinely recorded. Interestingly, we had a 99% response to this item on the service user questionnaire that we invited qualifying patients to complete, although providing this information for research purposes as opposed to service use may have very different connotations. However, it does suggest that IMHA services need to review their practice and ensure that they are not inadvertently compounding the stigma and discrimination on the basis of sexual orientation.

One of the IMHA services, where we undertook a shadow visit, had recently secured funding to work with LGBT people experiencing mental health difficulties, primarily in the community but also in hospital, and worked with a colleague to meet the needs of LGBT service users who were detained. It will be useful for this service to share the learning concerning its experience on the distinctive needs of LGBT people in relation to IMHA provision.

## 9.7 People with learning difficulties

Any service that relies on patients understanding enough to request services is inherently discriminating to those who lack capacity in various aspects of their life. People with learning difficulties have struggled to receive appropriate mental health services with mental health professionals sometimes lacking the appropriate skills (Gregory, Newbigging, Cole et al, 2006). In contrast, Learning Disability services are likely to be more aware of capacity issues and of advocacy. Thus people with learning difficulties who qualify for IMHA services may find it difficult to access them if they are reliant on mental health service professionals for access.

We found that the access for people with learning difficulties varied between sites. In one site, the advocacy organisation had recently formed two organisations; one providing advocacy services for people experiencing mental health problems and the other providing independent advocacy to vulnerable people including people with learning difficulties and older people. However, only the former service was commissioned to provide IMHA services but was not providing IMHA services to any qualifying patients with learning difficulties, thus creating a gap in provision. The other service then found itself in a difficult position, understanding the specific needs of people with learning difficulties but not having any advocates qualified as IMHAs nor being commissioned to provide this service. In another site, the commissioners developed two separate service specifications – one for instructed and one for non-instructed advocacy services, and included the IMHA provision in the specification for instructed advocacy. This immediately created a gap in provision for people who qualify for IMHA services but lack the capacity to instruct an advocate.

In contrast to this, another site had an IMHA manager who had experience of working with people with learning difficulties and it was evident that this service was taking steps to ensure access and that the needs of people were actively considered in service provision. The advocacy organisation was commissioned to provide IMHA services to people with learning difficulties who were under the MH Act. The experience of provision at the other sites was somewhere in between, with evidence that people with learning difficulties were accessing IMHA services but that not enough attention was always being paid to communication and providing information in appropriate formats. However, we also came across examples of good practice;

*"The majority of them (IMHAs) who have been with us for more than 12 months, have been on inclusive communication training so there's myself and another Advocate who are trained in the use of talking mats and then there's myself and another Advocate who are trained in Makaton Sign Language and there's a third Advocate who's trained in British Sign Language, so between us we do have these skills within the service."*

*IMHA Manager*



Access to IMHA services for people with learning difficulties can be facilitated by their previous experience of advocacy other than IMHA. This was the case for one young man living in supported accommodation, who had previously had an appointee, and thus with the support of the residential staff approached the IMHA service. As with older people, there may be an issue for people with learning difficulties who lack capacity, in relation to access to non-instructed advocacy.

### **9.8 People with physical disabilities and/or sensory impairment**

As noted earlier (section 3.6.2), we interviewed a number of people with physical or sensory impairments, although this did not include deaf people. The physical accessibility of IMHA services was not raised because IMHAs tend to visit people on the wards, in mental health service and occasionally at home. Partnerships with organisations that have particular knowledge and skills in the area of disability had been fruitful:

*"We can provide easy read literature from our service, we also have someone who can provide ... she works for the Blind Society, she would do anything you know in terms of looking at our literature for somebody who's visually impaired."*

*IMHA Manager*

The main issue we identified was appropriate provision for hearing impaired and deaf people, who are inpatients. The same issues existed as for people in relation to people from BME communities in terms of appropriate promotional materials and access to interpreters as well as cultural competence. Deaf people are a linguistic minority and, in 2003, British Sign language was recognised as a language in its own right (NMH DU, 2011). Access to IMHAs who can sign was identified as being more effective than a hearing advocate with a BSL interpreter, both in terms of the rapport established with the service user and the cost. However, an understanding of or identity within deaf culture was also highlighted. One ward manager commented that people would prefer to use a deaf advocate who might not be qualified as an IMHA in preference to a hearing IMHA:

*"A deaf person won't... you know especially someone that's mentally ill responding to their own or whatever, so a hearing person coming in who will then need to use an interpreter, that would cause a barrier straight away with the patient, so I would imagine that the pick-up would be poor."*

*Ward Manager*

Access for deaf people within this unit was provided by a deaf advocate, who was not trained as an IMHA. Just as with BME advocacy organisations, it seemed to be the case that the deaf advocate was from an organisation that did not receive funding to provide IMHA services but did so anyway because of concerns about unmet need.



**Meeting the diverse needs of qualifying patients – Key Findings**

- The development of IMHA services is based on a model of instructed advocacy provided by mainstream advocacy providers. This may inadvertently disadvantage qualifying patients who have specific needs including people from BME communities, older people, children and young people and those with sensory impairments.
- IMHA services tend to be confident about their capacity to respond to the diversity of qualifying patients but our findings indicate some key gaps in provision that need to be addressed.
- The proportion of children and young people accessing IMHA services was relatively low and the variation reflected differences in commissioning and whether specific provision had been developed.
- The uptake of IMHA by older people, particularly those requiring non-instructed advocacy varied across the sites with only one advocacy provider in one site having developed specific expertise in providing IMHA for older people with dementia.
- The commissioning and provision of IMHA services largely fails to recognise the particularly negative experiences and perceptions BME communities have of mental health services. There was a general lack of culturally appropriate services, which goes beyond thinking about language, to having a deep and accurate appreciation of cultural issues. There were few examples of partnership working with BME organisations or upskilling these organisations to provide IMHA services.
- The staffing profile of IMHA services – predominantly female- may limit choice on the basis of gender. It was not clear how significant this was, although in general gender was not identified as important. It was more likely to be identified by women, and reflected either cultural issues or a need for relational security.
- IMHA services do not routinely capture information about the sexual orientation of qualifying patients and this makes it difficult for them to evaluate their approach.
- Where advocacy services for people with learning difficulties were commissioned separately from IMHA services, there were disadvantages for qualifying patients with learning difficulties accessing IMHA.
- It was suggested that the cultural issues for deaf people need to be considered alongside language and communication, and that deaf IMHAs, should be available to provide IMHA services within specialist mental health units for deaf people.

Where the advocacy needs of qualifying patients are not being met, this gap in provision may well be filled by a community organisation that is not funded to do so.

## 10. THE MENTAL HEALTH SERVICES CONTEXT

### 10.1 Introduction

It is clear from the earlier chapters that contextual factors play a central role in determining the experience and quality of IMHA services. In particular, the attitude of mental health professionals and the organisational culture will influence access to IMHA services and the nature of the service context within which they operate. We found broad consensus around the need for a positive disposition towards advocacy in mental health services. This can be formulated as part of the commissioning process or an engagement protocol, but grass-roots relationships will be worked out largely on the basis of whether there is mutual understanding and realistic expectations of each others' roles. This chapter explores the relationship between IMHA services and mental health professionals and draws on some of the findings presented in earlier chapters to develop a typology that provides an explanatory framework for the response of mental health services to IMHA provision.

### 10.2 Practical facilitation of advocacy

As discussed in chapter 5, mental health professionals have a central role to play in promoting access to IMHA services. Alongside this, mental health professionals can practically support the advocacy service through making IMHAs feel welcome onto the ward, making sure rooms are available or a quiet space for meeting service users, and generally keeping alert to the safety of the advocate, such as communicating basic information about wellbeing or risk prior to IMHAs seeing particular service users. Furthermore, they can alert IMHA services to qualifying patients, help IMHAs access notes, as necessary, and organise meetings so that IMHAs are able to attend. This contribution to creating a supportive context for IMHA provision was articulated by a number of mental health professionals, particularly those from inpatient settings:

*"Our staff should be courteous, polite, make sure they have open access to any areas they should have access to, you know, and give them explanations if there's things that have to be kept confidential or things that can't be shared."*

*Service user Involvement Worker*

When mental health professionals adopt this approach it makes a positive contribution to relationships with IMHAs:

*"When the IMHA just comes to the ward the ward staff will go out of their way to assist them with what they need because they'll need access to certain things obviously won't they? They'll need information a lot of information from us as well. In these cases, mental health services staff will*

*feel obliged to take steps to support advocacy and this can make a positive contribution to relationships."*

*Ward Manager (PICU]*

When the relationship works well there will be some contact between the IMHA and ward staff prior to meeting with service users and the advocates appreciate this:

*"You know, so we will be coming to you and saying 'is it okay to see so and so today?' And if you say well actually today is not a good day because, you know, as long as you've got, you know, a reasonable rationale for that, that's perfectly fine by us, we're not here to come in and knock down doors and demand to rifle through filing cabinets."*

*IMHA Manager*

Ward staff can also be aware that they potentially act as the gatekeepers for the IMHAs access to inpatient areas:

*"We always welcome them onto the ward, no matter what, I've never, ever refused anybody."*

*Staff Nurse (Acute ward)*

It is not always the case, however, that all mental health professionals are aware an advocate is present on the ward, stressing the importance of introductions on entering ward space:

*"First to begin I wasn't told he was an advocate, he came into my ward, I wasn't told and, fair enough the social worker brought him and she introduced him to the patient but I wasn't told and then he left. And it was only after he left someone said to me; 'Oh he was the advocate', I said 'But hold on, there's another client who wants to see him'."*

*Team Leader (Medium secure unit)*

Some of the mental health professionals interviewed clearly saw it as one of their duties to be responsible for the personal safety of any visitors to clinical areas, including advocates and some IMHAs reported being issued with personal alarms or having attended training for lone workers.

*"You know we'll make sure that the IMHA is safe on the ward so they'll be given an alarm you know because often they won't want staff with them as such because they need to do what they need to do with the patient without the staff there, but we'll make sure that they feel safe and I think that all kind of comes into the positives of the relationship."*

*Ward Manager (PICU]*

Some features of particular mental health settings can be an impediment to the development of positive relationships, complicating the setting of conditions that

would allow for positive relations to emerge. For example, the nature of acute inpatient wards in terms of the profile of patients and the turnover of patients:

*"I don't know how much they feel welcome on the wards to go and introduce themselves to people and to generally make themselves known.... Since things like beds were reduced and current in-patients are perhaps more acutely unwell than they were at one time ... it seems to be quite more intense on the ward and people coming in from outside don't always feel particularly welcome on the wards and that's from Community Teams within the organisation as well as perhaps independent workers."*

AMHP

There can, however, be practical and logistical problems with facilitating advocacy involvement, including accommodation and staffing issues. How these are managed may reflect the value accorded to the IMHA role:

*"I've been asked to interview a client in the dining area off the day room before today, even though we always make an appointment in advance ... but quite frequently they'll say 'Oh no the side rooms are being used, I'm sorry we haven't got a private area for you to interview the person in' so you're a bit at their mercy."*

IMHA Manager

*"There is a shortage of nursing staff on the wards, for them to come and get you, for example, if you're on the forensic units you have to go through an air lock ... and then be escorted across the courtyard to the different wards, so for somebody to come off the ward and get you means that they've got to have staff to cover people on the wards. So you know I've stood outside there for nearly 50 minutes waiting."*

IMHA

Advocates are thus acutely aware that they rely upon mental health professionals for their access and support in navigating wards and meetings, and sometimes this can be frustrating:

*"I think the only sort of challenge I've had along the way, is of responsible Clinicians not wanting me involved which I've had three times now because they're in a hurry and they ... just they won't get the Advocate involved in a ward round or whatever it was, would delay things because they wanted to just chop, chop, chop, discharge, get rid, but those same ones have been happy to work with me subsequently."*

IMHA

There can be problems associated with having to think about the advocate on top of coordinating the input of other professionals, as this AMHP explained as the reason

for not involving an IMHA in the readmission of someone who had previously been detained:

*"You have to arrange two psychiatrists to come with you, you have to arrange ... try and see if a bed is available, then ... a lot of times you have to involve the police, the ambulance and coordinating all of that, to have an advocate there as well and also it becomes quite difficult for a patient, under a lot of stress, and then you're adding yet another person to the mix, it's difficult enough."*

AMHP

As reported (see 8.5), IMHAs repeatedly raised the problem of key meetings being cancelled, rearranged at short notice or of failure to ensure that they were notified so that they were unable to attend and provide the support that had been previously requested and agreed with a qualifying patient. In some senses the efforts made by mental health professionals to facilitate and support access to IMHA services reflects their understanding of and the value accorded to the role and this in turn impacts upon the quality of the relationship with the IMHA. This may reflect wider issues about their views of people experiencing mental health issues: for example by adopting a somewhat paternalistic view, a mental health professional might fail to see the value of arranging an advocacy visit early on in an admission if a person is acutely unwell, psychotic or irrational, feeling this is a waste of time or might even add to a person's problems.

### 10.3 Building relationships over time

Across the various case study sites, different experiences of advocacy, including before the introduction of IMHA, have coloured professionals' views and either enhanced or problematised the development of effective relationships. This may have involved a negative experience of a whole service:

*"When we first started we had to go round and introduce ourselves ... and we took a lot of flack from people who obviously bore scars and we had to put our hands up and say, you know, we accept that, you know, whatever has happened in the past you have been hurt. We hear what you're saying, we have come with a model which has worked elsewhere, we know it can be made to work. We are not the same people as you were dealing with, we are very willing to listen to what you have to say, in fact we not only will listen, we expect you to tell us things."*

IMHA Manager

Rebuilding relationships then becomes the focus for the IMHA to enable them to work constructively in a particular setting.

Alternately, sometimes there is a previous relationship that helps maintain constructive working relationships:

*"I'm very into service user involvement, it's something I'm very passionate about, so we would chat so that's how I first met the IMHA and then when I came down here, blow me she was providing the advocacy and IMHA here ... We would meet at the forum because I used to attend that quite regularly and I'd see her pottering about the wards in between seeing patients or whatever, or she would grab me if she wanted to chat about something, so we had a good link there."*

*Psychiatrist*

Better relationships are forged when there has been a tradition or history of working effectively with advocacy pre-IMHA or an on-going commitment to progressive working around service user involvement or PALS; where the bedrock of respect and understanding is in place already. The IMHAs in the case study sites describe working hard at developing these relationships with staff, and enhancing staff knowledge of key aspects of IMHA such as its independence and the fact that they work on the basis of service users' expressed wishes, not taking a view on best interests. There has often been a need to take care to establish trust or minimise the extent to which staff may have viewed advocacy as a threat or something that exists to make their life difficult. This relationship building is as much about advocates modelling behaviour and demonstrating their worth through practice as talking to and persuading staff of the value of advocacy. The advocates report investing significant time and effort in making this happen:

*"I think it's taken two years to build it up, I think when I first went in there it was kind of 'Advocacy, what's that?' ... well I came here in 2009 and prior to that we did have a Mental Health Advocacy but we certainly didn't get the referrals that we get now and I think that's from consistency at being me getting known, promoting the service, I would say considering the service has only been going two years yeah we've got a good working relationship."*

*IMHA Manager*

Overall, there was a sense that the introduction of IMHA has led to advocacy being taken more seriously and to mental health professionals having a more developed understanding of the contribution of advocacy; or a sense of advocacy working in a professional manner is welcomed:

*"So there wasn't a great relationship between the hospital and the last service provision. Having said that, the feedback I do hear about the new services ... they have a more professional approach to doing that."*

*OT Manager*

The reported time taken to change the organisational acceptance of advocacy has varied for the respective advocacy services, and for some, the change is slow or not yet complete.

#### 10.4 Positive relationships with IMHA services

Some of the mental health professionals we interviewed were knowledgeable about advocacy and willing to recommend it, but had little or no direct experience of service users in their care making use of it. However, it was evident that mental health professionals' appraisal of advocacy reflected their understanding of the need for IMHA and that such advocacy was of value to and was appreciated by service users:

*"The team actually don't have a problem with that [independent advocacy] because again that they would see that we are using legislation to actually impose nearly sanctions on some individuals and they would feel that the service users needed protecting from us because we're the ones that are imposing the sanctions."*

*Team Manager (Assertive Outreach Team)*

Sometimes the IMHA's contribution was appreciated because their involvement made the professional's job easier or complemented their role:

*"I've got colleagues who have dealt with quite a few sort of DOLS situations and safeguarding situations and they've been involved with IMHA and I've often felt that that's been in a lot of ways really quite supportive of the role that we, as mental health professionals, play. So I think my colleagues who I've heard talking about them have found them really useful, have found the service they provide as being one that complements ours rather than works against it."*

*CPN (Psychosis team)*

In several instances mental health professionals remarked that the advocate was in a better position to elicit the views of service users than themselves, acknowledging the quality of the advocacy relationship that made this possible. IMHAs also explained how they could enhance the efforts of practitioner staff by eliciting information about service users' wants and needs:

*"I also feel like sometimes that it is part of the role that they wouldn't have to do really as well because rather than trying to pull out themselves what the actual... the client wants at that particular moment, we've done that, we've got that list of what they want, what they want to ask for, we've talked it through with them ... so they don't have to dig through everything and try and find out what that person wants."*

*IMHA*



And that this is welcomed by staff who can appreciate the link between effective expression of service users' views and their subsequent wellbeing or recovery:

*"When they've worked well they've worked alongside primarily the nursing team and I think they can provide a conduit for information going both ways whereby they can allow patients obviously to express their wishes, also allow patients to understand the position they're in regarding the Act, or medication."*

*Psychiatrist*

Mental health professionals appreciated the IMHAs actively feeding back information about service user advocacy issues (insofar as this is appropriate), service user well-being and/or risk issues:

*"They'll feedback on what they can feed back on, what they're allowed to and I guess if there's anything they need to tell us i.e., they're saying things, they might target somebody, they're going to do this, they're going to do that, then they'd always let us know that as well, so yeah they share information with us when they need to definitely."*

*Ward manager*

And in this instance, where the IMHA checking the veracity of a complaint with staff was appreciated:

*"She had a really good rapport ... what I liked about her was she came to the ward and the patients complained to her, she would come to me and she would ask 'does this really happen?'"*

*Team Leader (Medium secure unit)*

These positive views of the working relationship were translated by some professionals framing the advocacy input as an extension of team-working. For example, IMHAs pointing out to staff how they could helpfully intervene to the benefit of individual service users, especially in a context of complex cases. For these staff, the IMHA occupies a sort of hinterland: not one of the team, but very helpful for the team.

Examples of mental health professionals and advocates working in partnership to develop initiatives that improve the service, making a positive difference for individuals or enhancing the extent to which the IMHA can protect rights were also reported. These included IMHA involvement in the routine monitoring of seclusion practices, a Wellbeing Time project on wards in a secure unit, and IMHAs involvement in service user involvement initiatives. The case vignette described here (see Figure 11) provides an example of this sort of working between advocates, managers and ward staff in a secure unit. In such instances the IMHA and the mental health professionals concerned had identified issues of collective concern and sought

innovative ways of addressing them. Such initiatives have been largely enabled because significant effort has gone into building relationships, sometimes spanning years before the introduction of IMHA, where the same provider has been in place.

The advocate found that a certain issue was being raised by a number of service users over a significant period of time. The service users were all entitled to an amount of escorted leave away from the ward; for some of them on a daily basis. What became apparent was that there was insufficient ward staff to ensure that everybody could take all of the leave owing to them at the same time as providing for safe staffing levels on the ward. For any one individual it was an accident of timing or circumstance whether they would be able to take their leave as it was allowed for. As a result, there were numerous examples of unfairness; some people seldom getting their leave entitlement, others getting the lion's share; nobody receiving the full allowance. None of this had the appearance of being planned for.

Rather than continue to take this up on a case by case basis, the advocate entered into meetings with managers and key staff to try and find a collective solution to the problem. Eventually, a system was applied whereby access to the leave entitlement was allocated much more fairly and individuals gained a fairer share of the staffs' time for supporting escorted leave. This meant that everybody got some leave every week, but still many people did not exhaust their full entitlement. There was also a clearer appreciation of who was getting what leave when, and how this tallied with their overall entitlement. The service users were much more satisfied with the new arrangements, because they had a semblance of transparency and leave allocation was more fairly distributed. Interestingly, however, it may have been the case that the efforts of the advocate were hidden from the service users, as the problem-solving occurred in a forum where no individual service users were present.

**Figure 11: Case Vignette – Solving the problem of off-ward leave**

### 10.5 Boundaries and independence

Balancing the desirability of having constructive working relationships with mental health services posed challenges for individual IMHAs, and advocacy services, who may come to be seen by service users as no longer independent and too close to mental health professionals. As one IMHA commented *"slowly but surely we are becoming part of the statutory regime"*. Attention to boundaries and maintaining an independent relationship is therefore important. For the advocate, having a visible presence on the wards helps build these relationships, though there is a balance to be struck in the closeness of relations with staff and maintaining a sense of independence:

*"You see you have to bear in mind that we do say to staff that we will not spend too much time in the office with them because we are conscious of the*

*fact that it is like a goldfish bowl and the patients will look in and see us talking to them and they will misconstrue that. We might be talking about, you know, how many goals West Ham has been defeated by but the patients will assume that we're talking about them individually."*

*IMHA Manager*

Conversely, if the advocate is not in close contact with the staff it can be difficult to establish relationships to the detriment of effective advocacy and service users also recognise the need for the advocate to have a relationship with the staff. The need to preserve the independence of the IMHA is something that mental health professionals who understand advocacy are aware of, and this interacts with the aforementioned sense of collaborative working:

*"I was trying to get my thoughts around the way that staff, patients and advocates interact is totally different to what it was ten years ago. Because I think the three work together in a triangulate approach but each keep their identity... I think there's professional boundaries come into play. It's like any relationship like, you know, as long as you've got a knowledge of each other's professional accountability I think it's quite easy to be honest."*

*Modern Matron (Secure service)*

In secure units, where access to parts of the built environment is via locked doors, the advocates typically carry keys and are inducted into safety and risk management practices. In the High Secure service, neither IMHA partners nor IMHAs felt that the visible use of keys compromised the extent to which advocates were seen as independent. Indeed, for the IMHAs, the ease with which they can move about is preferable to any image problems that might arise from being seen to use keys. The general feeling, shared amongst service users too, is that these features of secure environments are more or less taken for granted and do not adversely affect relations between advocates and service users.

Sometimes there can be confusion or difficulty articulating the distance the advocate must maintain between themselves and the care team:

*"Em, it is separate but I'd still feel that they are part of the team... No I don't see it as a conflict, it's part of an enhanced role, it's like a CPN's role and a Social Worker role, an OT role in that we're all part of a team, we all work together but we all have our jobs and it enriches the service for that patient... In a way they are outside but I suppose to a degree they have to be because they have to be seen as the independent, as speaking truly from the patients prospective."*

*AMHP*

This notion of working together raises some issues about boundaries and the extent to which a valued close working relationship might become too enmeshed, and work

against the principles of advocacy, perhaps with advocacy co-opted; fulfilling aspects of the care-team role or as part of a pacification process. Such practices tread a fine line between advocating for the person's wishes or ensuring the process has the appearance of fairness and reasonableness:

*"I think given the experience of the advocates, quite often they know what the answers to some of those questions would be. So if somebody was asking for a rehabilitation trip, the advocates would know the policy and that it's highly unlikely that they're going to get one, so they're already probably preparing the patient for that outcome. So they'd put the point of view across and ask questions so that they make sure that you've reasoned it through, you're not just making a decision without considering the impact. So I think they just raise the issues for a debate, but quite often they know what the underlying policies are and what's going to be possible and not possible."*

*Psychiatrist*

Or helping the service user accommodate to disappointment, referred to by a Psychiatrist in another site:

*"If they know what's happening from the team's point of view they can reinforce. So for example if the answer is no to unescorted leave at the moment and the patients... 'I haven't got unescorted leave', the IMHA can say: 'No but remember what was said at the CPA I was there and your team said you've done brilliantly the last six months, and they're going to write to the MOJ [Ministry of Justice] so within about two, three months, all going well, you should be getting shadowed leave, this is really, really good.'"*

*Psychiatrist*

On occasion, mental health professionals questioned the objectivity of the advocate (this connects with the variant on staff disappointment with advocacy for not being a potent enough force in defending rights, as discussed in the next section):

*"The down side is, I sometimes question her independence because she knows us so well and... it works for us but... as lovely as she is, the IMHA... I think I'd be a lot clearer on what the patient's view was and would be a lot more questioning'... so I think I would be taking a lot more firmer line."*

*AMHP (Forensic learning disability service)*

Where boundaries are more tightly drawn, mental health professionals and IMHAs commented on efforts to maintain a degree of distance in the relationship, though sometimes this causes them to question the relational skills of the IMHA or feel slighted. Other mental health professionals were conscious of confidentiality issues and did not feel it was part of their role to offer advocates comprehensive information about individual cases. Mental health professionals were also aware of

the confidentiality of the advocacy process and shared an understanding of appropriate communication channels:

*"The Advocacy is working for them it's between them and the person they're working with so they're not going to... you know I'm not aware of the stuff they're talking about."*

*Ward Manager (Acute ward)*

*"We do, on the whole, have that good communication pathway and a good understanding of what they can say to us and what they shouldn't say to us if they don't want us to pass it on to our clients."*

*Advocacy Manager*

Understanding of advocacy and the IMHA role helps place relationship issues in perspective. The IMHA has an interest in developing good relations because then mental health professionals will support the advocacy role:

*"There's no doubt about it, she's[the IMHA] there for the service user, she's not there for the staff but you still have to have a working relationship... I think you still need to build that on the wards and in turn they will refer."*

*IMHA Manager*

One ward manager reported only thinking about the idea of the team's relationship with the advocate during the course of the research interview, and this provoked a reflection to give it more thought.

## **10.6 Negative relationships**

Mental health professionals also expressed a range of negative experiences of IMHA and dissatisfaction, which could impact on the quality of working relationships between themselves and IMHAs. Negative appraisals of the contribution of IMHAs often reflected a mismatch between expectations and experience. This had a number of dimensions. Some felt that IMHAs had not challenged services enough on service users' behalf. Or they expected IMHAs to be more proactive in encouraging the person to speak for themselves:

*"Sometimes you just wish that there was that little bit more oomph which they could give for the patient you know when they actually see something themselves which maybe isn't right in the patient's care and you just sort of wish that they could actually push forward... not necessarily their opinion but push forward the discussion with the patient I suppose about what's going on to try and get them to speak up more."*

*Team Leader*

Underpinning these accounts was a positive view about advocacy but a sense that IMHAs could do more to really understand the issues of service users and to promote their rights and ensuring their voice was heard:

*"I do think that people [IMHAs] need to spend more time with the people, I am aware that their workloads are massive but I sometimes think that they do dip in and out and I'm not always sure that that always gives them a good grasp of what actually is going on in the person's life... they should be a finger a bit more on the button around what's going on."*

AMHP

A minority, mainly community-based staff, were critical of IMHA as being of no benefit or value to individuals, or were critical of what they perceived as a rather ineffective service:

*"I've tried to make referrals to the service and, as I say, they haven't been particularly sort of effective."*

AMHP

There were some mental health professionals whose experience of IMHA had been of an unreliable service. Others, some psychiatrists, referred to instances where IMHAs had not been available and expressed their dissatisfaction with this:

*"There's been a few occasions where advocates haven't turned up for ward rounds and the patient's been disappointed."*

Psychiatrist

In this instance, the IMHA was expected to conform to the ward routine and it was not clear what had been agreed or whether this was practically possible. However, it was evident that the visibility of IMHAs was judged as important by mental health professionals:

*"They left and the new ones came and as I say introduced themselves in the forum, but they do it slightly differently. By appointment only I think, or are specifically invited to a specific meeting. So they're not coming to an open visit to the wards... the impressions I have is that the advocate isn't around an awful lot and they have to be specifically invited."*

Psychiatrist

However, participants sometimes gave conflicting accounts about the visibility of IMHAs, in the context of inpatient wards. For example, an advocacy service recalled attending team meetings and making presentations to ward staff but the staff we interviewed appeared to be relatively unaware of the service. There can be differences between staff on the same ward, as in this instance:

*"I mean there certainly is a lot of Advocacy on here, it is a regular,... you know more often than not a person will turn up at a meeting with an Advocate and we do quite often refer to Advocacy."*

*Staff Nurse*

*"I can't recall having seen an IMHA on this ward, I'm not saying there hasn't been but if there has been it's been on an extremely rare and... if at all."*

*Ward Manager (Acute ward)*

In this instance, while both were aware of advocates' presence on the ward, they were oblivious to the fact that advocates were IMHAs. Deficits in understanding the advocacy role can lead mental health professionals to be concerned about what advocates do after they visit the ward areas, implying they would like to know more:

*"In terms of knowing what they do when they come to the wards, I wouldn't then know what they do after that, I wouldn't know what they do back at the office or what they do with the information then that they get here."*

*Ward Manager (Medium secure unit)*

This speaks of the independence of the relationship, but also hints that not all mental health professionals were aware of how various problems or issues brought to advocacy are resolved, or what the advocate's role might be in this.

There was some dissatisfaction with IMHA services expressed by mental health professionals that related to IMHA's knowledge base including of mental health conditions and of the role and types of mental health service including the limitations of their own role.

One service had also had experience early on of IMHAs not being properly vetted prior to working on the wards, with the implication that this may have coloured their view of IMHAs:

*"We've had a few problems with people not being thoroughly vetted and that's led to people perhaps who shouldn't be working in inpatient sites with vulnerable people working there ... we've got quite stringent procedures and CRB checks so we have to reinforce those in first year I think that problem arose, or second year."*

*Patient Involvement Lead*

A variation on mental health professionals' views on the lack of depth of knowledge, or qualification, possessed by advocates was the extent to which they were vexed by the advocate assertively pursuing service user's wishes against what the care team sees as in the person's *best interests*. This was often framed in terms of naivety but in reality reflects a fundamental misunderstanding of the advocacy role (as discussed in Section 6.4).



This was an opinion expressed in particular by psychiatrists and ward staff who sometimes felt the advocates was unrealistically challenging the care team or was wasting their time. Advocates who did not do this were seen as more knowledgeable or mature:

*"There are Advocates you know who understand, they are very mature enough to understand where they should say 'no you know we should know more before saying that' but sometime I'm saying that problem does crop up where you know the Advocate people they keep on pressing hard."*

*Psychiatrist*

Some mental health staff expressed frustrations with the communication between themselves and advocates, which led on to a wider dissatisfaction with advocacy generally – questioning their value to patient care:

*"What I found a bit quite confusing was really them saying 'and has the patient really said that they do want to see us, have they got some... you know have they really got an interest in seeing the Advocate?' and I didn't really know the answer to that at the time because the person had just gone on a Section 3... They seem to want me to tell them what support the person needs rather than them come in and see and get to know the patient and finding out what the patient feels they need support with..."*

*AMHP*

There were mixed views on whether some disciplines are seen as more or less enthusiastic about IMHA:

*"The people who aren't so positive occasionally are doctors, they can be a little bit dismissive of those sort of things as being a bit woolly and a bit sort of patient centred."*

*Patient Involvement Lead*

Conversely:

*"I feel like we work quite well with the Psychiatrists really cause they sort of recognise us, there's a couple of times they've said 'oh well we know who you are' and it's quite nice that the actually do know what the IMHA Service is and they're more than happy for us to be in the ward rounds and support the person and they always say 'is there anything else' and they'll say 'has the IMHA got anything else to add to it, anything you may have forgotten or...'"*

*IMHA Manager*

Though, professional dominance is asserted when felt necessary:

*"I haven't particularly ran into any personal differences with advocates, I think once I've said, 'you know, you've gone beyond your limits, you're outside your area of expertise' then I think they have realised."*

Psychiatrist

The quality of working relationships depends upon mutual understanding and appreciation of each others' roles. A major impediment to understanding and appreciation of the advocacy role is confusion over the notion of best interests, as discussed in Chapter 6. There can be resistance to advocacy and the IMHA role from staff and a degree of conflict in relations; in the extreme these can result in major rifts and this is discussed in the next section.

### 10.7 Resistance and conflict in relationships

Reports of conflict in the relationships between mental health professionals and IMHAs were not uncommon, and often linked with the various ways in which professionals failed to appreciate advocacy and the IMHA role. Not surprisingly, IMHAs also described resistance and the sense that some professionals see them as interfering and were aware that they added to their workload. At the extreme, IMHAs were perceived as an irritant to and their professionalism was called into question:

*"They're a bloody nuisance! ... They're amateurs meddling."*

AMHP

Mental health professionals can also perceive advocacy interventions as slights on their professionalism, as this nurse explained:

*"I've been called into a room where the advocate has gone through the list of the patient's grievances so to speak in quite an abrupt manner. And I've said 'yes we sorted that yesterday, yes they're getting that tomorrow,' you know, I've just stood there and I suppose in a way I've resented the implication that we haven't addressed those issues."*

Nurse

A number of IMHAs made it clear they did not take a negative response personally and considered that it was a necessary part of the job. Numerous participants highlighted conflict in the relationship between IMHAs and mental health professionals. The nature of the nursing role in contemporary psychiatric services places them in the front line of criticism and perhaps raises sensitivity to the potential for criticism:

*"We have to do the unpleasant... stuff, it's the nurses that do it. So you do develop this sort of mentality, a siege of mentality that you're under attack, everything is your fault, so when other people come in, you've got the siege of mentality because that's how you're used to working."*

Ward Manager

Some IMHAs demonstrated an understanding of this:

*"Maybe there are instances where maybe a patient has complained about the staff and they say they are bringing in the Advocate ... that can be quite unsettling you know... the moment the Advocate walks onto the ward you can tell that this person is a bit uncomfortable because they don't know what the patient is going to be telling the Advocate about them."*

*Team Leader (Medium secure unit)*

Service users perceived mental health professionals' antipathy towards advocates could act as a barrier to effective working relations:

*"Oh they hate them with a vengeance, they hate them. Because they think that the advocate is out to get them personally and that's just, that's not true at all you know?"*

*IMHA partner (Acute ward)*

Tensions in the relationship can lead to lip service being paid to advocacy.

*"I don't think they like advocacy... this is the impression I'm getting... Well you know the way they didn't want me to go ahead with the tribunal and they don't tell people here that they can get advocacy, I don't know why, it's very obvious."*

*IMHA partner (Acute ward)*

Complete rifts in relations can occur, with some detailed examples of fraught relations over time between specific mental health services and advocacy providers were reported. The effect of which was to dilute people's access to their rights:

*"There was a time when [the advocacy service] and [the mental health service] were at absolute loggerheads and [the advocacy service] were making complaints to me about how [the mental health service] were implementing IMHA... were, in their view, being very obstructive, wouldn't let them go in, weren't referring to them when it was their statutory duty to do so and were generally being obstructive."*

*Joint Commissioner*

In one instance, staff had been suspended as a consequence of the IMHA's intervention. In another instance, the IMHA involved the police because there was a real concern about a safeguarding issue. The advocate was subsequently accused of stirring up trouble and not allowed back into the mental health service. The advocacy service described this as both illustrating the importance of their independence but also the power that mental health services have to limit their effectiveness. A fractious history with advocacy can become part of the folk memory of the institution and even newer service users can be aware of it:

*"They've done this so many times in this hospital because I spoken to other people who have been here ten years and every time an issue comes up that the IMHA campaigns for and always wins, they actually change the IMHA and then they've to start all over again."*

*IMHA partner (Low secure unit)*

Conflictual relationships were also evident in some reported examples of advocacy practice that antagonise staff such as airing complaints outside of the formal procedures for complaints.

When relationships break down there is a sense of taking sides and clearly the notion of independence is crucial to resolving some of these fractures.

Some mental health professionals thought that the IMHA has to press hard on the service user's behalf so as not to lose face with them, and this can cause stress in their relations with care teams:

*"Sometime the advocates they think that if they have not been able to bring or achieve what their patient has asked them to, they are going to fall down in their eyes and then they are going to be told off or it means you know they have failed to achieve what they were meant for."*

*Psychiatrist*

Or, particular patient groups were seen to exploit IMHA to make trouble for the care team or to inadvertently become involved in complex dynamics between ward staff and a particular individual. This can influence their willingness to promote IMHA services for specific individuals or in particular settings, as discussed in Chapter 5. Mental health professionals also feel aggrieved if certain issues are returned to continually. Discontent with advocacy and the IMHA role can lead to personalising any problems and stereotyping of advocates, and a tick box approach to promoting IMHA services. This suggests that mental health organisations need to be alert to these potential difficulties and have a clear agreement in place with the IMHA service as to how IMHAs can raise concerns, and how to address potential rifts in the relationships between mental health professionals and IMHAs that will ultimately impact on the service user's right to be heard.

## **10.8 Effective working relationships**

Effective working relationships were evident when mental health professionals were already well disposed to the idea of independent advocacy:

*"The last time I had an IMHA on an assessment and that was for a CTO... I was asked to stay behind and I spoke to both the patient and the IMHA about just clarifying what my role was, and clarifying the stipulations of the CTO because they were both a bit concerned that it was a bit vague... it needed clarity cause at the time CTO's were new anyway and people were*

*still finding their way around them... instead of having a two-way dialogue we actually had a three-way dialogue and it was only when everybody was happy that you know 'that's it, job done' so yeah it was good."*

*AMHP (Older adult service)*

This included viewing the challenge posed by advocacy as a good thing:

*"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."*

*AMHP*

We also found that the quality of working relationships is strongly linked to mutual understanding of roles and expectations, or the constraints that each other work under:

*"I think what establishes a good working relationship is their understanding because they can see that we can help and support the patients, we are there for the benefit of the patient if that's their request."*

*IMHA*

*"But I think it's just an on-going thing as each understanding a bit more of each other's service and you know them understanding a bit more of what constraints we're under, us knowing say a bit more about where do they fit in ... so it's just that bit more understanding on both parts I think."*

*Ward Manager (Acute ward)*

As we have shown mental health professionals' understandings of best interests or their own role as advocates for service users (see Section 6.5) can be associated with misunderstandings of the IMHA role and have a detrimental effect on the quality of working relationships and fuel a negative disposition towards advocacy. Not understanding each others' roles can cause anxiety or mistrust. Furthermore, appreciation of the fact that advocacy does not concern itself with appraisal of best interests can make for less frustration on the part of staff and better relationships:

*"We might have a brief chat after we come out of a meeting and just say you know 'I don't envy you, you know for having to put these requests' because the Advocates themselves they know whether you know they're asking for a reasonable thing to occur or not but nevertheless their job is to request whatever their views are, they have to be totally neutral."*

*AMHP*

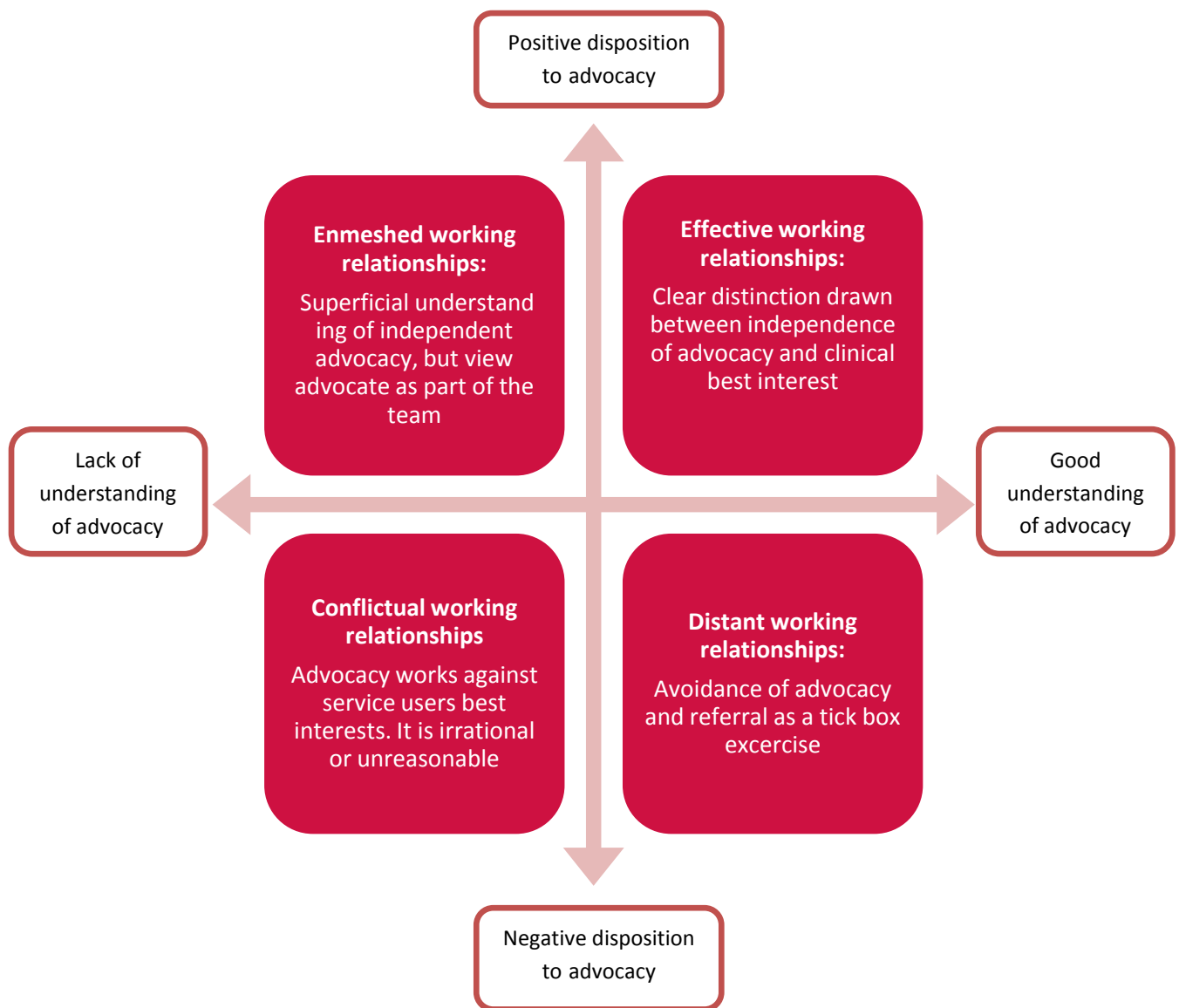
### **10.9 A framework for analysing the relationship between mental health services and IMHA**

These different views on the relationship between IMHAs and mental health professionals reflect different dispositions towards advocacy and different understandings of IMHA. Our analysis indicates that these can be broadly grouped into four different types of response, organised along two interlocking dimensions; disposition to advocacy and understanding of advocacy and the IMHA role in relation to their own role. This is illustrated in Figure 12.

This shows that when mental health professionals are well disposed to advocacy but lack any depth of understanding of advocacy, particularly the importance of independence, they are likely to view IMHA services as part of, or as an extension of, the team. They are more likely to become upset when service users seek support from advocates rather than themselves as they lack the understanding of the difference in role. By contrast, when mental health professionals have a poor understanding of advocacy, and are also negatively disposed towards it, they can construe IMHA services as working against the person's best interests. Advocacy is viewed as irrational or unreasonable and the challenge posed by advocacy is frustrating. In this instance, the problems may be located personally with the advocate and the result is highly charged and conflictual relationships.

Mental health professionals may have a good understanding of advocacy but have a negative view of it. They may be emotionally affronted by the presence of advocacy, viewing it as slighting their sense of professionalism and viewing advocacy as not needed for them to do the best job they can. In this instance, they are likely to avoid IMHA services; referral becomes a tick box exercise and no efforts are made to accommodate the IMHAs.

Finally, there is the position that will support the full implementation of IMHA services and positive and effective working relationships between mental health professionals and IMHA services. Here there is a clear understanding of advocacy and its distinction from best interests and a positive disposition towards it. This is reflected in mental health professionals accepting that it is important that they may be challenged by IMHAs, on behalf of qualifying patients, and they feel comfortable with this. In this instance, mental health professionals will provide the supportive context within which IMHA services can properly operate and ensure that the rights of qualifying patients are protected and that they are fully involved in decision-making.



**Figure 12: The impact of mental health professionals' understanding and disposition to independent mental health advocacy on their relationships with IMHA services**

Despite some reported improvements in mental health professionals' knowledge and appreciation of advocacy, the need for IMHA services to have to make considerable effort to engage with mental health services in discussions and training about role and expectations is somewhat troubling. Leaving aside the new aspects of the IMHA role, it might be thought that psychiatric services by now should have a reasonable understanding of the notion of independent advocacy and its value. As far back as 1987 an early independent advocacy service in Leeds was reporting 'a mixed reception with a great deal of their time being spent on initial negotiation about their role with hospital staff' (Mind 1992). It appears that not much has changed in this regard, suggesting that resistance to advocacy remains strong in some quarters, or that the training and induction effort is failing to meet its objectives.



Even the most knowledgeable staff, who were well disposed to advocacy, and could speak of constructive working relationships, were often in the dark about their statutory obligations, especially in terms of IMHAs access to records. Given that these mental health professionals could also on occasion report engagement in mandatory training and induction about IMHA, this would suggest a need to enhance these training programmes to more completely cover the responsibilities of staff to supporting the practice of advocacy. Further, many professionals did not understand fully the notion of independence in relation to advocacy, becoming confused about the boundaries between this and the sorts of advocacy they themselves might provide in the course of their professional practice. These considerations are complicated further by the fact that various mental health professionals become frustrated or even angry with advocacy interventions that they see as operating against the best interests of the service user. Our findings indicate that the most constructive working relationships between IMHAs and mental health professionals occur when there is mutual understanding of each other's roles and the constraints each other work under. Therefore, it would be opportune for staff training to explicitly address such issues, perhaps in the context of developing reflective practice using vignette case examples or role-play scenarios.

### **The mental health services context – Key findings**

- In delivering IMHA services the importance of building constructive working relationships with mental health services was emphasised.
- Some mental health professionals clearly welcomed the IMHA role in protecting the rights of service users under the MH Act; others clearly experienced it as challenging, even irritating and inappropriate.
- Relationships between IMHAs and mental health professionals are complex and multi-faceted. The organisational culture and disposition towards advocacy of mental health professionals impacts upon the extent to which the mental health context is supportive of IMHA provision and takes steps to actively welcome it.
- Accounts of positive relationships reflected an understanding of the needs for IMHA provision; its utility and potential outcomes for qualifying patients. On the other hand, negative accounts of relationships were often framed around uncertainty or lack of achievement of desired outcomes, and certain aspects of the way the IMHA service was delivered.
- Where there are positive working relationships advocacy is understood and appreciated and any challenges to mental health professionals are dealt with equanimity.
- On occasion there is resistance and conflict and this can lead to complete fractures in working relationships between IMHA and mental health services.
- Previous experiences and history of advocacy involvement with services, often predating the introduction of IMHA, can be influential in the current reception afforded advocacy.
- Understanding of advocacy, the IMHA role in relation to the mental health professional's role and best interests emerged as critical in influencing how mental health professionals viewed, responded and supported IMHA interventions.

## 11. MAKING A DIFFERENCE

### 11.1 Overview

A recent evidence review of independent advocacy made a key distinction between the benefits arising from the process of advocacy and those resulting from the outcomes, and further, that the outcomes of independent advocacy may not always be perceived as beneficial, even when the process has been positive (Townsend, Marriott & Ward, 2009). The consensus of opinion in our study, particularly among service users, was that IMHA was of benefit to qualifying patients, and that this was both as a process and in terms of outcomes or impact.

At one end of the spectrum, IMHA could be life changing while at the other, its benefits might be limited, especially when outcomes desired by service users are not realised. As preceding chapters have explained, IMHA was implemented under the 2007 Mental Health (Amendment) Act to help qualifying patients understand the legal provisions to which they are subject, and the rights and safeguards to which they are entitled, and to help those patients exercise their rights through supporting participation in decision-making. This chapter now analyses the different views about the impact of IMHA by first exploring aspects of satisfaction and dissatisfaction with IMHA support and then examining the benefits associated with the process as well as outcomes.

### 11.2 Satisfaction with IMHA

Commonly, IMHA partners (in hospital and the community) expressed satisfaction with IMHA and felt they benefited in some way from the help and support of their advocate. Satisfaction was not a straight forward measure however. A few IMHA partners reported both satisfactions and dissatisfactions with the same IMHA, which was closely related to the distinction between feelings about the process compared to the outcome. IMHA partners' satisfactions with IMHA were rooted in both the advocate's approach and manner, for example, because they listened and made sure the service user's voice was heard and, secondly, because the advocate had helped them to achieve desired outcomes. Often it was said that IMHAs helped them navigate around the sometimes bewildering and frightening territory of mental health services, and at times seemed to be the only person on their side:

*"I'm pleased with what she'd done, I think she's been very good ... I think she's excellent at her job and I think she's you know experienced..."*

*IMHA partner (Acute ward)*

*"I've definitely seen a lot of help going on and I think the bottom line is where will the people be without them...because very often like your family*

*or, people haven't got family to deal with that have they, or friends or... and they need somebody on the ward."*

*IMHA partner (Acute ward)*

Where IMHA partners were dissatisfied, this tended to be because they did not think the advocate had helped them change anything about their circumstances. A view expressed by a significant minority of IMHA partners was that advocates were powerless to influence mental health services and so any benefit from IMHA was always going to be minimal. A tiny minority felt that the advocate had not spent enough time with them; a perception that was supported by what some mental health professionals also observed:

*"They're very good when they're in the meetings but I just sometimes think there needs to be a bit more preparation around what it is the person wants... I do think that they need to spend more time with the people. I am aware that their workloads are massive but I sometimes think that they do dip in and out and I'm not always sure that that always gives them a good grasp of what actually is going on in the person's life... they should be a finger a bit more on the button around what's going on."*

*AMHP*

A couple of partners felt IMHAs should be more knowledgeable about care issues and/or medical terminology than they were, especially when they themselves were more knowledgeable than the IMHA. Similarly, a few mental health professionals remarked that IMHAs knowledge base, including what they knew about mental illness or distress, as well as about services, was limited:

*"I'm continuously dealing with doctors and I talk at their level and I have that understanding and therefore I remain at that level and to actually to engage with somebody who is not understanding that, it is difficult for me. Especially when I'm unwell...it took a lot of effort for me to, to put it into crystal clear... I have to do all the explanation...and the explanation wore me out."*

*IMHA partner (Rehab ward)*

*"Sometimes, depending on the worker, they don't always perhaps understand the full extent of mental illness, and it might be that somebody's gone in and said whatever they're not happy with but it's all wrapped up with their illness as well, and they [IMHA] don't always seem to be able to kind of think, they're very fixed sometimes in like this person said this, you must do something about it, and actually it's not quite as simple as that."*

*Ward Manager*

More negatively, a few IMHA partners regarded some advocacy inputs as ineffectual, for instance they wanted more than an IMHA "dropping by asking 'how are you

doing?” Others, who were otherwise satisfied with their advocate, were unhappy with progress on agreed actions, or felt the advocate was not keeping them well informed:

*“He said he’s going to speak to the Dr about these places, he’s going to tell him that it means ‘he’ll be off his section’, but I don’t know if he’s seen him yet so...”*

*IMHA partner (Forensic learning disability service)*

Even where a specific change had occurred as a result of IMHAs’ input, the benefits to IMHA partners could be short lived and, in the longer term, some felt there was a ‘price to pay’ when the advocate challenged aspects of institutional life; benefits that ultimately came at a cost:

*“...I got the impression that she didn’t really understand that on some things there’s a price for us that we pay and I suppose in real terms of what I’m saying is that the advocate can help us achieve something but further down the line, whether it’s the next week or the next month, we pay a political price for it and that’s the way the poisoned piece of institutional life, that’s the way that it is.”*

*IMHA partner (Low secure unit)*

Many mental health professionals interviewed for this research were neither satisfied nor dissatisfied with IMHA on account of having little experience of it. Some were knowledgeable about advocacy generally (especially AMHPs) and were keen to recommend it, but had little or no direct experience of service users in their care making use of it. This was particularly, but not exclusively, the case with community based staff working in CMHTs, Psychosis Teams and Assertive Outreach Teams, or hospital based professionals from one or two sites. The tone of professionals’ appreciation of IMHA tended to be less positive than service users, and was often framed in terms of it not having been problematic (perhaps hinting that some problems had been anticipated but failed to materialise or there had been initial problems):

*“To my knowledge, we haven’t experienced any particular issues with IMHAs. There hasn’t been anything that’s raised any concerns or you know ward staff haven’t come to me and said ‘we’ve got this issue’... and similarly from the IMHAs point of view they haven’t raised any issues that staff have been resistant to give them access... as far as I’m aware there aren’t any problems.”*

*MH Act Administrator*

Professionals’ satisfaction was mainly with the process, for example, mentioning the conduct and/or skills of the IMHA in communicating with service users and the important part they played ensuring service users had a voice:

*"The IMHA's we've had come in have developed very good relationships with the patients very quickly and they've done that very well and in a way with what can be a very difficult client group. And they obviously come in with a fair amount of confidence in themselves to do that because it can be quite a daunting environment to walk into, so I think that's all credit to what they're doing."*

*Ward Manager (Forensic ward)*

As was discussed in the previous chapter, mental health professionals sometimes highlighted the benefits of IMHA in relation to their own role when it was perceived as complementary. It was also the case that the benefits of IMHA were less well recognised by professionals than service users, partly because some felt they themselves played an advocacy role with their patients and saw no need for independent advocacy.

*"I know that we're not independent advocates but we do sort of try and act in the best interests of the patient so there wouldn't necessarily I don't think be a great divide in what the advocate would wish for or the patient would wish for that's ultimately achieved in the end."*

*Deputy Ward Manager (Acute ward)*

Other professionals were highly sceptical of its effectiveness:

*"Sometime you wonder whether the services of the advocate are cost effective because if the patient is well communicative and is in the ward round, the patient is asking everything and then the advocate they say 'we have got nothing to add' which means you know you start thinking that these days it's a matter of time and money, and for each patient the advocate spends roughly two, three hours you know, so is it worth it?"*

*Psychiatrist*

In one site, a ward manager working in deaf services questioned the effectiveness of the IMHA service for this particular client group, suggesting that in reality it was "a bit of a paper exercise". Not only that, but some professionals, particularly psychiatrists and ward staff, considered IMHAs' input as sometimes counterproductive to the clinical team's interventions and service users' 'best interests', which suggests they had misunderstood the role of independent advocacy:

*"...sometime I think you know the advocates they have been pressing a little harder than they should be for things like obtaining leave when they have been explained you know it is not possible or it is not in the interest of the patient to give the leave, but they still insist."*

*Psychiatrist*

More unusual were those mental health professionals who were dissatisfied with it because they felt IMHA had not lived up to its own expectations in that it had not challenged services enough on service users' behalf. Some professionals felt that the potential benefits from IMHA had yet to be realised:

*"...the way it was talked about in the Act is not what we're getting. I expected even them showing their teeth really, almost like a Solicitor, in fact having more powers than a Solicitor because they're not controlled by money and time and legal aid. I expected them to come and really be a 'pain in the arse'... I expected people to be constantly asking to see our files, constantly asking to see our notes, constantly on the phone asking what we're doing and why we're doing it, what's gone wrong, constantly harassing the doctors you know 'you're saying the person was having treatment, why aren't they having the treatment?' and it's just not happened."*

AMHP (Community team)

### 11.3 Impacts of IMHA

While the end outcome of IMHA might not be, for example, that a Section is removed, that leave will be granted, or detention in hospital reduced, or anything as tangible as these effects, the significance of IMHAs acting to safeguard service users' rights was emphasised repeatedly, as expressed by a mental health professional:

*"Even though the outcome for the patient might not be always what they want, at least the processes are there to try and enable them to exercise some influence on the processes that are going on rather than it just being a sort of like a done deal as it were, and that's it, 'right okay you're sectioned', there's no recourse for you to challenge that or to have somebody put across your point of view, and I think that's vitally important."*

Ward Manager

Similar to the distinction made by Townsley, Marriott & Ward (2009), our findings point to a key difference between the benefits associated with the *processes* of IMHA and the benefits resulting from the *outcomes* of that process. It was also the case that even when the process was reported as positive and service users were satisfied with the IMHA, the outcome might not always be viewed as beneficial:

*"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 (Rehab unit)

In other words, a clear causal relationship between a positive process and a positive outcome was not always found, which as Townsley et al (2009) suggest, is something



that warrants further research attention. A minority of IMHA partners and some mental health professionals in reality could only identify minimal or no impact from IMHA. In some cases, there was a lack of appreciation of the impact (on process for instance), or lack of knowledge about what constitutes a recognisable outcome of advocacy. A sense of this complexity was conveyed by what one partner said:

*"If I hadn't got what I wanted I could be saying 'oh she was useless' but that wouldn't really be a reflection on her ability. That could be a reflection on my mental health you know. I could have been reassessed for leave and the decision could have been very clear that I wasn't well enough, but she'd made the request and got me that reassessment. So I think it depends on your personal outcomes as to how you view how effective they [IMHA] are."*

*IMHA partner (CTO)*

The lack of positive impact for some was laid at the door of poor quality and unresponsive care services with some service users being fatalistic – *"there's nothing the IMHA can do, they (staff) don't listen"*. Furthermore, independent advocacy was limited in what it could do to tackle structural causes of distress or disadvantage, with any help given addressing only the symptoms not the root causes of such problems. As an IMHA pointed out, IMHA services alone might have little impact given some people's social circumstances:

*"They're leaving hospital with great issues that probably led to their deterioration. It's a case of you are back to that one bedroom flat in the back of beyond and all the debt letters that you've been getting and all the eviction letters that you've been getting from the landlord or whoever and everything else that was going on in your life that was the reason why you ultimately sat down and decided 'I've had enough' and did something about your mental health and deterioration... going back to exactly the same situation prior to coming to hospital."*

*IMHA (Focus group)*

There was also a notable strand of critique that dismissed that advocacy had any impact at all. Some nursing professionals who were hard pressed to identify the impact of IMHA on their work did so because they saw themselves as the *"patient's advocate"*, and as being capable of addressing the same concerns as the IMHA, or they were happy that their own work was of sufficiently high standard not to warrant criticism. Even where mental health professionals were positive about the contribution of advocacy, a few preferred to believe that they would do a good job without independent advocacy, thereby negating its' benefits.

The process and outcome impacts of IMHA identified by participants in this research are summarised in the table below. The distinction is usefully explored, even though in some cases the impact may be both in relation to process and outcomes, thus

making it impossible to disentangle one from the other. In the next paragraphs, we discuss process and outcome separately as far as possible, commenting where relevant on the overlap between process and outcome.

Process	Outcomes
Ensuring service users have a voice	Service users' understanding and knowledge of rights and of treatment increased
Increasing service users' confidence	
Increasing service users' sense of well being	Helped towards service users' recovery
Someone alongside, on your side	Service users empowered to exercise rights
Providing information to increase understanding	Service user participation in decisions affecting their care and treatment
Supportive, empowering approach	Acceptance of the status quo
Performing an important safeguarding function	Successful resolution of complaints increased

**Table 10: Summary of identified impacts of IMHA in relation to process and outcomes**

### 11.3.1 Process

Consistently, the answer IMHAs and advocacy managers gave when asked about the difference that IMHA made was that it ensured the voice of service users was heard, and that they were supported to exercise their rights while subject to compulsion. Such rights might include the right to appeal the Section under the MH Act, or to have an IMHA involved at meetings discussing their care and treatment. The following was a typical response, also supporting the earlier point that while the outcome of IMHA might not always be what the service user had wanted, the process had still been positive:

*"The outcome is about ensuring that person's voice is heard and that they understand what their rights are and that they've had an opportunity to exercise those rights. So it's not necessarily about them getting what they want in the end of that, it's about the process of supporting them, ensuring that they're kept at the centre of the decisions that are being made about them, and that they could feel confident that they've been listened to and understood by services."*

IMHA

Similarly, much of the impact identified by IMHA partners and mental health professionals was also process-related. When asked about the difference IMHA made, these participants frequently spoke about IMHAs ensuring the service user's voice was heard, providing information to increase service users' knowledge and understanding, making a difference through a supportive, empowering approach, and increasing service users' self-confidence so that ultimately they felt empowered to say what they wanted.

### **☞ Supporting the service user voice**

Various examples confirmed that IMHA was influential in adding weight to the service user's voice. This in itself was considered by many as the key benefit of IMHA. As the following quotations highlight, IMHAs had ensured service users' voices were raised within mental health services. Through active support and encouragement, IMHAs enabled advocacy partners to speak out, especially important in situations where there were competing viewpoints:

*"She was there for me when I wanted her... She's a good support and she's sort of like encouraging me to talk out and speak about it and it's not a stigma... the best thing is it's not a stigma and I've got to get that over to people."*

*IMHA partner (Acute ward)*

*"They're quite vocal for the patients if the patients wish it and they do want to be engaged and do want to be involved with the meetings because we have a lot of cases where even though families are involved, there's pressure from families on the individual, and sometimes that patient's voice is not heard, so it's sometimes very important to get the IMHA..."*

*Ward Manager (Older persons' ward)*

*"[In hospital] I felt like I was being punished, I felt like I was on remand rather than in hospital, and it was nice that I had the advocate because I felt like it was the only voice I had apart from my own, you know..."*

*IMHA partner (PICU)*

This notion of voice was central and was often expressed as shorthand for the impact of IMHA. Supporting the service user voice has a number of corollary effects including enhancing self-confidence, positive sense of agency and identity, and, for some, improved relations with mental health professionals and concordant treatment programmes, ultimately impacting upon, and improving, individual well-being.

For some, the process of ensuring the individual's voice was being heard had resulted in tangible outcomes. For instance, there was an improvement in one IMHA partner's treatment on the ward after the IMHA made sure that her special dietary

requirements, which had thus far been ignored by nursing staff, were heard and acted upon. The IMHA commented:

*"All I did was tell them what she'd already told them, and they [nursing staff] went, 'oh I didn't realise, we'll sort that out right now.'"*

IMHA (Focus group)

For some professionals, this support to ensure the service user's voice was heard was identified as an essential element of proper care planning and delivery, acknowledging that sometimes service users will not be as open with the professionals involved in their care about their needs or problems, or that professionals may fail to pick up on these. Alerting professionals to new ideas from a service user perspective and challenging them not to take matters for granted or assume their own view of service user needs is completely accurate is as much about an organisational approach as an individual care issue:

*"I mean obviously when they're in meetings people are aware they're there and aware that they're going to you know say what the service user's view is, and it's not always what you're thinking, and so that's sometimes a bit of an organisational thing. You think 'we weren't aware they were thinking that.'"*

AMHP

## **Having someone alongside**

Related to supporting the service user voice, was the sense of there being someone who service users felt was on their side, someone who essentially was fighting their corner. Positive experience of IMHA was associated with how their input reduced service users' feelings of isolation within what was to some a bewildering and frightening system (see also Chapter 4). Having someone else who was "on your side" and listening to their point of view was invaluable:

*"It is important to have someone to talk on your behalf if you can't. It helps your confidence. I felt more comfortable to know that someone really understands and cares about you, alongside you, not just a stereotype."*

IMHA partner (Medium secure unit)

*"Well practically there wasn't much of a difference, the doctor didn't respond to her and respond to her suggestions....but I felt more empowered, I felt more able to get the right outcomes, with somebody there who was on my side. She made me feel like, yes I can deal with these issues that I wasn't getting anything, any help with. She made me feel empowered basically."*

IMHA partner

## ☞ Providing information on rights and treatment

As would be expected, IMHAs impacted on the experience of compulsion as a result of the process of providing information on rights, the part of the MH Act which applied to the individual, the care and treatment service users were or might receive, and so on. IMHA services made an important contribution to the process of increasing their partner's knowledge of the restrictions they were placed under and understanding of their rights under the law. Advocates, for example, researched aspects of care and treatment at the IMHA partner's request so that they had a better understanding of proposed treatments, and by recording what was said in meetings were able to chase progress:

*"They will tell you what they're going to do, note down everything you say, tell you what they're going to do and keep you informed on things so that you know exactly where you are and what's going to happen."*

*IMHA partner (Acute ward)*

*"She went beyond the call of duty like going on the internet and looking up and finding out what schizoaffective disorder was, printing it out and bringing me the printouts of the definition and how it's diagnosed, I thought was beyond the call of duty."*

*IMHA partner (Acute ward)*

## ☞ Supportive and empowering

Numerous IMHA partners and mental health professionals provided examples of IMHAs helping service users to exercise their rights, including representing them and speaking on their behalf, and supporting them in a range of other ways to ensure they were able to participate in the decisions made about their care and treatment. The person-centred approach of IMHAs alongside individual advocate's approachability and ability to relate to people at all levels, were often mentioned by IMHA partners as having an impact on how they felt as well as on what happened to them:

*"If he's on the unit and he's got ten minutes he'll sit down and have a cup of tea, and people will either make an appointment with him for some other time or they'll just chew the fat in general you know."*

*IMHA partner (Low secure unit)*

*"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, you know because I haven't had me glasses, you*

*know. So things come out as you're talking, you know, so she's sort of like putting down into words on paper what you might be gabbling on about."*

*IMHA partner (PICU)*

## **A safeguarding function**

Several IMHA partners and some mental health professional identified how the presence of IMHAs on the ward and at various meetings acted as an important safeguard against poor practice and as such was potentially a force for changing practice. IMHA activity and presence was considered by service users to open up the ward space to external scrutiny:

*"Once a week there's two young girls come from the advocacy service and they're on the ward, it opens it up, it makes things transparent... it changes the dynamic... The fact that they're on the ward is a positive thing, is a great thing and the more professionals that are in here rummaging around and opening this place up the more that light that comes on it and the more open and transparent it becomes... [Staff] are being a little bit more careful, are being a little bit more wary..."*

*IMHA partner (Acute ward)*

Mental health professionals linked the notion of independent scrutiny and involvement to provision of a good quality service, and as having a check and balance effect on services becoming overly controlling of people's lives:

*"...just knowing that there is an independent service out there that the patients can be referred to, that they can access and that will listen to their point of view, I think that in itself is a major sign of providing a quality service... I think it's a safeguard as much as anything because otherwise I think there's a danger that services can, if you like, exert too much control and we can have too much influence... if you've got an independent ... it's going to keep us on the straight and narrow..."*

*Ward Manager*

*"I think their coming in is actually improving the service we provide... in Tribunals... there's more challenge, there's not just the Judge, the advocate is there, the IMHA is there. So it also improves the way we work and it gives us that extra, wanting to do things better, knowing if you are not, you are just going to face it in Tribunal."*

*Social Work Manager*

As part of the process, IMHAs might contribute to better quality hospital discharge plans: in supporting an individual to have a voice, an IMHA might for instance challenge arrangements for housing and aftercare support when these seemed inadequate and at odds with what the individual wanted to be in place. Effective

advocacy practices had also helped increase mental health professionals' confidence that they had adequately balanced the ethics of safeguarding patients' rights alongside a duty to protect the public:

*"Protecting the public, protecting the service user, that's a very fine line that you walk around... so it's good that the service user has somebody there who's not part of that decision process..."*

AMHP

### 11.3.2 Outcomes

Given the purpose and role of IMHA, the outcomes might be expected to include: improved understanding of rights and provisions under the MH Act; service users exercising their rights more often; and improved participation in decisions affecting their care. While evidence pointing to IMHAs enabling service users to better understand and exercise their rights was plentiful, it was less substantial in terms of improved participation in decision making across mental health services. A number of outcomes were identified by research participants and these are now discussed.

#### ☞ Increased understanding and awareness

For IMHAs, an obvious outcome from their input was that service users' knowledge and understanding of what was happening to them, and what their rights were under the MH Act as well as how to exercise them had improved ultimately ensuring that individuals made informed decisions:

*"I want that person to know about their rights, be fully aware of the legalities of their Section... so that they're going in to get their own rights upheld... That's the sort of outcome that I would like. I don't want people saying 'oh the IMHA said that, oh the IMHA said that', because again you know it's all part of... advocacy is all about empowering people."*

IMHA

Indeed, increased understanding and awareness of rights under the legislation was mentioned as the key benefit from IMHA by several IMHA partners and mental health professionals. Importantly, from IMHA partners' perspective, this had resulted in greater insight into their own situation:

*"He made me understand a lot of things... he explained a lot of things all the time, he made me understand why I was in hospital. He made me understand my rights and my voice and everything..."*

IMHA partner

*"I wouldn't be as well as I am I don't think today without their help or if I was I wouldn't have so much insight shall we say so it helps with insight which is something psychiatrists are very fond of saying, you know, 'they*



*have insight' or 'they don't have insight', and it's looked on as a good thing. So to have more insight I think is perhaps how it helps particularly."*

*IMHA partner (Focus group)*

Furthermore, having a better understanding of the MH Act and rights was believed to be an important safeguard to avoiding future unnecessary detention:

*"In my case it was the CTO, the Community Treatment Order, knowing about that, providing with the information which I also sent to my nearest relative in London so she would know about it and I spoke to my dad about it as well... It helps my family understand and I told my sister about it because she lives abroad now so therefore I informed my support network, my immediate support network so that they would understand that I wouldn't fall through a safety net again and end up in a place like this, through no fault of my own."*

*IMHA partner (CTO)*

### **Supported 'Recovery'**

Closely linked to having better understanding and awareness of rights under the MH Act and of treatment options, was what a few participants referred to as an increased sense of control or agency. Some participants directly identifying IMHA as helping towards their recovery:

*"It's about outcomes in relation to people having a sense of control and, if you can hope for that, a better experience of being statutorily detained... That within the context of their illness and crisis understand as best they can why what is happening to them is happening to them and have a sense of control over that instead of feeling victimised by it, and I think it's something to do with patient experience partly but it's also... people's management of their own condition."*

*PCT Commissioner*

The importance of IMHA services in assisting service users regain a sense of personal agency and recovery was further emphasised by another mental health professional who hypothesised that IMHAs involvement could potentially lead to individuals leaving hospital earlier:

*"It's about taking ownership and helping people if you like on the journey to recovery I would actually suggest that the role of the IMHA will reduce the need for hospital stay, should reduce the length of time people are on a section, which is actually helping make the journey towards wellness a lot smoother... it probably has a very significant impact on people's speed of*

*recovery, the difficult thing is I don't know whether that's quantified anywhere."*

*AMHP (Older adults)*

Some IMHA partners confirmed this belief that having an IMHA had helped them to leave hospital quicker than they might otherwise have done, and had thus contributed positively to their recovery:

*"She [IMHA] was able to help me get some leave and that was good for me. Getting off the ward was beneficial to me and the fact that she helped me be able to kind of cheat the system a bit so that I wasn't detained under the Section 3, that helped me a lot because I'd given up... She helped me to have some time away from the hospital to start to think and to start to realise that life outside wasn't quite as awful as I perceived it to be. So yeah she did help me get better but by enabling me to have something positive happen."*

*IMHA partner (CTO)*

*"Well he thinks that he got released from hospital quicker due to her help because she was like... well kind of really like a therapist who was listening to his concerns... He thinks that he was released from hospital quicker due to those meetings."*

*Interpreter for IMHA partner*

## **Empowered to exercise rights**

Cases where IMHAs were felt to have enabled or empowered service users to exercise their rights were mentioned both by advocates and IMHA partners. While a concrete outcome (such as changing the level of restriction, or lifting the Section) might not be what is achieved for some people, there was evidence of IMHAs enabling their partners to actively participate in forums where they could exercise their rights, for instance:

*"I've got one patient and she wouldn't go into her clinical review but because I was there she agreed to come into it. Now if that's empowered her to go into reviews in the future, that's an outcome for her. Although you may not actually have changed anything, you've enabled her to go into that meeting, and for her voice to be heard in the meeting."*

*IMHA*

IMHA partners felt that the IMHA had not only made them aware of their rights but had been essential in ensuring that they had been able to exercise those rights in reality:

*"It makes a difference. It was faster to get a solicitor. I don't know how else I*

*would have got my notes without the IMHA. I wanted to see my medical notes and I got to see them."*

*IMHA partner (Medium secure unit)*

*"Very, very useful because they told you how to set about doing this and giving you all the legalities and how you had a right to... and even which laws to use and which bit to quote and all the rest of it which was very, very useful."*

*IMHA partner (Acute ward)*

Indirectly related to increasing service users' rights, was the impact on referral for IMHA services: some suggested that advocacy activity on the wards had increased professionals' understanding of qualifying patients' right to have an IMHA, thus resulting in higher referral rates of qualifying patients to IMHA services.

### **☞ Participation in decisions affecting care**

With the help of their IMHA, some IMHA partners had successfully challenged aspects of their care and treatment, and in some cases, affected the level of restriction they were placed under. While such accounts were not common, a few IMHAs and partners did identify situations whereby support from an IMHA to express their point of view had resulted in significant change as in the following example:

*"A lady who was on a psychiatric intensive care ward was being sort of regularly restrained and forcibly medicated, which was really distressing as you can imagine, and she was able to tell me why she was getting so upset and why she was getting so angry and she wanted them to stop doing that but she couldn't stop the way she was feeling... She was able through me to tell them and... they were able to have that discussion and then she didn't have to be restrained any more, and she went onto a normal ward and she was quite relieved."*

*IMHA (Focus group)*

One of the most difficult issues for IMHAs to engage with effectively was identified as supporting service users who were seeking to negotiate change in their medication plan. Some IMHAs reported limited success in this aspect of decision making on account of a prevailing psychiatric culture that did not perceive service users as 'experts by experience'. Nonetheless, as the following case vignette powerfully illustrates, we did find some positive examples of IMHAs having supported individuals to participate in such decisions.

### Case Vignette: Finding My Voice

A young asylum seeker was effectively rendered mute through his experience of mental distress when he was detained under the MH Act. Over time, and with the help of an IMHA, he eventually found his voice and was able to successfully negotiate with his care team about his drug treatments. When the care team had not acceded to his wishes, they provided meaningful explanations for their decisions and left future possibilities open. This has involved progressing from depot to oral medication. The service user was happy with this, and ultimately he could see the benefits of taking medication for himself. He advanced from not speaking at all, to being able to speak up for himself, via a period when the advocate spoke for him (initially through the medium of reading notes which the service user wrote down). Being supported by an IMHA to have a voice promoted satisfaction with services and concordance with treatment plans by having a say in them, even if the eventual plan was a compromise between his demands and the care team's judgment.

**Figure 13: Case Vignette – Finding My Voice**

#### ☞ Acceptance of status quo

A consequence of IMHA identified by a minority of IMHA partners and mental health professionals was that communication between service user and the care team was improved, and service users felt the IMHA had helped them to come to terms with or be more accepting of the status quo as this would be of benefit to them in the longer term. The following excerpt from an interview shows that although the partner felt the IMHA had helped her to have a voice in the system, she had also been helped to understand how the system worked and when to ask and when not to ask questions:

**IMHA partner:** *"He [IMHA] made me realise what expectations the doctor wanted from me and the nurses and all the staff and that's I think ... without him I suppose, you know it was like coming to my senses to realise what they wanted from me."*

**Interviewer:** *And what sort of things did they want from you?*

**IMHA partner:** *Em... well there was so many things, em... you know there was so many things really and... em... when I realised that I started to react in a different way and that's what was a help to me."*

**Interviewer:** *So you changed your behaviour and stuff?*

**IMHA partner:** *Changed behaviour and the way I felt, you know and not a lot of confrontation with the nurse... I didn't have any arguments with the nurse but not to ask them too many questions, sort of said things in some ways so that I can get out as quickly as possible 'cause I used to go up and*

*ask them questions all the time you know things like that I used to say to them 'when are we going to have our fresh air?' you know things like that, it's like I started to realise it wasn't a battle anymore, it was... I've had to agree with what they say and go with what they say for the moment, even though I had a voice or even though I thought things were wrong or things wasn't right I had to agree with certain things you know."*

Similarly, some professionals suggested that IMHAs helped to facilitate more constructive relationships with the care team to service users' benefit. On the contrary, others reported minimal or no impact on this relationship. A corollary effect was the IMHA's role in diffusing problems and easing service users' settlement into ward environments:

*"I think they add to what we have to offer to our patients and they can often help to defuse general problematic situations by being involved and providing something at a way that's delivered at a patient level and sometimes not directly from the care team... and that supports patients in the settling into what can be a difficult environment."*

*Ward Manager*

### **More successful resolution of complaints**

Some mental health professionals reported a reduction in complaints as a consequence of IMHA, and also improvements in the services' capacity to resolve complaints, together with a sense that increased service user satisfaction with mental health services was to everyone's benefit:

*"[IMHA] does sometimes help the patients see another solution before going a formal route. And I think as well the nurses have become much more adept at trying to resolve issues locally and that might be saying to somebody, 'Well if we can't do it will you talk to an advocate and see what's going on?,' so I think generally the complaints have gone down because there's been an effort by the nurses as well to resolve."*

*Psychiatrist*

Conversely, some mental health professionals felt that the involvement of IMHAs had served to increase the volume of complaints, and this was backed up by the views of some advocates and their perception of professionals' views on this matter.

## **11.4 Measuring Impact**

The importance of demonstrating that IMHA, indeed any advocacy, is making a difference to individuals and communities is undisputed. However, there were different ideas among participants in this research on how this should be done. Action for Advocacy (2009) - in examining how to define, describe, measure and monitor outcomes that are relevant to the advocacy sector - recommends

developing monitoring systems that incorporate multiple viewpoints. In this study, there was evidence of a number of tools already in use by IMHA providers including satisfaction ratings scales, user feedback forms, *Advocacy Outcomes Star* (Action for Advocacy, 2009). However, there was room for developing more robust information. Service users had been asked to provide feedback on the support they had received, although this was not consistently the case across all IMHA services. Commissioners were making varying demands on services to produce evidence of their outcomes.

There was a degree of consensus that the most appropriate measures should be based on measuring the outcomes associated with the key role and purpose of IMHA for example qualifying patients' increased knowledge and understanding of their rights, a decrease in the number of unlawful detentions and an increase in the number of appeals or challenges to decisions and the system. However, the latter was also viewed as a rather crude measure and some suggested that it was the quality of appeals that had changed that could be attributed to IMHA services.

This research found the impact of IMHA to be differentiated in terms of process and outcome, and also that service user satisfaction with each can be different. Therefore, a sole focus on proxy outcome measures would seem overly simplistic and unhelpful. Any measurement needs to take account of the complexity, as well as of multiple stakeholder perspectives. Likewise, measures of satisfaction must look at aspects of satisfaction with both process and outcome. The following is one example from our study of how an IMHA service, in response to a demand from its commissioner to look at developing outcomes measures, identified potential measures. This was developed after a telephone survey of former clients.

- The person using advocacy will feel they are making progress with the issue(s) they bring to advocacy.
- The person using advocacy will feel they are being heard/listened to more.
- The person using advocacy will feel they know more about their rights and options.
- The person using advocacy will feel they have more influence over decisions.
- The person using advocacy will feel better supported/less distressed in relation to the issue(s) they brought to advocacy.
- The person using advocacy will feel more confident about dealing with the issue(s) they bring to advocacy.

**Table 11: Six personal outcomes of instructed mental health advocacy including IMHA**

Some mental health professionals raised the issue of cost effectiveness, and the need to measure this in respect of IMHA services. One service had begun to do some work on the social return of investment for advocacy services and this is an important development. We were unable to look at cost-effectiveness in this study because of

the quality of the information available. However, if one of the outcomes from IMHA provision is that people receive a more appropriate service, informed by what they want and consistent with their personal recovery goals, then it seems likely that IMHA provision will both be cost-effective and provide a social return on the initial investment.

In conclusion, while the findings of this study provide some useful data on process and outcomes, there remains a need for more systematic information monitoring of the impacts of IMHA. This needs to include both service user defined outcomes, as illustrated above as well as aggregated outcomes. These measures will rely on a variety of both quantitative and qualitative measures to measure outcomes, developed with IMHA partners, other service users and carers. They could include:

- Quantitative data (through case note audits or analysis of routine data) on the changes in unlawful detentions; the number of people exercising their rights for example to appeal against a Section, and changes in the care and treatment under the MH Act.
- Qualitative measures (through surveys, interviews and routine feedback from service user groups or through questionnaires) on the quality of appeals: changes in qualifying patients' knowledge and understanding of their rights; changes in the service user's confidence and ability to self-advocate; assessment of involvement in decision-making about care and treatment; satisfaction with the IMHA service, both the process and the impact.



### **Impact of IMHA – Key Findings**

- Service users were highly satisfied with IMHA and the majority felt they benefited in some way.
- Both IMHA partners and mental health professionals recognised the main benefit from IMHAs was ensuring service users had a voice.
- Similar to other studies, this research found a key distinction between the impact of IMHA in terms of the process and outcomes with most impact identified being in relation to the process.
- As expected, IMHA had empowered service users to exercise their rights by, for example, appealing the Section, accessing legal representation, and participating in CPA, Managers' hearings, ward round meetings and Tribunals.
- For some IMHA partners, the outcome of IMHA was that they were more accepting of the status quo because the IMHA had helped them understand that this was the way to achieve the outcome they wanted.
- While a concrete outcome (such as changing the level of restriction, or lifting the Section) might not be what is always achieved, there was a high level of satisfaction with the process of IMHA.
- A minority of IMHA partners and some mental health professionals in reality could only identify minimal or no impact from IMHA.
- While there were examples of IMHA impacting on individuals' care and treatment, it was less likely overall to be thought to increase participation in decision making.
- Proxy or crude measures of outcome to assess the effectiveness of IMHA would be unhelpful. Any measurement needs to take account of the complexity and to incorporate measures of both process and outcome.
- A few mental health professionals felt that the full potential of IMHA has yet to be realised.

## 12. COMMISSIONING IMHA SERVICES

### 12.1 Introduction

The critical role that participants considered commissioning plays in the development of good quality IMHA services was clear from all the data sources. This chapter provides an overview of how IMHA services were commissioned in the eight case study sites, findings in relation to the commissioning process and how commissioning could be strengthened in the transfer of responsibility for commissioning IMHA services to local authorities in 2013.

### 12.2 Introduction of IMHA services

From the interview and focus group data it was evident that the majority of PCTs were poorly prepared for the introduction of IMHA services, with the majority commissioning the existing provider on the basis of historical patterns of use, as most advocacy providers pre-2009 were providing independent advocacy to inpatients, including those detained under the MH Act:

*"When we first looked at IMHA what I did was create a contract variation for the existing advocacy service so that they could provide IMHA in the time frame that we had available, it was the most expedient solution."*

*PCT Commissioner*

Thus, specific concerns about the quality of commissioning and the process of transition were raised, with participants describing gaps in service provision whilst areas waited for new organisations to take over service provision. IMHAs commented on the apparent lack of recognition of the time and resources that it takes to train staff and build the organisational capacity and relationships with qualifying patients and mental health services to deliver effective IMHA services:

*"At the start up I mean you get start up costs which are nothing to do with what the advocacy is doing but you know the actual start up of providing an advocacy service where one hasn't existed before isn't something that you can't do within a few weeks or sometimes even within a few months, It's quite a long process to get established and quite a long process sometimes to build up trust with the client group that you're working with."*

*IMHA (Focus group participant)*

Not surprisingly, some advocacy providers felt that IMHA had been imposed on them and that what was needed was well developed generic mental health advocacy services that could address a broad range of issues, including protecting people's rights under the MH Act. Indeed, some IMHAs felt that the introduction of the IMHA role under the 2007 Act had little impact on their role but felt that it had led to

restrictions on the range of advocacy provision and consequently a loss of valued colleagues and high calibre staff:

*"The commissioning side of things had a choice whether to keep their hand running mental health advocacy services or just run the IMHA services. They had a statutory duty to have the IMHA service so they thought 'fine we'll just take that' and they've jettisoned the existing one which had been around for many years, been built up a very, very good relationship with the... with both staff and client groups."*

*IMHA (Focus group)*

However, it was also evident that some commissioners had used the opportunity to rationalise advocacy services:

*"What we decided to do, was to bring together a lot of smaller pots of money and bits of work in terms of advocacy into one big contract and this included the existing services for Learning Disability Advocacy, Mental Health Advocacy, a small Physical Disability Advocacy service plus a pilot that we were running for IMCA, plus we put into the DOLS service that would start on the same date and IMHA."*

*Joint Commissioner*

This commissioner explained that the purpose behind this was twofold. First, to achieve benefits of scale and thus reduce costs on duplicating systems or performance managing a number of small contracts. Second, the hope was that the service would be more responsive for people who didn't automatically fit just into a particular category and would thus be better served by bringing the different types of advocacy services together.

Comparisons were drawn by IMHA services and commissioners in particular, to the contrasting arrangements for the implementation of IMCA services, and to features of this process that would have been helpful to support the implementation of IMHA services. In particular, the transparency around allocation of resources and the centrally driven monitoring requirements, allowing comparisons across different area to be made, were highlighted.

### **12.3 Commissioning arrangements**

The arrangements for commissioning IMHA services varied across the eight sites with a mix of joint commissioning and PCT commissioning. Appendix 9 provides further detail, and the majority of services were being commissioned by PCTs, two jointly and one by a Specialist Commissioning Team.

However, at the time of this study, commissioners were clearly testing the market with six out of eight commissioners having tendered for IMHA services within the last year.

As discussed below, there was little evidence of an approach to commissioning based on systematic needs assessment and equality impact assessment, although this was more likely to be the case for services being commissioned within the last 12 months. All of the service specifications reviewed made reference to a general need to reflect the diverse nature of qualifying patients. However, only two commissioning organisations confirmed that they had undertaken an equality impact assessment; although one was unable to locate this to share with us.

Further, it was evident that involvement of IMHA partners, other service users or carers, more generally in the commissioning process, was largely restricted to mechanisms for monitoring service quality. In two instances, the commissioning organisation had relied on the IMHA provider to involve service users in looking at the service specification but there was little information available on the impact that this had made. Several PCTs indicated that this was an aspiration but did not have clear plans in place for how it might happen.

#### **12.4 Needs assessments**

From focus group participants, it was evident that IMHA services were still being commissioned in some areas on what had previously been provided rather than on potential needs and demands. In other places, a needs assessment had been undertaken and the identification of gaps alongside regular monitoring of service quality had enabled the commissioners and IMHA service to understand the gaps in meeting needs:

*"We identified the number of people on qualifying sections in the area, you know the number of sections and the number of individuals, some people have multiple sections in a year, so what we thought was a realistic estimate of the number of those that would actually need and would actually come forward and then there was a tendering process where my providers actually had the opportunity to say what resources they needed to meet that identified need".*

*Commissioner (Focus group)*

However, consideration of the diversity of needs of qualifying patients either by commissioners or the IMHA services in the commissioning process was extremely limited. None of the case study sites had undertaken a dedicated needs assessment for IMHA services, although several indicated that they had looked at the number of detentions under the MH Act and estimated potential demand.

One area had completed a gap analysis, which was used but not initiated by the PCT. Another area explicitly stated in the specification that the demand for IMHA had been estimated from the number of formal detentions and the use of IMHA, but it was unclear whether this took account of the increasing use of Supervised Community Treatment (SCT). Further we found no evidence that data on the

disproportionate detention of people from specific BME communities (for example the Count Me In Census data (for example Healthcare Commission, 2008; CQC, 2011) had been considered.

The value of good quality information, both demographic and related to the MH Act, was viewed as central to commissioning for diversity by BME advocacy providers. Thus, the absence of needs assessments for IMHA services was a source of concern alongside an awareness of gaps in service provision. Participants commented that a thorough needs assessment would take account of the diversity of qualifying patients and well established and emergent trends in relation to the use of the MH Act. Specific mention was made of:

- The disproportionate use of compulsion and number of people on CTOs for BME populations
- Increasing numbers of people being detained under the MH Act and on CTOs
- Demographic changes with an increasing numbers of older people with dementia

From the data collection in the case study sites, we identified gaps in provision for the following:

- Culturally relevant arrangements for qualifying patients from BME populations
- People with learning disabilities
- Deaf people
- Older people
- Children and young people
- People placed out of area

It was originally estimated that 42,000 people per year would qualify for IMHA services. We estimate that the figure may be nearer 50,000, based on figures for the first two years of IMHA provision, as illustrated in Table 12. This difference reflects the increase in numbers of people detained during this time period. These figures do not take account of informal patients who qualify for IMHA services (see 2.2.2).

	2009-10	2010-2011
Number of people formally detained in NHS hospitals (by most restrictive legal status) <sup>8</sup>	42,479 <i>(Number of detentions under the MH Act: 47,725)</i>	42,818 <i>(Number of detentions under the MH Act: 49,417)</i>
Number of formal admissions to independent sector hospitals	2717	2,621
Number of people on SCT (NHS and independent sector)	3,325	4,291
Number of people on Guardianship Orders <sup>9</sup>	418	433
<b>Total</b>	<b>48,939</b>	<b>50,163</b>

**Table 12: Estimated number of qualifying patients 2009- 2011<sup>10</sup>**

It is unlikely that all qualifying patients will want to access IMHA services and it is not possible to establish an accurate level of demand from our study, because of the widespread barriers to access that we have identified. This indicates that commissioners and IMHA services should model and cost different scenarios reflecting the needs of the local population and potential demand. This will need to take into account information about bed occupancy, the rate of turnover and the nature of the client group. As noted in Chapter 5, the demands on IMHA services in inner city areas are likely to be substantially greater than in rural areas or in secure services, where the population may be more static.

## 12.5 Service specifications

Standardisation of service specifications reflecting local needs assessments emerged as the hallmark of commissioning quality IMHA services. IMHA managers

<sup>8</sup> Source: NHS Information Centre (2011b). Mental Health Bulletin: 5<sup>th</sup>: Report for Mental Health Database Annual Returns.

<sup>9</sup> Source: NHS Information Centre (2011a) Analysis of Guardianship under the MH Act, Annual Figures England 2011.

<sup>10</sup> Where possible, the number of people rather than the number of admissions has been used and this will be higher than the number of admissions per year as some people are detained or on a SCT for more than one year.

commented on variations in current specifications that they had observed in relation to:

- Specified response times
- Nature of the activity specified (i.e. type and timing of activity and whether non face to face activity was included or not), number or time limits to contacts.
- Training and/or qualifications of IMHAs.
- Responding to diversity of qualifying patients (for example specifying delivery to BME groups, children and young people, older people).

We reviewed the available service specifications for IMHA providers in the case study sites and many had adapted the template provided by the NIMHE Commissioning Guidance (NIMHE, 2008). However, there was variety in terms of the detail and in respect of which groups were covered by the specification, as noted above. As commented on in Chapter 9, difficulties can arise when there are separate specifications for instructed and non-instructed advocacy or when advocacy arrangements for particular groups are specified separately. We found this in relation to people from BME communities, people with learning difficulties and deaf people. In one site the original specification had not made any reference to provision for children and young people or for people placed in secure services, and the commissioners had remedied this in response to a gap analysis.

Some of the specifications related to the provision of IMHA services only, whilst others provided a specification for a broader range of advocacy services, and one also explicitly covered support and coordination of service user involvement in addition to advocacy.

## 12.6 Investment in IMHA services

The issue of whether or not IMHA services are being adequately funded was raised by a number of participants, particularly IMHA managers and staff. It was mentioned by a few mental health professionals who were concerned about the availability of IMHAs or the impact of the restrictions on legal aid on increasing demand for IMHA services.

Clearly the absence of robust needs assessment leaves this question unanswered at a local level and this was recognised by commissioners:

*"I guess most of us need to do some form of modelling and we need to look at previous demand patterns and flows and we need to use it over a long enough period to actually make a reasonable projection forward. So now having three or four years' experience and data, we might actually look at it and go, well yeah we don't have enough capacity."*

*PCT Commissioner*



Furthermore, some commissioners pointed to the difficulties of costing the IMHA input:

*"It's so difficult to actually cost out IMHA services, it's so varied what patients need and actually to proportion out exactly how everyone's time is distributed it's very difficult and we've had problems in the past with IMHA services in which our local service is used by people who do not live in our area but are admitted to a local unit."*

*PCT commissioner*

There is a large range in the numbers of people requiring IMHA services per PCT, with as noted before much higher numbers in inner city areas. This is illustrated by Minimum Mental Health Dataset, which indicates that the number of inpatients subject to detention per PCT for 2010-2011 ranged from 15 – 832 (NHS Information Centre. 2011b).

We have used projections to look at the data that we have about potential need and investment to understand the investment per qualifying patient and the variation in spend. Excluding the high secure service, the median investment across the case study sites was £162 per qualifying patient, (£130 after reducing for on-costs). IMHA services highlighted costs in addition to face to face contact, which were necessary to build the organisational capacity and relationships with qualifying patients and mental health services to deliver effective IMHA services. These covered:

- IMHA training.
- Training and raising awareness of mental health staff.
- Costs for interpreters.
- Costs associated with data collection for service monitoring.
- Publicity and promotion, particularly outreach to inpatient wards.
- Travel and travelling time, an issue for services covering large rural areas.

The actual spend per qualifying patient will need to include this and time for supervision, meetings, administration, service promotion, outreach work etc. From our data (referred to in Chapter 7), one IMHA service allowed four hours for a CPA and six for a Tribunal and we estimate that the current level of investment equates to approximately three hours per qualifying patients, allowing time for other necessary activities. Further work needs to be done on this, both nationally and locally. However, this level of investment is going to be inadequate for IMHA services to deliver high quality services and is reliant on some qualifying patients not using the service (which of course will be the case), or the IMHA service and/or the mental health service gatekeeping access. Indeed, several IMHA services indicated that they would not be able to cope with the demand if every qualifying patient used the

service as it was intended. This confirms the need for commissioners and IMHA services to model costs against potential needs for the service in their area.

Unsurprisingly, IMHA services considered that standardisation to guide local commissioning decisions, including resourcing as well as service specifications, would be helpful in addressing potential inequalities and mismatch between need and provision. The comparison was made with the national formula for IMCA services, which although described as imperfect, was valued for its transparency and its contribution to facilitating local service developments.

Particular concern was expressed about the practice of spot purchasing and ‘*earned income*’ compromising continuity and stability of provision as well as the capacity of IMHA services to provide outreach and promote access. Further, it created an administrative burden for the IMHA services, the costs of which may not be met.

Reference was made to the current financial situation, with several focus group participants describing cuts in public sector funding to services and expressing concern that reduction in funding, even if they did not adversely affect IMHA services, were likely to lead to a reduction in other forms of advocacy provision, on which the IMHA services depend:

*“I have a statutory obligation anyway to maintain the IMHA, so those particular specialisms within the advocacy have to be maintained.”*

*PCT Commissioner*

We found some instances of funding on advocacy provision being reduced. One of the advocacy services had experienced a 50% reduction in funding and another reported a reduction of £35,000 for the current year. In both instances, this was impacting adversely on the provision of non-statutory advocacy, although the services were doing their best to continue to provide this service. In addition, the financial pressures on health and social services appeared to be having an impact on the quality of commissioning generally:

*“Because of our restructuring we’ve reduced our involvement in a lot of these local services just purely because of pressure of numbers really and I don’t know whether that’s a general theme of local government but it seems that we’re now monitoring these services rather than working in partnership with them as much as we used to do, that was always the preferential way of working but now it’s just monitoring contracts, quality and cost really.”*

*Local Authority Commissioner*

## **12.7 Tendering and contracting**

IMHA participants suggested that the widespread adoption of tendering was having an impact on the market with concerns that locally valued providers were being squeezed out. Our attention was drawn to the current climate of competition, with

fears that rather than raise the quality of provision, this may lead to costs being curtailed:

*"I guess development will be hindered because there's this constant bid and competition for funding, which means services are trying to undercut other services when they apply for a contract, which means at the end services are actually going to start going downhill because people will be saying 'well I can do 18 wards with just one part time Advocate' because they're desperate to have the contract. So the quality is going to go down with all this competition unless there's like a standardised I guess sort of requirement from Commissioners as to what kind of service needs to be provided."*

*IMHA (Focus group)*

These concerns had a practical impact on our research with some IMHA services being reluctant to share financial information with us.

Concerns were expressed that larger organisations were better placed to respond and that smaller, local organisations were disadvantaged in the process of tendering for IMHA services, jeopardising local knowledge and networks. The tendering process was seen to privilege larger providers as they have a more developed infrastructure for responding to bids, although this does not necessarily mean that they will provide a locally responsive service. One IMHA manager related their service's decision not to bid for a tender because of their concerns that the available resource was insufficient and could therefore lead to damaging their reputation as a provider of high quality advocacy services. BME advocacy providers were concerned that they could be disadvantaged in the tendering process, not only because of size but also as a result of a limited understanding of the needs of diverse BME communities, arising from inadequate needs assessment and different conceptions of advocacy. This point was reinforced by a commissioner who described the rules for procurement as risk adverse, leading commissioners down a particular path towards more established services.

There were also concerns about the length of contracts, with IMHA services asserting that contracts needed to be for a reasonable duration to enable their services to develop and be financially viable. Short-term contracts had been a particular problem in the early days of IMHA provision with several advocacy services having contracts for six months or a year that were then rolled over, often at short notice. From the questionnaire returns, the lengths of contracts were roughly split with a third having an annual contract, a third having a contract for two years and a third having a contract for three years. In one instance, a twelve month contract was offered following a tendering process. This situation obviously causes a significant administrative burden for smaller organisations and creates uncertainty for IMHA staff, as observed by a mental health professional:

*"Towards the end of the process of course staff are looking for jobs because three years is up, they know the contract might get lost, they know things are changing. So I think year one great, enthusiasm, year two, steady progress, year three eye off the ball, lack of reports, lack of involvement in our meetings and probably less advocacy taking place though I can't prove it."*

*Service Manager*

In instances where PCTs have gone out to tender and there had been a change of provider, IMHAs often went through the TUPE process and moved to the new provider. However, there were concerns about how these processes of transition were managed, not only for staff but also for qualifying patients. It became apparent that it was easy for the focus to shift to the complexities of service reorganisation and away from service delivery without careful thought and preparation. This is pertinent to the proposed commissioning arrangements for IMHA services in 2013.

## **12.8 Monitoring arrangements**

All commissioners had monitoring arrangements in place and required activity data to be provided, usually on a quarterly basis. This included data on:

- Number of referrals
- Reasons for referral
- Number of people seen
- IMHA partner characteristics: typically age, gender and ethnicity but rarely type of section to be provided or other information about previous number of detentions
- Location
- Issues raised
- Activity including meetings and training

As described earlier (see 7.6), several IMHA services described providing both activity figures and case studies in monitoring reports to commissioners and reported that the individual case studies were valued. As well as describing the nature of the IMHA activities, such case studies also attempted to capture the service user's journey to self-advocacy. It was often not clear how this information was being used, but it did serve the function of enabling commissioners to understand the service. Regular meetings between the IMHA service and the commissioner enabled specific issues or difficulties to be aired and these were generally valued by both parties:

*"We have a good commissioning relationship with our Commissioners. They listen to us in terms of the needs of the service and they do ask for quite a lot of reporting information from us which we provide on a monthly basis but they do listen to us and they do appreciate the need for the service."*

Several of the specifications detailed the outcomes for the service but then lacked any detail on how these were to be measured, making reference to the development of an outcomes tool or adapting the *Advocacy Star* at a later date. Emphasis was given to capturing service users' experience of using IMHA services. For example, one service specification stated that the key questions that would be looked at were:

- ☞ How can we tell people are being affected beneficially by the service, how has this changed over time?
- ☞ What is the service like to use?
- ☞ How well does the service provide what people ask it for?

The type of data and the method for capturing it were not described and many IMHAs referred to challenges in obtaining feedback from service users:

*"Somebody who's detained, when you started with them and when you finished with them, was their understanding of their detention under the Mental Health Act was that greater at the end than it was at the beginning, so those are the sorts of things that the commissioner is asking us to do and the difficulty is when you start with somebody, they don't want to fill it in because they're too unwell and when you finish with somebody they've left hospital and they don't want to fill it in."*

IMHA

As discussed in Chapter 11 and evidenced by the service specifications and the case notes we reviewed, there is a clear need for development of meaningful process and outcome measures. Further, our experience of the general lack of systematic recording of information on access and uptake indicates that further work is needed on this too.

It was also suggested that mental health services could be monitored on activity in relation to IMHA services and their responsibility in facilitating access to IMHA support:

*"We're fortunate that we have a commissioner who has asked us to collect data on ward round delays because a huge amount of time of IMHAs is lost in ward round delays, delays of two three hours at a time somebody can be waiting for a ward round to happen, or they may spend an hour travelling to the unit to find that the ward round has been cancelled and they weren't notified or it's already happened not at the time that it was scheduled for, so we're collecting that data to feed back to the commissioner on hours lost, so that the commissioner can then bring that back to try and influence something in terms of the way the consultant's managing the ward round scheduling."*

## 12.9 Commissioning for people placed out of area

The lack of clarity about commissioning arrangements for people placed out of area was a source of concern for IMHA providers, commissioners and mental health providers. Two areas of concern were identified. First, a lack of clarity as to the responsibility for commissioning and thus provision. In the independent sector case study site, the local PCT commissioned the local IMHA to provide IMHA services to people detained in the secure unit on their patch. Another PCT also commissioned the IMHA service to provide IMHA services to all people from their locality placed out of area in 25 different units, including this particular unit. In the case study with a high secure hospital, the IMHA service was being commissioned by the Secure Specialist commissioning group, which had commissioned one IMHA provider for these services and more recently had re-commissioned the service to include medium and low secure services on its patch.

*"One of the things I think that this has raised for me is that I think it is a bit murky about where people access their IMHAs from and if you're out-of-area whether you have access to the local scheme or a scheme that's sponsored by your placing authority or whether you have a choice between the two?"*

*Joint Commissioner*

This lack of clarity meant that some independent sector providers were commissioning their own IMHA services. This practice was by no means unique and the response to our survey from one independent sector provider, that collated responses from ten of its units in England, indicated that four of its own services were commissioning the service and the arrangements were unclear for another two units.

The second concern for qualifying patients placed out of area relates to service continuity as some of this group of people may move to another unit out of area. Hence, the decision by the PCT in the independent case study sector to commission the local IMHA service to provide access to IMHA for all its out of area qualifying patients. The IMHA manager responsible for this identified continuity of provision, thus facilitating access and the quality of provision, as one potential advantage of this arrangement. However, this needs to be balanced with the time IMHAs spend travelling, the relative inaccessibility of the service and the reality that mental health providers would have to relate to many different IMHAs from different organisations.

In some instances, commissioners had developed an arrangement with one PCT commissioning IMHA services on behalf of the others. This was the case in one of the sites that had several NHS specialist units taking people from outside of their area. They commissioned these services and the costs for the IMHA provision were included in the service costs and charged back to the patient's PCT in their area of

residence. The advantage of this arrangement to the IMHA commissioner was that there was no cost and thus they could focus on commissioning to meet the needs of qualifying patients:

*"I don't feel it's necessary to balance the books, it's more, essentially we're there to make sure that the services that we're providing is in line with the needs of the patients."*

PCT commissioner

## 12.10 Commissioners' understanding of IMHA

The seniority and experience of the commissioner with responsibility for IMHA services varied across the sites and it was evident in two of the sites that the commissioner was relatively new to the role and junior within the organisation. In one of the sites the commissioning of IMHA services was being undertaken by a team and this meant that there was expertise to draw on in relation to aspects of the commissioning process for example contracting and procurement.

The experience and knowledge of commissioners in relation to advocacy and understanding of the IMHA role, as well as the mental health services context, was seen as critical in determining their approach to commissioning IMHA services:

*"How much knowledge has that Commissioner got when it comes to what the patients are like on the ward and what relationships they have with the people that come to see the IMHA? It seems to me they tend to be quite detached from all of that, they're just looking at the amount of time that an IMHA goes into the ward but not necessarily what goes on while that IMHA is there and what is going on outside of that relationship... they're very detached from all of that."*

IMHA (BME advocacy services, Focus group)

This had been particularly problematic in the early days of commissioning IMHA services:

*"The following December, so sort of nine months on we went for a review at the PCT with some other managers within our service, and the first thing that they asked us is, "Would you mind explaining the difference between generic advocacy, mental health advocacy and IMHA?"*

IMHA (Focus group)

This has implications for the transfer of the commissioning responsibility to local authorities. A limited understanding of advocacy and IMHA was associated with commissioning that focused on time limited contracts, and with IMHAs experiencing pressures to terminate the advocacy relationship or limit the amount of time spent on non-face-to-face contact (for example running drop-in sessions or visiting wards) to meet contractual demands.



*"We've had lots of stresses and worries about certain clients we spend too much time with and think, 'oh we should perhaps close this one because commissioners will be concerned'".*

*IMHA (Focus group)*

However, a particular commissioner's limited knowledge could also work to the benefit of the IMHA service, creating an opportunity to influence and shape local provision. Conversely where commissioners were knowledgeable, this could work to the disadvantage of the service, particularly if the commissioner had different ideas about how advocacy should work.

### **12.11 Commissioning a whole system approach to advocacy**

Commissioning that was valued by IMHAs supported flexibility and did not limit the service to providing IMHA services only, but saw it as a part of a whole system of advocacy provision alongside other forms of advocacy, particularly generic mental health advocacy:

*"One thing I would say that's especially good about the service that I give is that our Commissioners have said 'well if you're spending all day on X ward then see the informal patients as well, be a Mental Health Advocate alongside being the IMHA so that the informal patients don't feel as if you know 'those people have got an Advocate, why haven't I got an Advocate?' so I give a service to everyone on the ward regardless of whether they're detained or not'".*

*IMHA*

Providing IMHA services alongside generic mental health advocacy services was reported to enable advocacy services to manage their resources effectively and to be able to respond promptly to requests for an IMHA:

*"You've got to really have your eye on the ball all the time to make sure that we get a call in from IMHA, that one of the IMHAs goes off and does some IMHA work for what they've purchased, those other hours being covered as well. I mean there's plenty of work so we could cover the hours but if they pull the generic then we're left with a spot purchase and where's the running costs for anything like that."*

*IMHA (Focus group)*

It also facilitated continuity of relationships and support when service users ceased to qualify for IMHA services, and enabled a broader range of issues to be addressed. In some instances, generic mental health advocacy services are provided by another advocacy provider and this was seen as problematic by several IMHAs that took part in this study.

Further, providing IMHA services alongside IMCA services meant that IMHAs could work flexibly, were likely to be dual trained as IMHAs and IMCAs and thus comfortable with using non-instructed advocacy, if necessary. We were not able to establish whether such models of provision were more cost effective.

One of the trends that we saw was for PCTs starting to commission advocacy organisations to provide a range of advocacy provision, including IMHA and IMCA services. Whilst this has the potential to enable advocates to work flexibly it may make it less likely that specific needs can be met unless arrangements are put in place for example through the employment of specialist workers or through Service Level Agreement with specialist providers or community organisations.

### **12.12 Commissioning mental health services to support IMHA services**

Commissioners were seen as key players in supporting effective working relationships with mental health services. Commissioners included the relationship between mental health services and advocacy providers in service specifications and in particular the requirement that they agree an engagement protocol. This would cover how they would work together and specific arrangements, such as access to notes; acknowledging the appropriateness of IMHA providers posing a challenge to mental health provider organisations on key issues or problems raised by service users. Typically, in such contexts, commissioners felt that Trusts dealt well with this feedback and responded to issues. However, in the early stages of commissioning IMHA services it could be a bone of contention to get Trusts to sign up to this, although the statutory responsibilities proved helpful:

*"You've got to remember this is a legal requirement, so if the Trust don't want to sign up in terms of working with the provider we need to take it further using the contract because it's not on, you know."*

*PCT Commissioner*

The advocates reported using their relationship with commissioning to resolve communication problems with services in the course of formal meetings convened for the purpose:

*"That used to be a bigger problem than it is currently because we took it to the Commissioners and the people who run the wards as well, the Ward Managers were there at a meeting... and we highlighted this to them, so they have started getting a bit better at that..."*

*IMHA*

Or to seek assistance with recurring problems brought to them by service users, such as blockages to discharge:

*"If there appears to be, I don't know, a really significant blockage somewhere we would discuss that with the Commissioner of Services because they're the*

*people buying places at that unit... So we will say to them look there is an economic case, we're looking at somewhere else for, you know, three individuals that we're aware of, you may know more."*

*IMHA Manager*

Sometimes the commissioners help to facilitate feedback in the most appropriate forum:

*"I think Advocacy were doing the right thing... and [the Trust] didn't, they weren't against being challenged, I think it was just the form, the actual, the setup they were actually being challenged in, you know, in front of other organisations which perhaps wasn't as appropriate as it could have been. And now we've agreed and that's written into the contract that Advocacy and [the Trust] will meet on a regular basis to discuss issues. "*

*PCT Commissioner*

The findings reported in Chapter 10 on the relationship between mental health professionals and IMHAs point to the importance of commissioners specifying in contracts with mental health provider organisations the need to provide a supportive context in which IMHA services can operate, and staff training and professional development arrangements to contribute to a positive organisational culture, within which IMHA services can flourish.

### **12.13 Commissioning for quality IMHA service in the future**

Our findings have a number of implications for the future commissioning of IMHA services, which will move from PCTs to local authorities in 2013. This transfer of responsibility means that IMHA services could benefit from the local authorities' role in relation to Health Watch and understanding of the local community and its diversity. It creates an opportunity for Local Authority commissioners to learn from their PCT colleagues and to remedy the shortcomings in the current arrangements that we have identified. In particular, our findings indicate that local authorities can use this opportunity to:

- Ensure there is a proper needs assessment in relation to IMHA provision, building on the Joint Strategic Needs Assessment and engagement with community groups.
- Undertake an Equality Impact Assessment when developing advocacy services and associated policy.
- Review the level of investment and ensure that it is appropriate for the level of potential demand.
- Engage with qualifying patients, mental health service users and carers to co-design IMHA services.

- Clarify the arrangements for IMHA provision for people placed out of area, so that arrangements are in line with the Health and Social Care Act, 2012 and ensure that IMHA services are not being commissioned by independent sector providers.
- Clarify the interface with specialist commissioning for IMHA provision to national specialist services.
- Consider the potential of small local organisations that have particular skills, knowledge and networks that could support the development of access to appropriate forms of IMHA provision for potentially disadvantaged groups.
- Establish an agreed information system to be able to evaluate access and uptake.
- Develop meaningful outcome measures, in partnership with qualifying patients, mental health service users and carers.

One of the major challenges that local authorities may face is knowledge of the mental health services context and it will be vital for them to work in partnership with health commissioners to ensure that the context within which IMHA services are operating is a supportive one. Commissioning represents an opportunity for service development rather than merely contracting. However concerns were expressed by participants that the transfer of responsibility to local authorities will lead to a reduction in service or a dilution in the IMHA role because of financial pressures, or a lack of capacity for local authorities to commission effectively.

The next chapter provides quality indicators as a basis for developing further guidance for Local Authority commissioners.

**Commissioning IMHA services – Key Findings**

1. The critical role that commissioning plays in the development of good quality IMHA services was clear, from all the data sources.
2. It was evident that PCTs had been poorly prepared for the introduction of IMHA service in 2009, but we found evidence of systematic approaches to commissioning with a number of PCTs having tested the market in the last year. Most had detailed service specifications, based on the NIMHE guidance, although these differed in terms of whether they focused on IMHA services only or included IMHA as an element of a more comprehensive approach to advocacy provision.
3. There was little evidence of commissioning based on needs assessment and equality impact assessment and thus the basis for the level of investment in IMHA services was typically unclear.
4. There was evidence that specific needs had not been considered; gaps were evident in relation to people from BME communities, people with learning difficulties, older people, children and young people were highlighted.
5. Generally service users, particularly qualifying patients, or carers are not being directly involved in the commissioning process or in monitoring contracts.
6. Commissioning arrangements for people placed out of area are confused and commissioners, mental health providers and IMHAs requested clarity.
7. From the data we have, 50,000 people a year qualify for IMHA services. The current level of investment in IMHA services appears to be inadequate and relies on some qualifying patients not taking up the service and IMHA services or mental health services gatekeeping access.
8. Excluding the High Secure service, we estimate the median investment across the sites was £162 per qualifying patient (or £130 after on costs are taken into account).
9. Spot purchasing has significant limitations and threatens the financial viability of IMHA services and compromises strategic planning.
10. Tendering processes can privilege larger organisations over smaller ones and this can inadvertently disadvantage smaller community based organisations that may be particularly well placed to respond to specific diverse needs.

## 13. QUALITY OF IMHA SERVICES

### 13.1 Introduction

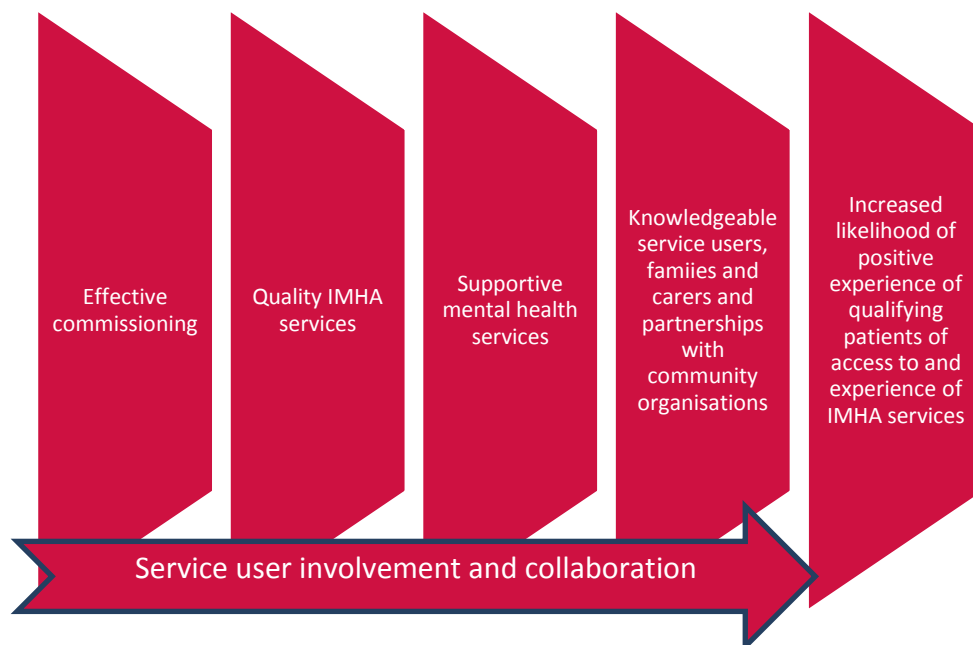
A working definition for the quality of IMHA services, developed by the research team is:

A quality IMHA services is: easily **available**; one in which the service user has **confidence and trust**; enables them to **express their views and be heard** and thus **potentially influence decisions** about their care and treatment under the MH Act and thus ultimately **is likely to support their journey to recovery**. This reflects our understanding that people detained under the MH Act have a **right to be heard**.

This chapter is developed from a synthesis of the findings from the different data sources to provide quality indicators for IMHA services that reflect this definition. As many of the key themes are the subject of chapters in their own right in respect of the case study findings, they are only briefly outlined here to avoid duplication. They provide a basis for discussion and further refinement.

### 13.2 A framework for the quality indicators for IMHA services

Ascertaining the quality of IMHA involves a complex understanding of the various contributions of commissioning, the host mental health services, and the organisation and management of IMHA services. This all takes place in a context of inter-relationships between service users, families and carers and relevant partnerships with community organisations.



**Figure 14: Dimensions of quality for IMHA services**

The implication of this is that any attempt to set quality standards needs to take account of the complexity of contributory factors, and not merely focus on the advocacy provider. Commissioning relationships are crucial, particularly the level of funding and the service specification. The operating context provided by the mental health services organisation and relevant staff is necessary for the support of high quality advocacy. Social networks, including family, other carers, peer support networks and community organisations can be influential in facilitating access to advocacy. Similarly, informed and knowledgeable service users are better placed to utilise advocacy to its fullest extent.

### **13.3 Quality indicators for IMHA services**

There are 30 indicators, organised around the following eight over-arching themes:

1. Effective commissioning for IMHA services
2. Availability and accessibility of IMHA services
3. IMHA Service Characteristics
4. Organisation and management of IMHA services
5. The IMHA role
6. Meeting diverse needs
7. Monitoring and outcomes of IMHA services
8. The mental health services context

The framework of quality indicators that we developed from our analysis considers these different elements (illustrated in Figure 14) and differs from other approaches to setting quality standards for independent advocacy services that have largely focused on the role of the advocacy provider. The following quality indicators need to be understood with this framework in mind and viewed as cross-cutting themes.

This is particularly well illustrated by access, which is reliant on a commissioning process that has assessed needs for IMHA services, developed the specification and commissioned accordingly. Access is also dependent on mental health services understanding and promoting the role of the IMHA service. It was suggested that this would be further helped by carers and families, service user and community organisations, understanding and promoting the service, which may need to be delivered in partnership with community organisations to meet specific needs. Finally, it is also dependent on what the IMHA service does to promote access, including through building understanding and awareness of advocacy and IMHA services.



### 13.3.1 Effective Commissioning

#### ***Quality indicator 1 – Working in partnership with mental health commissioners***

Those commissioning IMHA services work in partnership with commissioners of mental health services, so that the impact of IMHA provision on mental health service development can be understood and maximised.

#### ***Quality indicator 2 – Assessment of need for IMHA services***

Commissioning IMHA services should be based upon:

- A local needs assessment, which considers:
  - the demographic profile
  - the disproportionate detention of people from specific communities
  - the potential number of people who might require non-instructed advocacy
  - nature of the geography
  - challenges facing the mental health service provider in terms of patient mix, turnover.
- On an understanding of the factors influencing historical patterns of demand for and use of IMHA services.
- On the views and experience of qualifying patients of IMHA services and of community organisations with specific experience of potential needs of under-served communities.
- On an equality analysis to ensure that provision is non-discriminatory and meets the diverse range of needs.

#### ***Quality indicator 3 – Co-design with mental health service users and carers***

- Commissioners work with a diversity of service users, particularly IMHA partners, and carers and community organisations to ensure a thorough understanding of IMHA services and co-design appropriate services.
- Service users, particularly IMHA partners and carers, are involved in the tendering process.
- Service users, particularly IMHA partners and carers, are involved in contract monitoring.
- Support and appropriate reimbursement, is provided to support service user and carer involvement in commissioning.

#### ***Quality indicator 4 – Designing IMHA services***

- The design of IMHA services includes instructed and non-instructed advocacy.

- IMHA services are designed to meet the diverse needs of qualifying patients and attention is paid to IMHA provision for: children and young people; older people; people from BME communities; gender-sensitive provision; LGBT people; people with learning difficulties, physical disabilities or sensory impairments.
- The design reflects a whole system approach so that the interfaces with other forms of advocacy are easy to navigate, particularly generic mental health advocacy, IMCA services, peer advocacy and advocacy for specific groups.

#### ***Quality indicator 5 – Investment matched to need***

- The level of investment in IMHA services reflects the local demands and needs, as established through the needs assessment process.
- This is reassessed on an annual basis and adjusted to reflect changing rates of qualifying patients and specific issues encountered by the IMHA service.

#### ***Quality indicator 6 – Service specification and contracts***

- Local commissioning of IMHA services adheres to national minimum standards and agreed service specification and reflects minimum levels of investment, agreed nationally.
- Service specifications and contracts include time for activities other than direct contact, particularly in relation to building awareness of the role, stimulating demand for the service and infrastructure costs including staff development and training and administrative time to support service monitoring and time to train mental health professionals.
- Service specifications and contracts include measures to ensure that the diversity of qualifying patients are able to access appropriate IMHA services. This may include specifying partnership arrangements with community organisations and/or investment in community organisations to develop their capacity to provide IMHA services. It also means ensuring that IMHA services are available across the age range and as people move from one service to another.
- Contracts with IMHA services are established for a minimum of three years.
- Commissioners fund IMHA services for people using mental health services in their area, including people who are not ordinarily resident in their area. Thus clear arrangements are in place for funding IMHA services for people placed in services out of area, including on their return to the locality.

#### ***Quality indicator 7 – Monitoring***

- Commissioners monitor IMHA services on specified outcomes of IMHA provision, agreed with IMHA providers.
- Commissioners monitor statutory mental health services on providing information and facilitating access to IMHAs for qualifying patients.

- ✎ There are clear methods for people who have used IMHA services in providing feedback on their experience.

### **13.3.2 Availability and access to IMHA services**

#### ***Quality indicator 8 – Availability of IMHA services***

- ✎ Minimum provision and other standards for IMHA services are agreed nationally.
- ✎ There should be a sufficient number of local IMHAs to meet assessed need and a suitable number and variety of IMHA services are funded to meet the diversity of local need.
- ✎ The availability and access to all eligible people including people from diverse communities, people with physical disabilities, people of all eligible ages and people on CTOs is monitored on a regular basis and involves service users and carers in this process.

#### ***Quality indicator 9 – Access***

- ✎ An opt-out, as opposed to an opt-in, system where IMHA services are routinely offered on detention and discharge is in place.
- ✎ Information is shared between mental health NHS Trusts and IMHA services about who qualifies for IMHA services.
- ✎ IMHA services are easy to contact and respond promptly.
- ✎ Easy access to interpreters, for people for whom English is not their first language, or signers for deaf people, where services aren't provided directly by people from those communities.
- ✎ A proactive approach to address inequalities of access.
- ✎ Mental health professionals understand the contribution of IMHA services and their role in facilitating access.
- ✎ The responsible health authority/NHS Trust ensures that all qualifying patients and their carers receive information about entitlement to IMHA and the IMHA providers in their area.

#### ***Quality indicator 10 – Service promotion***

- ✎ Promotional materials in a range of formats are available in the full range of mental health services.
- ✎ IMHA services provide and promote clear, accessible information for qualifying patients about the IMHA role, how it relates to other forms of advocacy and how to access an IMHA. This includes posters with information clearly displayed and pictures of the IMHAs in wards and community settings as well as leaflets and DVDs particularly aimed at those with communication issues.

- IMHAs operate regular drop-in sessions on hospital wards and in community-based services.
- Mental health services routinely provide information to the nearest relative and carers about IMHA services.
- Information about IMHA services is widely disseminated through service user and carer networks.

### ***Quality indicator 11 – Strategies to increase uptake***

- Advocacy services are able to evidence what proactive strategies they have used to increase uptake from marginalised groups (for example access to specialist services for people from diverse communities, collaborative working with community organisations, specific outreach sessions etc).
- Mental health services and IMHA services are able to provide evidence of measures to provide information about entitlement and access to IMHA services to people on CTOs.
- There is a reasonable uptake by people on CTOs, determined by local needs assessment and monitoring information.
- Where necessary, there is ready access to interpreters and training for IMHAs to work with interpreters, with agreement about how the costs of interpreters are to be met.

### ***Quality indicator 12 – Understanding of IMHA role***

- Advocacy services have clear, accessible information for service users and carers about the IMHA role and how to access advocacy services.
- Advocacy services take steps to raise mental health professionals' awareness and understanding of the IMHA role and responsibilities.
- Mental health staff have received specific training on advocacy and the specific role of IMHAs and how this differs from their role.

## **13.3.3 IMHA Service Characteristics**

### ***Quality indicator 13 – Independence***

- IMHA services are independent organisations from statutory mental health service provision.
- Mental health service users and their carers are confident that the IMHA service is independent from statutory provision.

### ***Quality indicator 14 – Person-centred focus***

- IMHA services have a clear person-centred focus and the centrality of relationship to advocacy work is recognised in service specification and contracts.

- There is a tangible commitment to equality, equity of access and providing a culturally relevant approach.
- IMHA services involve and work with mental health service users, to co-design, develop and monitor the provision of IMHA services.

***Quality indicator 15 – Recovery focus***

- The IMHA service has a clear recovery focus and identifies and links with opportunities for peer support.

**13.3.4 Organisation and management of IMHA services**

***Quality indicator 16 – Strategic planning***

- The IMHA service has the capacity to plan for future provision and can ensure that the service could respond to changing needs and retain high quality staff and expertise.
- Services can describe how they involve people who use their services in service design and development and people who use IMHA services are aware of opportunities to be involved in and influence service developments.
- Services have assessed and considered how to best meet the diverse needs of qualifying patients.

***Quality indicator 17 – Leadership and management***

- The IMHA service has clear leadership, coordination and a clear direction.
- The IMHA service can show clear plans for how IMHA provision will be delivered, including a system for managing IMHAs.
- The IMHA service has clear policies and procedures, as well as clear lines of accountability.
- There is a system in place for managing caseloads that takes account of the complexity of cases as opposed to number of cases.
- There is a culture of continuous learning and improvement and investment in monitoring and regular reviews of the service, which includes people who have used the service and their carers.

***Quality indicator 18 – Organisation and staffing***

- IMHA services are provided as part of a suite of advocacy services and sit alongside generic mental health advocacy, IMCA and peer advocacy.
- IMHA services are staffed by suitably qualified and experienced staff as defined by nationally agreed standards.
- The size and experience of the IMHA service reflects the local needs assessment or formal partnership arrangements are in place with other organisations, that

have specific skills and knowledge to draw on to enable all qualifying patients to have their advocacy needs met appropriately.

- ✧ There are arrangements in place for the regular support and supervision of IMHAs.
- ✧ Services have sufficient administrative support to enable them to carry out regular monitoring and review.
- ✧ IMHA services are equal opportunities employers.
- ✧ The organisation has standard policies (including equal opportunities, lone worker, health & safety etc.) for IMHA provision.
- ✧ IMHA providers publish clear statements about the service response times service users can expect.

### ***Quality indicator 19 – Caseload management***

- ✧ IMHA services are able to provide a degree of choice of advocate and/or work with other relevant organisations to facilitate this.
- ✧ IMHA services have caseload management and review mechanism in place and review caseloads frequently.
- ✧ IMHAs are able to devote the time needed to each individual case by having a balanced caseload.
- ✧ IMHA services are able to demonstrate a strategy for meeting individuals' broader needs.

## **13.3.5 The IMHA role**

### ***Quality indicator 20 – Role clarity for IMHAs***

- ✧ Job descriptions for IMHAs outlining responsibilities in relation to generic mental health advocacy and non-instructed advocacy.
- ✧ IMHA services have a strategy in place for the continuity of advocacy, should it be required, when a person no longer qualifies for IMHA services or there is a transition between services on the basis of age.
- ✧ The ways in which IMHA can help increase service user participation in decision making are clear.
- ✧ IMHA services have the capacity and the flexibility to support clients in relation to issues pertaining to their legal rights under the MH Act in the context of a holistic and client-centred approach to mental health advocacy.

### ***Quality indicator 21 – Promoting self-determination***

- ✧ The IMHA provides information about Advance Directives and promotes their use.

- The IMHA is knowledgeable about peer support and service user initiatives and facilitates access to these, as appropriate.

### **13.3.6 Meeting diverse needs**

#### ***Quality indicator 22 – Meeting diverse needs***

- There is an operational plan in place detailing how the service will be delivered to people with a diverse range of needs.
- The IMHA service employs specialist workers as best represents the local population and/or works in partnership with organisations with specialist skills and knowledge.
- The IMHA service has undertaken an equality analysis.
- The IMHA service has an equalities and diversity training programme in place.
- IMHA provider can demonstrate links and joint working with other specialist agencies.
- The IMHA service works with community organisations to upskill workers to provide IMHA services.
- The service routinely undertakes equalities monitoring.

### **13.3.7 Monitoring the outcomes of IMHA services**

#### ***Quality indicator 23 – Systematic information capture***

- Commissioners, MH Act Administrators, and mental health services have agreed ways to record qualifying patients' access to IMHA.
- There is systematic monitoring information that shows when qualifying patients access IMHA support.

#### ***Quality indicator 24 – An outcomes-based approach***

- Advocacy organisations have adopted an outcomes-based approach to monitoring the effectiveness of IMHA support and are able to demonstrate that IMHA makes a difference for individuals and communities.
- There is a system in place to routinely capture information on IMHA outcomes.
- The measurement of outcomes takes account of the complexity of the impact of IMHA as well as of multiple stakeholder perspectives.
- Measured outcomes are associated with the key role and purpose of IMHA, including changes in qualifying patients' knowledge and understanding of their rights, a decrease in the number of unlawful detentions, as well as increases in the number of patients exercising their rights and participation in decision-making.



**Quality indicator 25 – Experience of IMHA partners**

- ↻ The IMHA service has developed and utilises user-focused measures to capture the experience of process and outcome of using IMHA services.
- ↻ Information about changes in partners' confidence and abilities to deal with various issues is captured.
- ↻ Independent service user-led monitoring of the experience of IMHA partners is routinely undertaken.

**13.3.8 The mental health services context****Quality indicator 26 – Promoting access to IMHA services**

- ↻ All mental health professionals in the service understand the contribution of IMHA services, how this differs from their role, other forms of advocacy and legal representation and their obligations in relation to IMHA.
- ↻ There are a range of methods for promoting the IMHA service to qualifying patients and not solely relying on posters and other written information.
- ↻ Information is freely available in a variety of formats, recognizing diverse needs and regularly reviewed to ensure that the information is up to date.
- ↻ There are protocols for referral of people on CTOs to IMHA services.
- ↻ The mental health service regularly reviews access to and uptake of IMHA services to ensure that all qualifying patients are being offered the opportunity and develops an understanding of the reasons that people may choose not to use the services.

**Quality indicator 27 – Respecting the IMHA role**

- ↻ There is an engagement protocol between the mental health service provider and the IMHA service in line with national guidance.
- ↻ Qualifying patients can contact and meet the IMHA service in private.
- ↻ Care is taken to involve the IMHA in relevant meetings by timetabling key meetings and providing advance notice to qualifying patients and the IMHA.
- ↻ There is a policy in place for access to notes and staff understanding is ensured.
- ↻ The IMHA is able to carry out their role whilst maintaining independence from the service.
- ↻ Arrangements are in place to address concerns that the IMHA has about fulfilling their role.

***Quality indicator 28 – Staff development and training***

- All mental health professionals working with qualifying patients have received an appropriate level of training that has involved service users and carers in its delivery.
- Mental health professionals working with those on CTOs have received training about their obligation to inform qualifying patients about their right to and eligibility for an IMHA.

***Quality indicator 29 – Addressing common concerns***

- There is an identified point of liaison between the IMHA service and the mental health provider so that issues to do with IMHA provision can be reviewed to ensure that all qualifying patients have the opportunity to access the service.
- There are clear arrangements in place between the IMHA service and the mental health service so that issues of collective concern about the mental health service can be addressed.
- IMHA service and mental health providers work with people who have used the service and carers to monitor and review mental health services and address specific issues of concern.

***Quality indicator 30 – Providing an organisational context for IMHA provision***

- The mental health service provider regularly reviews the measures that it has taken to provide a positive organisational context within which IMHA services can be provided and takes steps to strengthen these as needed.

## 14. DISCUSSION

### 14.1 Introduction

Independent Mental Health Advocacy has three overlapping dimensions: to provide a safeguard of individuals' rights under the MH Act; to support and/or represent an individual to get their voice heard and to promote and enhance participation in decision-making. The ideal is an individual able to speak for themselves as a consequence of support from an IMHA, and a care team that is open to hearing and involving that person in decisions about their care and treatment. The guiding philosophy underpinning IMHA services was consistent across provider services with a central commitment to the value of upholding individual's rights, person-centred support, independence of advocacy, and the service being free of charge. Ultimately, this ethos is all about empowering people such that they have a voice in challenging circumstances. Invariably we were impressed with the way in which practising IMHAs could articulate these values and describe examples in their work demonstrating their application.

IMHA has a central role to play in an individual's recovery through offering a degree of control and self-determination in a context where limits on freedom have been imposed. It has the potential to emphasise strengths and reconnect with hope, control and opportunities (Repper and Perkins, 2003). Beyond the individual journey, advocacy in general, and IMHA provision in particular, contributes to the development of mental health services that have a recovery focus. Advocacy can help shift the balance of power in the relationship between service users and mental health professionals, which is a crucial step in the journey towards recovery-oriented services (Shepherd, Boardman and Slade, 2007).

Our findings confirm that there is a role for IMHA and that this role is valued by IMHA partners. However, most is not being made of this opportunity. We have developed a detailed and nuanced picture of the access to, and delivery of, IMHA services and the factors influencing their quality. This chapter reflects upon all the study findings to discuss the three key areas - accessibility, appropriateness and effectiveness. It also reflects upon the relationship between IMHA services and mental health services and the quality of IMHA provision, and draws out the implications for policy and practice and future research.

### 14.2 Accessibility of IMHA services

The basis for evaluating access to and uptake of IMHA services requires attention. Our experiences of recruiting study participants gave us an insight into the nature and quality of the information that is currently being kept and access to this. We found in the majority of our case study sites that mental health services do not share information about the population of qualifying patients with IMHA providers, and conversely, IMHA providers are not under obligation to share information about who

has accessed or is using their service with mental health service providers. Indeed some advocates would argue that this is confidential information and should not be shared. While IMHA use may be recorded in an individual's case notes, there is a no systematic data to facilitate a review of access and uptake of IMHA support.

Overall, we found that less than half the numbers of people qualifying for IMHA services appear to be accessing them, with the exception of the site with a High Secure Unit, where the IMHA provider is routinely notified of any new admissions. Although our data is tentative, we found the percentage of qualifying patients accessing IMHA services ranged from as low as 19% to nearly two thirds (57%) giving a mean of 39%, of the qualifying population in hospital (excluding the high secure services) and from 5% to 55% of people, with a mean of 23%, on CTOs. Concern was expressed both by IMHA providers and commissioners about the levels of uptake in general and for specific groups, particularly groups with specific needs, and people on CTOs. This was more problematic in the inner city areas we studied, which is likely to reflect the nature of the acute in-patient wards with high occupancy rates and a perhaps more frequent turnover of patients, possibly with higher levels of need. It is not surprising that access is less of an issue for secure services where the population is more static and thus the relationship with the IMHA service more established.

The proportion of people on CTOs accessing IMHA services was even lower, ranging from 5% to 55%. IMHA services will not necessarily be aware of who is eligible unless they have been working with the person prior to discharge or the mental health provider informs them. It was suggested by mental health staff that people on CTOs are making less use of the IMHA service because the MH Act is less of an issue for them, but we have no evidence that people were being routinely informed of their right to access the IMHA service. This is further compounded by the lack of awareness that we identified amongst community-based mental health staff as to the role and purpose of IMHA services and the eligibility criteria for use.

Participants' accounts suggested a paradox: those who require IMHA services the most may be making the least use of them. This was usually expressed in terms of an individual's personal characteristics, i.e. being articulate, their educational level, their mental health status- with people with a diagnosis of personality disorder identified as most likely to access the service - or their understanding or previous experience of advocacy. Concerns were raised about qualifying patients with specific needs who are less well served by IMHA services: in particular, people from BME communities, particularly those who do not speak English; people with communication difficulties, particularly hearing impairment; and older people, particularly those with dementia.

We found little evidence of outreach strategies for these particular groups or of partnership working with or upskilling community organisations to facilitate better access and uptake. IMHA providers indicated that people from these groups were accessing IMHA services and appeared confident that their person-centred approach

enabled them to respond flexibly to a diverse range of needs. This finding resonates with that of Hakim and Pollard (2011) whose findings suggested that although IMHA providers were aware they did not fully cater for the needs of BME communities that they were fairly comfortable with this. We found that IMHA services tend to construe the needs of BME communities in relation to access in terms of language and not take account of other factors including negative perceptions of mental health services or specific cultural issues. Further, we found little evidence of strategic planning to address these specific needs in the current commissioning of IMHA services. For example, none of the commissioners in our study had considered the Count Me In Census data to understand the disproportionate rates of occupancy by people from specific BME communities and the implications of this for IMHA provision. There is a potential risk in that the introduction of IMHA services will jeopardize local advocacy groups and networks that wish to adopt a community-based user-led model (Simpson, 2011). This may have particular consequences for BME organisations, who may be disadvantaged in the tendering process (Hakim & Pollard, 2011) and who have developed a distinct model of community advocacy; valued and trusted by service users, who might be less likely to use mainstream IMHA provision. Careful thought is required by commissioners to consider how they can build on this, invest in these organisations, and upskill them to provide IMHA services.

The availability of IMHA services is directly linked to the level of local investment for IMHA provision. We estimate that the numbers of people requiring IMHA services in 2012 is at least 50,000, reflecting an increased trend in the number of detentions under the MH Act. We found little in the way of strategic needs assessment in order to inform the potential need for IMHA services locally and to help determine appropriate levels of resourcing. Further, our findings suggest that basing commissioning on demand is unreliable because of the factors that we have identified that impede access and uptake and this strategy is likely to perpetuate existing inequities in access. The quality of commissioning has improved in the time since IMHA services have been introduced, with some marked improvements and some commissioners having detailed service specifications in place.

Case load sizes vary markedly as do the areas or numbers of wards (i.e. potential numbers of qualifying patients) covered by individual advocates. The statistics describing rates of compulsion under the MH Act are important for making a continuing case for the need for high quality IMHA. The data collated by the NHS Information Centre<sup>11</sup> indicates that the number of people subject to restrictions under the MH Act continues to rise, with an increase by 5% in the number of people subject to the MH Act in March 2011, compared with the previous year. This reflects

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<sup>11</sup> KP90 data used to provide the Department of Health with information about the number of uses made of the MH Act 1983

an increase by 29% of the number of people on CTOs (NHS Information Centre, 2011b). These trends need to be directly reflected in the needs assessment for IMHA services.

We found a lack of awareness of, and confusion about, IMHA services, and among qualifying patients. Over two thirds of qualifying patients that we interviewed who had not used the service did not know what it was for, had confused its purpose with complaints advocacy, or did not know what the service could do for them. This contrasted with the explanations offered by mental health professionals as to why people were not using the service. They generally attributed this to the person exercising a positive choice, which we found to be the exception rather than the rule, when talking to people who had not made use of IMHA. This does not necessarily rule out numbers of service users who may choose not to use IMHA because they are relatively satisfied or confident in their own agency; though we did not locate such individuals. Other reasons such as the individual's mental state could also impede access and carers suggested that they could have an important role in such instances.

Not surprisingly, how and when the IMHA service is promoted emerged as critically important to influencing access. The quality of promotional materials that we saw tended to be rather limited, often giving basic details about the service. Qualifying patients wanted more detail including pictures of the local IMHAs so they could recognise them on the ward, and examples of how an IMHA could help them. It was evident that relying solely on written materials was an inadequate strategy for promoting access.

Accounts of the difficulties in engaging with IMHA services as a consequence of mental health status, circumstances surrounding admission and the sheer information overload people experience when being detained under the MH Act, all point to the need for there to be a more visible advocacy presence. This is particularly so on inpatient wards, and for mental health professionals to repeatedly ensure that the person has understood the purpose of IMHA, their entitlement and how to access it. There are, of course, resource implications to be considered in areas where advocacy services receive insufficient funding to commit to such a presence. We did find evidence of IMHA services that had cut this aspect of their activities to prioritise direct IMHA work.

At the moment, responsibility for identifying who and how to access the services lies somewhere between the IMHA service, the mental health service and the qualifying patient. The Code of Practice (Department of Health, 2008a) puts explicit duties on certain mental health professionals or the statutory organisations. Staff are willing and do refer, particularly on inpatient wards. However, this is reliant on understanding that access to IMHA service is a right and being predisposed towards advocacy and IMHA services. IMHAs expressed uncertainty about the quality of

information that mental health services provide to qualifying patients and whether this is treated as a one-off exercise. On the other, hand mental health services were uncertain how qualifying patients used the information provided, with both groups viewing self-referral as consistent with advocacy principles.

Our findings on access to IMHA services are consistent with the findings from the CQC (2010; 2011b). Access for many qualifying patients appears to be problematic and may be impeded by lack of understanding and, occasionally, active resistance on the part of mental health professionals. We have also identified that it may be the case that those people who need their rights protecting the most may be the least likely to access IMHA services. Furthermore, mental health professionals can act as gatekeepers to IMHA services making judgments about who might need to be referred to an IMHA or make most use of it. This does not sit comfortably with the spirit of the MH Act 2007 that promotes access to IMHA services as a right and thus should be universally available to qualifying patients.

There are two potential remedies to the issue of inequities and potential gatekeeping of access to IMHA services. The first is whether all qualifying patients should be automatically referred to IMHA services on detention or discharge to CTO, giving them the opportunity to opt out rather than opt-in. If such a development were to be adopted across the board, serious attention would have to be given to the capacity of advocacy organisations to cope with a subsequent increase in the volume of referrals.

A second option is to strengthen the overall advocacy presence, particularly on inpatient wards, in line with the recent NICE guideline (NICE, 2011). Having a presence on the ward to provide information in terms that qualifying patients understand would not only promote access but also facilitate access to the most appropriate form of advocacy. The way in which the service is promoted appears to significantly influence uptake with service users preferring an informal approach from the advocate. Thus, peer support and service user or community-led initiatives have an important role to play in increasing access.

### **14.3 Appropriate support from IMHA services**

The starting point for considering appropriateness lies with examining the suitability of IMHA services for the population of qualifying patients. On the whole, IMHA partners were especially satisfied and appreciated many aspects of the independent support they received from IMHAs. For those who accessed IMHA services, therefore, the support appeared to be relevant and suitable to the majority.

We found little evidence, however, that IMHA providers had comprehensively addressed the diverse needs of the qualifying population. Indeed we found scant evidence of the involvement of IMHA partners in the design or delivery of IMHA services, nor of all IMHA providers consistently working in partnership with



community organisations. This may well reflect the demands on their time but is clearly a shortcoming. The sites in our study were undertaking equalities monitoring, although this was largely restricted to gender, age and ethnicity and needs to be further extended. The unease about capturing data on sexual orientation needs to be addressed and could usefully be taken forward in collaboration with LGBT organisations.

Similar to the results of the advocacy workforce survey undertaken by Action for Advocacy (2008), we found that approximately three quarters of the advocates were White women, making the provision of choice of advocate in a context of diversity a potential challenge to deliver on. However, most users of advocacy services emphasised the quality and effectiveness of the advocacy support as opposed to the personal make-up of the advocate. To some extent, this finding is supported by our previous research into advocacy for African and Caribbean men (Newbigging, McKeown, Hunkins-Hutchison et al 2007; Newbigging, McKeown & French, 2011). In this study, the ethnicity of the advocate was important in terms of initial recognition and trust and, hence, was influential in some service users' decisions whether to engage with the advocate in the first place. Similar to the present study, once a relationship was established the ethnicity of the advocate was usually secondary to their effectiveness and other qualities. However, it is important to note that the number of people from BME communities in this study overall was relatively small and they represented diverse communities. Indeed, our earlier study, and other work has highlighted the importance of different models of advocacy to meet culturally diverse needs, including approaches that are much more embedded within communities and concerned with interdependence, with families for instance, than the defined model of independence embodied in IMHA ( Mir & Nocon, 2002; Rai-Atkins, Jama, Wright et al, 2002). This has not been explored within the current study but these previous studies and supporting commissioning guidance (Newbigging, McKeown, Habte-Mariam et al, 2008) provide resources for commissioners, IMHA providers and community organisations to develop appropriate services.

Another dimension of appropriateness is whether the right type of advocacy is available i.e. instructed or non-instructed. One of our key findings is that there was relatively little non-instructed advocacy taking place in our case study sites, creating a gap in provision, particularly for older people with dementia. There was the suggestion that IMHAs can be ambivalent about non-instructed advocacy and therefore may not be recognising or responding to the need. It is clearly a different style of advocacy and this has training implications for IMHA services as well as supervision and operational policies to support good practice. However it is also important to recognise that the need for non-instructed versus instructed advocacy is not always clear cut and may change over a relatively short period of time. Our findings suggest that the co-location of IMHA services and IMCA services, and dual trained advocates, mean that IMHA services may be more confident and comfortable

with providing non-instructed advocacy to qualifying patients and be able to respond flexibly to changing needs.

The IMHA role is a particular form of advocacy and it is clear that there is an important interface with generic advocacy, as people often need support in expressing their views on other issues that do not pertain directly to the MH Act but are relevant to their mental health issues, their recovery journey and broader health and social needs. We found evidence both that IMHAs experienced dilemmas in relation to this and felt that the introduction of the statutory role created boundaries to their practice, which can be an impediment to pursuing a more holistic form of advocacy. Further, for some advocates there was a sense that generic advocacy has been squeezed in the implementation of IMHA, with those service users not subject to compulsion missing out. We had limited data on this but our sense was that those IMHA services that also provided generic mental health advocacy interpreted the role in terms of a function, which also sat comfortably alongside an IMCA or Deprivation of Liberty Safeguards (DOLS) role, as well as retaining a broader focus on the health and general needs of people. This seemed to us to be within the spirit of the law and the guidance in terms of IMHA forming part of a broad spectrum of advocacy provision. However, there are implications for commissioning and for how IMHA services are organised, which need to be considered at a local level.

Whether or not the role of IMHAs in Tribunals and managers' meetings was always appropriate was raised both by IMHAs and mental health professionals. There was a suggestion that, to some extent, IMHAs were becoming quasi legalistic in relation to these activities and this, arguably, was not a positive development. Rather, IMHAs were at times substituting for legal representation as a result of changes in legal aid entitlement, and this was, by default, changing Tribunal chairs and panels' expectations and understanding of the role IMHAs.

#### **14.4 Effectiveness of IMHA services**

The study reports routine collection of monitoring information including satisfaction with IMHA services. Such endeavours are arguably crucial to making sense of the overall impact of advocacy, appraisal of its quality and supporting an effective commissioning process. Our study found there was a distinction between process and outcomes of IMHA provision, with many service users commenting favourably on the process and with less tangible evidence of outcomes. This reflects the distinction between benefits arising from the process of advocacy and those resulting from the outcomes of the process made by Townsley and colleagues (2009). Further, the outcomes may not always be perceived as benefits, even when the process is evaluated positively.

Approaches to measuring impact represent interesting thinking on outcomes and service evaluation and are clearly part of a broader process of professionalising the

organisation of advocacy, of which IMHA is an important part. There remains, however, a case for a more thorough review of different approaches to measuring the effectiveness of advocacy and the possibility of devising a standardised approach to IMHA evaluation that would address geographic variation in quality and render the commissioning process more meaningful and insightful. Such an approach need not preclude additional diversity in local monitoring nor the crucial need for user-defined outcomes to be a significant element of the approach.

We found that advocacy is appreciated when it has a tangible impact and the service user is empowered to get what they wish for. One feature of the service user experience of IMHA, however, that links process and outcome is the often remarked upon scenario wherein people don't get exactly what they want but feel better having experienced advocacy or perhaps arriving at a compromise solution or an approximation of what they were asking for. As we have observed, the process of delivering IMHA can on occasion be viewed as validating detention and, therefore, as a method of social control. Similarly, there is a view that an outcome of advocacy involvement may be that some service users make better-informed choices not to exercise their rights. Taken together with the aforementioned observation that advocacy can result in a reduction in formal complaints, these points can raise interesting questions regarding whether advocacy is actually always best thought of as working on behalf of qualifying patients or ought to be seen as part of a pacification process, assisting them to adapt to perceived wrongs rather than challenge them. The extent to which participants in the operation of advocacy are consciously aware of these possibilities will affect their appraisal of quality of the service.

The reported lack of impact of advocacy by some service users is cause for concern. Our study was not designed to track the impacts of advocacy interventions case by case, though we have mapped relevant influential factors. Hence, issues around lack of outcomes may be either because of an individual advocate who is ineffective, or the mental health service might be highly effective and not need advocacy or may be so poor that any impact is difficult to achieve. Further inquiry could usefully afford analysis of advocacy case work in more detail.

Further the question of the effectiveness of statutory advocacy in comparison to generic mental health advocacy remains unanswered but previous studies, from Australia, have suggested that a restricted focus on legal advocacy may be less effective than a model that attends to broader health and life issues (Rosenman, Korten & Newman, 2000; Beaupert, 2009). These studies reinforce the importance of locating statutory advocacy within a system of well resourced, well organised and ongoing advocacy services.

### 14.5 The critical nature of the relationship with mental health services

Advocacy will have different impacts, for different people, at different times in different contexts. In one sense, advocacy can be seen to be an important catalyst for opening up the discursive space of psychiatric practices and institutions, empowering individuals to be more actively involved in decisions about their care and recovery. Where this makes a progressive contribution to the democratising of these spaces, then advocacy can be seen to have something of a transformative or emancipatory role. In other regards, advocacy might be seen as a conservative force, merely helping individuals to adapt to the oppressive or liberty-limiting features of psychiatric regimes.

We might wish to distinguish between the readiness of various locations or care teams to engage with advocacy: different mental health settings will represent different sorts of social space for involvement (Spandler 2009). Quirk, Chaplin, Lelliot et al, 2011) note the degree to which psychiatrists, for example, put pressure on service users to agree to treatment plans or prescriptions that are seen to be in their best interests. Encounters could be described in terms of a three-way typology: they were either open, where decision making was freely negotiated with full user participation; or they were largely directed by the practitioner, with the service user co-operating, but being gently led towards the position preferred by the practitioner in the first place; or they were pressured where the psychiatrist more or less badgers the service user into accepting the practitioner point of view. Our study shows that many service users and staff recognise that the presence of an advocate in such encounters or collective meetings can alter the tone and arguably shift the decision making towards the more open end of the decision-making continuum.

Service users in our study have remarked upon the extent to which advocacy practice can be seen to open up clinical environments to scrutiny and greater transparency. The very presence of an advocate is felt to alter staff behavior towards a more respectful or empowering stance to service users. Care teams who are open to greater levels of service user participation arguably adopt a more democratic milieu to start with, and they may already have systems and processes in place that foster these ideals; we might consider these convergent spaces where the wishes of service users and staff for more open, participatory decision-making coincide. The relations between service users and staff in a context of compulsion into care are often not so cosy and, despite the rhetoric of participation, they may be characterised in terms of contention rather than convergence, strengthening the case for independent advocacy.

We should not lose sight of the extent to which advocacy and progressive mental health practices can promote and enhance the personal agency of individuals, supporting hope and recovery in a context of debilitating life circumstances (see Shepherd, Boardman & Burns 2010; Maddock & Hallam 2010). If the idea of mental

health recovery is conceived of in terms of 'hope, control and opportunities' then arguably this describes an element of what IMHA do – offer some sense of control in a situation where control and agency are taken away. In this sense, advocacy can highlight opportunities and a way forward, and consequently offer hope for people. In any event, with growing numbers of individuals subject to compulsion it would be foolhardy to dismiss advocacy wholesale as a mere palliative. Rather, it would be more appropriate to take a clear-eyed view of its limitations and seek to strengthen its role in empowering individuals to be active agents in their own care as much as possibly can be achieved. To some extent, the standpoint taken on this by services will depend on context and willingness of staff to accommodate the challenge of advocacy.

#### **14.6 Practice and policy implications**

Advocacy has a role to play in improving the experience and outcomes of service users detained under the MH Act, and can contribute to an organisational approach becoming recovery focused. The principles of respecting and promoting self-determination and improving opportunities for choice and control are central strands of current thinking on personalising health and social care. They also underpin the MH Act, current mental health policy (National Institute for Health and Clinical Excellence, 2011) and NICE guidance (NICE, 2011) to improve the quality of mental health care. Our findings shows that advocacy is valued and can lead to tangible benefits for mental health service users, even if these are not always well documented. It is also clear from our study that steps need to be taken to ensure full implementation of IMHA and that its introduction does not become a paper exercise, or that IMHA exists mainly to ensure detained people conform to professional views or demands.

This has two major implications. First, ensuring that the investment in IMHA provision reflects the level of local need and is based on a good understanding of the diverse needs of the local population for IMHA provision. Second, mental health services need to review their practices, such as ward rounds, to ensure that they are creating an environment within which the IMHA contribution can be optimised. For those in mental health services committed to developing a recovery-based approach, they will already be some way along this journey.

One of the difficulties with the introduction of statutory advocacy is the shift towards professionalisation of advocacy and away from its roots as a service-user led initiative. Statutory advocacy, thus, has to be seen as one form of advocacy and the provision of IMHA needs to be considered in the context of the different forms of advocacy and initiatives to strengthen service user involvement and peer support. Furthermore, there is considerable scope for the co-production of advocacy and IMHA services with mental health service users. Some qualifying patients may prefer

to have an IMHA who has a service user background and, from our findings, certainly value the opinion of their peers on the IMHA's qualities and effectiveness.

The NICE guideline on improving the experience of adult mental health care (NICE, 2011) and recent policy from the Welsh Government (Welsh Government 2011a) propose extending the availability of advocacy for all people admitted to psychiatric inpatients. The Welsh Government (2011b) also promotes universal access to advocacy for all children and young people. Further, the Centre for Social Justice (2011) has proposed that people from BME communities have a right to advocacy before detention.

Our findings indicate that there are concerns about the rights of people who are informal and maybe 'de facto' detained and that the introduction of IMHA services may have compounded this by prioritising resources to be spent on advocacy for detained patients. We believe that consideration should now be given to extending the opportunity to access advocacy to informal patients in hospital and those at risk of detention as part of a broader approach to strengthening service user involvement and opportunities for peer support. In practice, when IMHAs also provide generic mental health advocacy they are able to respond flexibly, both to the changing needs of individuals and also to the potential need for advocacy from non-qualifying patients. Investment in advocacy services needs to recognise this and ensure that IMHA services also have the capacity to provide generic mental health advocacy to informal patients.

There remains work to be done on the experience of people from BME communities in respect of mental health services and appropriate models of advocacy. Further, there is a need to look at the place of non-instructed advocacy, particularly for older people and people with a learning difficulty who lack the capacity to instruct an advocate. This points to a need for the development of policy for advocacy in mental health more generally to pull these and other strands, i.e. IMCA and DOLS, together.

Advocacy has developed at a rapid pace since the introduction of statutory advocacy and this is an opportune time to review and develop a whole system of advocacy and realise its full potential. The shift of responsibility for commissioning IMHA services to local government provides such an opportunity. It would be helpful if this could be supported by the development of government policy.

The transfer of commissioning responsibility from PCTs to the Local Authority could, however, also be problematic for IMHA service development, particularly if adequate resources are not ring fenced for this purpose. Furthermore, it will be important for local authorities to build on the progress and positive development of IMHA services that has taken place over the last three years. In addition, the importance of the mental health services context in determining the quality of IMHA provision needs to be recognised and, thus, Local Authority commissioners will need to work in



partnership with health service commissioners to provide the necessary conditions for the successful operation of IMHA services.

### 14.7 Future research

Future research could productively explore the many gaps in the evidence base for mental health advocacy, particularly in relation to measuring outcomes, and to follow up some of the key findings of this study in more detail. Overall, there is a need for more detailed and systematic service evaluations that would provide information about access and uptake of IMHA in different contexts.

Areas for future research that we have identified from this study are:

- A comparison of outcomes for users and non-users of IMHA services in relation to their care and treatment under the MH Act to examine the impact, or otherwise, of IMHA services, both instructed and non-instructed advocacy.
- Evaluating the access, update and cost-benefits of contrasting organisational models i.e. IMHA only or IMHA nested within a broader advocacy role.
- The advocacy needs, uptake, experiences and outcomes for specific groups (for example people on CTOs, those from BME communities) in relation to access and use of IMHA services and the implications for service design and delivery.
- An exploration of the role of advocacy in promoting empowerment of individuals, as opposed to pacifying dis-ease with compulsion into services.
- A review of the different forms of staff training for understanding the IMHA role and evaluation of the impact in terms of knowledge gained and impact upon actual practice.

There is also scope for action research or appreciative inquiry approaches to developing the relationship between advocacy service providers and host mental health services professionals in ways that preserve the independence of advocacy at the same time as locating it in the optimum forms of progressive mental health practice. Ideally, such a study would be designed to be cognisant of the problems identified in our study associated with a lack of appreciation of the advocacy role and the potential for misunderstandings or conflict.



## 15. CONCLUSION AND RECOMMENDATIONS

This research has found that the IMHA role is valued and appreciated by service users, although its full potential is not fully realised. This study has identified key factors that influence the quality of IMHA services. It is clear from the study that action to strengthen this has to be three pronged: through improving commissioning so that the investment reflects the diversity of need and potential demand; by developing supportive mental health contexts, through training and fostering constructive working relationships between IMHA providers and mental health staff; and thirdly, by strengthening the capacity of IMHA services to deliver high quality IMHA services to the full range of qualifying patients, including those who require non-instructed advocacy. These developments will be facilitated by investment in raising the awareness of service users, carers and health and social care staff in mental health in relation to individuals' right to IMHA services, and developing a rights-focus that maximises the potential for self-determination, in the context of the legislative framework.

We have organised the following recommendations from our research with reference to different organisations to facilitate further discussion and action but these may require collaborative working or have broader implications. These recommendations are particularly important given that a major change in the commissioning of IMHA services will take place in 2013, making local authorities the responsible body for commissioning IMHA alongside other forms of advocacy. This process of transition needs to ensure that the learning from the implementation of IMHA services informs the next phase of their development.

### 15.1 Recommendations for government

- People's experiences of admission and detention under compulsion reported here have implications for the general quality of care and treatment under the MH Act. They indicate that the core values and principles underpinning the MH Act of self-determination and agency need to be re-emphasised and supported by investment in implementing good practice initiatives both for mental health services, police and ambulance services. Translating these principles into practice is likely to lead to better individual outcomes and to enhance the service user journey to recovery.
- Through full policy implementation, government needs to continue to recognise the value of advocacy to a highly vulnerable group of people for whom the experience of detention under the MH Act can be frightening, bewildering and isolating. Having a voice in this process is vital and support recovery.
- Access to IMHA services needs to be clearly understood and framed as a right. It is critical that the prominence of advocacy and its value to safeguarding the rights of vulnerable service users needs to be of continued value and importance

in the planning and delivery of mental health services. This needs to be reflected in policy and practice.

- The policy and practice landscape has changed considerably since the introduction of IMHA services in 2009 and it would be timely to consider how IMHA advocacy relates to other forms of advocacy to ensure that the original intention of implementing IMHA as part of a broad spectrum of advocacy services to protect rights and empower service users is both sustained and developed.
- Consideration should now be given to extending the opportunity to access advocacy to informal patients in hospital.
- The provision of IMHA services has not yet reached its full potential. Attention needs to be paid to measures to further improve access and ensure that there is adequate investment to reflect properly assessed local need, the national increase in detentions and use of CTOs under the MH Act.
- Systematic information requirements should be introduced across England to capture data on the number of qualifying patients and referrals to IMHA services in order to provide a firmer basis for evaluating access to and the uptake of IMHA services.
- Consideration should be given to establishing an opt-out rather than an opt-in system to promote access to IMHA services and ensure that those most in need of IMHA services are not missing out on the opportunity. This should involve consultation with service user groups, particularly with those with experience of compulsion, carers and organisations that represent specific interests –BME communities, children and young people, older people, people with learning difficulties, people with physical disabilities or sensory impairments and LGBT people.
- Consideration is given to extending IMHA provision to all in-patients, as recommended by NICE (National Institute for Health and Clinical Excellence, 2011) and introduced recently by the Welsh Government (Welsh Office, 2011a).
- There is a need to clarify the arrangements for commissioning and providing IMHA services for people placed out of area in the independent sector and in NHS services that have a national catchment area. Our research suggests that these should be based on the place where the person is receiving care and treatment but we would recommend that there is consultation with IMHA services to explore different arrangements for providing out of area services.
- Although we have identified considerable variation in the quality of IMHA services, we believe it is important to recognise existing good practice and support the sharing of this amongst advocacy organisations and their networks.

## 15.2 Recommendations for the Care Quality Commission

- This research has produced draft indicators for assuring the quality of IMHA services. We propose that these are further refined to provide a basis for IMHA providers, commissioners, mental health services and service user and carer groups to review the quality of their local IMHA services, and for the CQC to review provision in the context of regulating the MH Act.
- There is a need to establish a mechanism for IMHA providers to take forward concerns when they encounter a clear breach of an entitlement under the MH Act and have reached the limits of local resolution.

## 15.3 Recommendations for commissioners

- Commissioners need to undertake a thorough needs assessment to determine the local needs for and required configuration of IMHA services. This assessment needs to pay particular attention to groups and communities who may encounter particular barriers in getting their voice heard and take account of patterns of detention under the MH Act, particularly for BME communities.
- The development of dedicated IMHA services for children and young people, older people, people from BME communities and deaf people is likely to increase the uptake of IMHA services by children and young people. Commissioners need to consider the best organisational arrangements for meeting the advocacy needs of these diverse groups. This will include co-location with other forms of advocacy and/or commissioning small local providers and facilitating collaborative working between community organisations and IMHA providers. This can be essential in ensuring access for all qualifying patients and ensuring that their rights are upheld.
- Investment in IMHA services needs to provide a sustainable basis for delivery, in line with good practice guidance. We suggest that this needs to be for a minimum of three years. The practice of spot-purchasing, except in exceptional circumstances, should be discontinued as it threatens the financial viability of IMHA providers and makes it difficult for them to plan and therefore to provide a quality service.
- The investment in IMHA provision should include infrastructure costs and the costs of training and supervision for staff and associated development activities. It needs to recognise the administrative requirements in relation to monitoring activity and outcomes.
- There are currently different systems in place for monitoring IMHA services which are inconsistent and place uneven demands on the advocacy sector. There needs to be an agreed and standardised system for capturing information on both the process and impact of IMHA provision.

- Commissioners should involve a range of IMHA partners in the commissioning process.
- Requirements in relation to the role of mental health services in providing a supportive context within which IMHA service can operate should be included in contracts for mental health providers.

#### **15.4 Recommendations for mental health services**

- Mental health services play a central role in ensuring that qualifying patients access IMHA services. They need to take steps to ensure that all staff understand that access to IMHA services is a right, are aware of the purpose and role of IMHA and are knowledgeable about local services.
- Mental health services need to consider how to provide a supportive context within which IMHA service can operate. This should include:
  - Developing an organisational culture that promotes self-determination, recovery and advocacy as a right not 'best interests'.
  - Adopting a range of methods for promoting the IMHA service to qualifying patients and not solely relying on posters and other written information. However, these should be freely available in a variety of formats, recognizing diverse needs and regularly reviewed to ensure that the information is up to date.
  - Care being taken to involve the IMHA in relevant meetings by timetabling key meetings and providing advance notice to the qualifying patients and the advocate.
  - Respect for the advocate role means ensuring that qualifying patients can contact and meet the IMHA service in private.
  - Ensure that there is a policy and understanding of access to notes.
  - Recognising the unique role that IMHAs can play and how this is complementary to, and not an alternative, to legal representation.
  - Having an explicit focus on improving relationships between mental health staff and the IMHA service and the importance of IMHA maintaining its independence.
- MH Act Administrators as well as ward and community based staff should ensure that they have a supply of up to date information about all of the IMHA services in their area, especially where there are multiple providers, and ensure that qualifying patients have access to the relevant local information.
- Mental health professionals working with those on CTOs should receive further training about their obligation to inform qualifying patients about their right to,

and eligibility for, an IMHA and should develop more protocols for referral of people on CTOs to advocacy services.

- ✎ The variable relationships between MH Act Administrators, mental health professionals and advocacy services should be noted and steps taken to optimize learning from good practice.

### **15.5 Recommendations for IMHA services**

- ✎ IMHA services should review their model of provision and practice to identify any measures that they might need to take to ensure that they are providing an equal opportunity to access and use IMHA services.
- ✎ IMHA services should be consistent in recording equalities data for all categories to enable them to properly monitor and improve uptake by different groups.
- ✎ Proactive strategies should be developed for improving access and provision for under-served groups including those on CTOs. This is likely to involve outreach activities and collaborative working with other organisations with specialist knowledge and networks and ensuring arrangements for easy access to interpreters are in place.
- ✎ Provision for under-served groups raises fundamental questions about the appropriateness of current advocacy provision for specific groups. Advocacy services need to review this in partnership with organisations and services users that best represent those interests.
- ✎ Information about IMHA services should be promoted and disseminated through service user and carer networks.
- ✎ Advocacy services should review the written information – posters, leaflets – about the IMHA service, ensuring this is accessible and effective. Mental health service users should be involved in any redesign of promotional materials. These could include:
  - ✎ Easy read, colourful, well-designed posters and leaflets with pictures of the IMHAs, to enable a service user to identify the IMHA when they came on to the ward.
  - ✎ Using questions, examples of issues and scenarios illustrating the purpose of IMHAs and how they could help would facilitate understanding of the role and purpose.
  - ✎ DVDs in appropriate languages, including British Sign Language.
  - ✎ Use of social networking methods to promote IMHA services and experiences of using them.
  - ✎ Material targeted at the general public explaining the MHA, rights under the MHA and access to IMHA services.

- Advocacy services could help improve the understanding of, and access to, IMHA by publicising anonymised case studies and other information which clearly demonstrates the use and impact of IMHA. This needs to include the use of IMHA for those on CTOs and non-instructed advocacy.
- Training and preparation of the future generation of IMHAs is needed and consideration of opportunities for career progression in order to retain and develop high calibre staff.
- Review and ensure a systematic approach to non-instructed advocacy through training and learning from each other through advocacy networks and sharing best practice. This could sit alongside thinking about how to strengthen access for services to older people, particularly those with dementia.
- Develop the links between IMHA and the production of Advance Directives.

### **15.6 Recommendations for service user, carer and community organisations**

- To respond constructively to opportunities to engage in consciousness raising amongst service users around human rights in mental health services. Being aware that the most vulnerable of service users may be the least able to be active members of service user forums – so outreach is important (for commissioners regarding funding, and mental health services to open up these opportunities).
- Self organised user groups to consider the nature of any alliances with advocacy organisations; being a critical friend with an eye on both the value of advocacy but also its limitations, such as the acknowledged potential for pacification.
- Raise awareness and understanding of Advance Directives.
- To critically engage with the reflections here about the balance between the potential for advocacy to promote agency and the peril that it acts as another form of social control.

### **15.7 Recommendations for Higher Education Institutions and training providers**

- Pre-registration training should explicitly address the meaning of advocacy in the context of the professional role for health and social care professionals.
- Consider the development of an academic focus for advocacy which would develop the theory and practice of advocacy and build the capacity of advocates to lead their own research agenda.

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## **Appendix 1: Members of the Project Advisory Group**

Collette Byrne (until August 2011)	Action for Advocacy
Jakki Cowley (from September 2011)	Action for Advocacy
Julian Christopher	Equalities National Council
Zulekha Dala	Aawaz, the Voice of Asian Women across Lancashire
Polly Falconer	The Afiya Trust
Professor Bill Fulford	University of Warwick
Rezina Hakim	National Mind
Professor Chris Heginbotham (Chair)	Institute of Social Commissioning (from 01.02.2011)
Keith Holt	eMpowerMe
Ian Hulatt	Royal College of Nursing
Ramesh Kanani	Carer
Mat Kinton	Care Quality Commission (CQC)
Walid Malik	Aawaz
Ernie Mallen	Comensus
Karen Newbigging	University of Central Lancashire
Marcel Vige	National Mind

## **Appendix 2: Members of the Service User Reference Group**

Fiona Jones	Comensus
Dr Dina Poursanidou	University of Central Lancashire
William Park	Comensus
Lou Rawcliffe	Comensus
Martin Rukin	Shift
Jacqueline Thorne	Manchester African Caribbean Mental Health Service

### Appendix 3: Stakeholder Panel

Collette Byrne	Action for Advocacy
Julian Christopher	Equalities National Council
Kaaren Cruse	UCLan Project Team (Facilitator)
Zulekha Dala	Aawaz, the Voice of Asian Women across Lancashire
Polly Falconer	The Afiya Trust
Professor Bill Fulford	University of Warwick
Rezina Hakim	National Mind
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Keith Holt	eMpowerMe
Doreen Joseph	UCLan Project Team (Facilitator)
Ramesh Kanani	Carer
Mat Kinton	Care Quality Commission (CQC)
Walid Malik	Aawaz
Ernie Mallen	Comensus
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Karen Newbigging	University of Central Lancashire (Facilitator)
Robert Nisbet	British Association of Social Work/College of Social Work
Dr Julie Ridley	University of Central Lancashire (Facilitator)
Caroline Russell	Hertfordshire Partnership NHS Foundation Trust
Marcel Vige	National Mind

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**Appendix 5: Overview of the Case Study Sites**

<b>Case Study Site</b>	<b>Focus</b>	<b>Description</b>
A	IMHA provision for Black and minority ethnic communities	An NHS mental health Foundation Trust providing mental health services to an ethnically and socially diverse population of over 1.2 million, the majority of whom live in a city. There are 3 IMHA providers, three of which provide IMHA services; one to children and young people and the other two to different geographic locations. The IMHA services are commissioned by two PCTs. This case study focused on the city location and paid particular attention to IMHA provision for BME communities in the area.
B	IMHA provision for people living in mixed urban/rural areas	An NHS mental health Foundation Trust in a mixed urban/rural area including coastal areas, providing mental health services to adults of working age and older people and substance misuse services for a population of around 1.4 million people. While in some areas covered by this Trust the population is predominantly White British, in others there is a significant Asian population. The vast majority of both inpatients and outpatients are White British. There are five PCTs and four advocacy services providing IMHA in geographically distinct parts of this NHS Trust. While three of these provide an IMHA service which is co-terminus with single PCTs, one is commissioned to provide IMHA by two PCTs. This case study initially focused particularly on two main geographical areas for pragmatic reasons, although research participants were drawn from across all four IMHA providers.
C	IMHA provision for people living in rural areas	An NHS mental health Foundation Trust in a largely rural area providing services for a local population of approximately 0.75 million people, as well as specialist services for people in other parts of the region. The population is geographically dispersed,

Case Study Site	Focus	Description
		living in semi-urban, rural and coastal areas. Inpatient services are located in three different locations. The IMHA service is provided by a service, based just outside the main population center and is well established, although has recently undergone a major reorganisation as part of merging with a national advocacy provider. The IMHA service is commissioned jointly by the PCT and the LA and the focus for this case study was to understand access issues for people living in rural locations.
D		An NHS mental health Trust covering a largely urban population, providing secure care facilities at all levels of security, high secure, medium secure and low secure. The case study site focused only on the secure care provision within the Trust. IMHA was organised by the same service provider to all of the secure units and is commissioned by specialist secure care commissioners. The high secure hospital has a national catchment, the medium secure unit covers the region and the low secure unit recruits city-wide; the latter two units have a small number of out of area placements. Because of national and regional policy in service configuration all service users are men. There are 330 high secure beds, 56 medium secure beds and 30 low secure beds.
E	IMHA provision to people placed out of area	A national independent sector provider specialist mental health services with a focus on low and medium secure services for adults aged 18 with a range of needs, including dual diagnosis, mild and moderate learning difficulties, a history of offending behaviour or complex needs. The case study site had approximately 150 places and qualifying patients were drawn from a 200 mile radius. All patients qualify for IMHA services and the majority were detained under Section but also Sections 37

Case Study Site	Focus	Description
		and 41. The IMHA services were commissioned by two PCTs, the local PCT (jointly with the Local Authority) for all qualifying patients detained in the hospital and a PCT 150 miles away, which commissioned IMHA services for patients placed in the unit originally from the PCT locality. There were therefore two IMHA providers; one locally that provided the majority of the support and the other provider, located 150 miles away. In addition to IMHA, the local IMHA provider provided the full range of advocacy services and was part of a larger organisation providing advocacy services in the region. The focus for this case study sites was to understand IMHA provision for people placed out of their area of residence.
F	IMHA provision across the age range	An NHS mental health Foundation Trust covering a largely rural area with several main centres of population, providing a focus for inpatient services. The PCT and LA are co-terminous with the area covered by the MH Trust. The Trust provides a comprehensive range of mental health and learning disability services to over 530,000 people. The Trust also has a specialist sub-regional facility for children and young people. There are two advocacy providers, one of which is commissioned to provide an IMHA service and includes an IMHA with a focus on children and young people. The service is commissioned by the PCT. The focus for this case study was to understand IMHA provision across the age range.
G	IMHA provision in an inner-city area	An NHS mental health Foundation Trust in inner city area providing mental health services to an ethnically and socially diverse population of 1.1 million. There are 5 IMHA providers and the services are commissioned by 4 PCTs.
H	IMHA provision to	An NHS mental health Foundation Trust providing a

Case Study Site	Focus	Description
	qualifying patients on CTO	<p>range of mental health, learning disability and substance misuse services for the 1.3 million people living in a varied geographical area which includes coastal, rural and industrial/urban areas. There are seven PCTs and local authorities and five main hospitals providing psychiatric inpatient services. The NHS Trust is divided into four main areas for provision of IMHA service and this case study focused particularly on one of these, a large urban area, with a higher rate of people on CTOs than other areas, which had one IMHA provider. Qualifying patients were drawn from this provider and were either based in the local hospital or community teams in two out of the four boroughs. Five different advocacy services provided IMHA. While three of the advocacy providers were commissioned by just one PCT, one national children and young people's service related to two PCTs, and another related to four PCTs. This case study initially aimed to recruit more people on CTO to the study but in practice this was limited for the reasons explained in the report.</p>

**Table 13: Description of the case study sites**

## Appendix 6: Overview of case study process

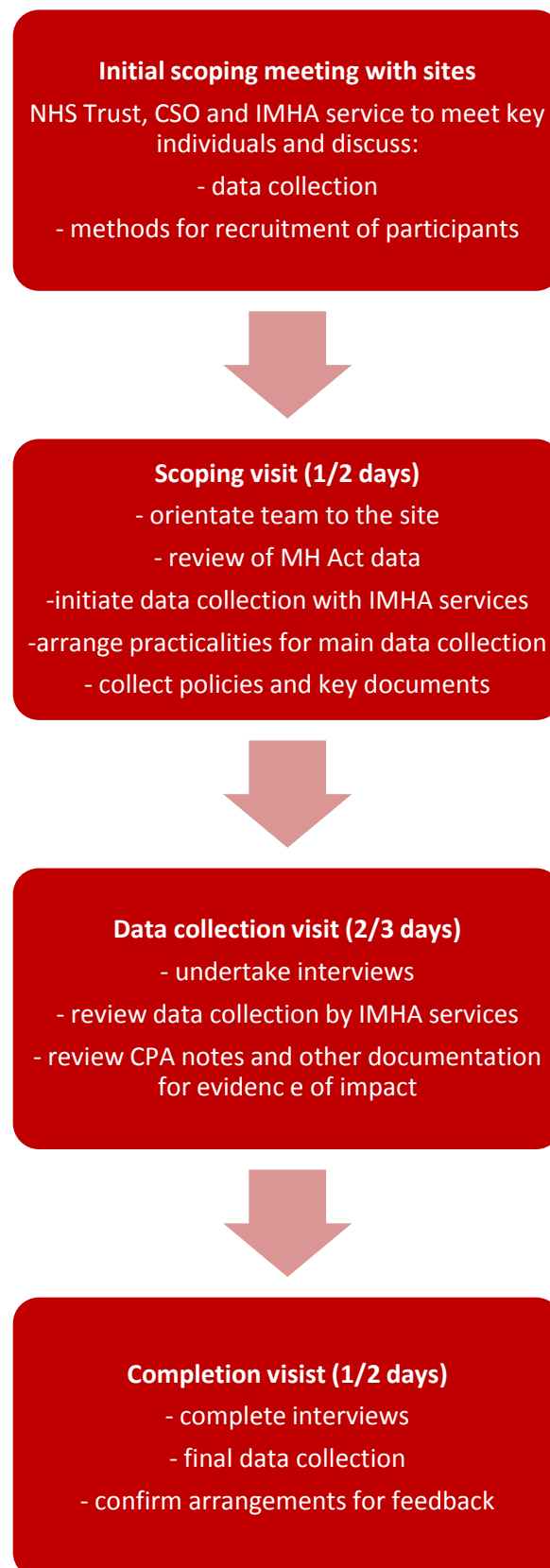


Figure 15: Data collection process in the case study sites

## Appendix 7: Sampling Frame

This sampling frame was used with Mental Health Provider Organisations

1. The aim is to identify a sample of 15 qualifying patients, including 10 who have accessed IMHA services and 5 who have not. The sample should include a spread of ages, a spread of people across the three different time periods within the two years, an equal number of men and women and representation of people from BME communities.
2. The CSO obtained a list from the MH Administrator or the Information Department of qualifying patients between 01.04.09 and 31.03.11 and then used the sampling frame below to randomly identify 200 qualifying patients.

<b>Dates of detention under the MH Act</b>	<b>01.04.09-31.12.09</b>				<b>01.10.09-31.8.10</b>				<b>01.09.10- 31.03.11</b>			
Age	16-24	25-40	41-65	66+	16-24	25-40	41-65	66+	16-24	25-40	41-65	66+
Number of potential participants (Equal M:F ratio) Include BME, and CTO if relevant	12	12	12	12	12	12	12	12	25	25	25	25

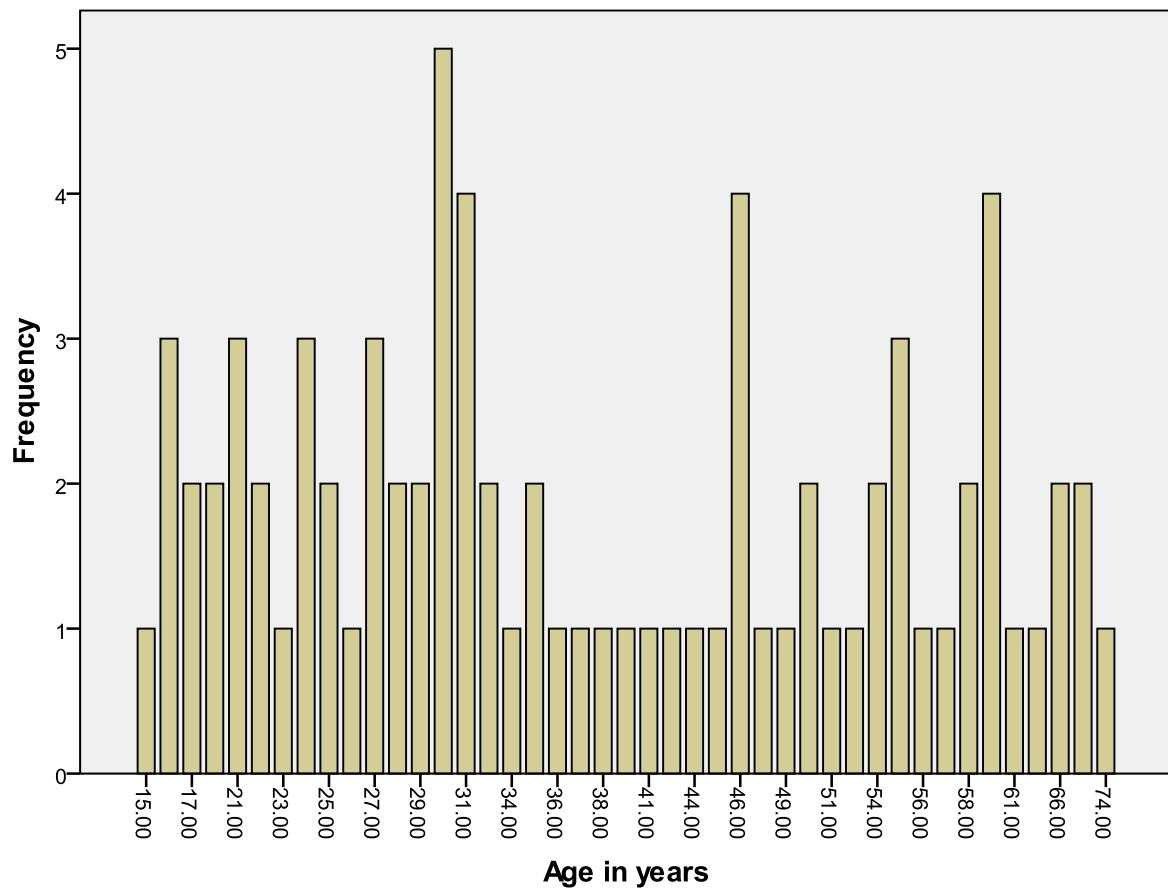
**Table 14: Sampling frame used to identify potential service user participants**

## Appendix 8: Profile of qualifying patients

This Appendix provides a summary of the information from the questionnaires completed by 91% of participants in the case study sites.

### 1. Age of participants

**Mean age = 38.7 years, Range = 15 years -74 years**



**Table 15: Age of service user participants in the case study sites**



## 2. Ethnic origin

		Frequency	Percent
Valid	White British	57	69.5
	White Irish	2	2.4
	White European	1	1.2
	White other	1	1.2
	Asian/British Asian Indian	2	2.4
	Asian/British Asian Pakistani	2	2.4
	Black/Black British African	4	4.9
	Black/Black British Caribbean	8	9.8
	Chinese/British Chinese	1	1.2
	Mixed/White and Black African	1	1.2
	Mixed/White and Asian	1	1.2
	Other	1	1.2
	Mixed other	1	1.2
	Total	82	100.0

**Table 16: Ethnic origin as defined by service user participants in the case study sites**

### 3. Types of disability

	Frequency	Percent
Not relevant	22	26.8
Learning disability	6	7.3
Arthritis	1	1.2
Mental health related for example: loss of confidence	2	2.4
Eating disorder	1	1.2
Mental health condition	17	20.7
Psychosis or schizophrenia	7	8.5
Respiratory COPD or emphysema	3	3.7
Multiple-mental health and physical health problems	2	2.4
Partially sighted	2	2.4
Physically disabled including wheelchair user	3	3.7
Autism or Asperger's syndrome	4	4.9
Bipolar	4	4.9
Unclear	1	1.2
No response	7	8.5
Total	82	100.0

**Table 17: Disabilities identified by service user participants in the case study sites**

**Appendix 9: Commissioning IMHA services**

<b>Case study</b>	<b>Commissioning arrangements</b>	<b>Commissioning arrangements for IMHA</b>	<b>Involvement of IMHA partners in commissioning</b>	<b>Needs assessment undertaken</b>	<b>Equality Impact assessment</b>	<b>Tendering process</b>
<b>A</b>	Joint commissioning, hosted in PCT	IMHA alongside generic mental health advocacy	Not directly but involved via IMHA providers	Gap analysis for IMHA undertaken by LINKs. Look at usage from 2009 and number of detentions.	Yes	Yes in 2011
<b>B</b>	Commissioned by the PCT and the advocacy provider is also commissioned by a number of other local PCTs	Commissioned as an element of independent advocacy for health and social care users	No but intends to involve them in the future	No. Estimated demand.	No but would do if re-commissioning	Yes in 2011
<b>C</b>	Initially commissioned by the PCT. Currently commissioned by the Local Authority on behalf of the PCT, reflecting Joint Commissioning arrangements	As an element of independent advocacy together with user involvement	No	Estimated demand from the mental health detentions and from the use of IMCA	Yes but unable to locate it	Yes in 2010
<b>D</b>	Commissioned by the Secure Specialist Commissioning Group	Initially commissioned IMHA provision for High Secure Hospital, but IMHA service now commissioned to provide services to MSU and LSU	No data available	Fixed and largely static population so easy to estimate and review patterns of demand		Yes in 2010
<b>E</b>	Two IMHA services commissioned by two PCTs: local Joint commissioning for all people	As an element of independent advocacy locally and IMHA only for out of area residents.	No	No	No	Yes in 2009

Case study	Commissioning arrangements	Commissioning arrangements for IMHA	Involvement of IMHA partners in commissioning	Needs assessment undertaken	Equality Impact assessment	Tendering process
	resident in the geographical area where the unit is located and a PCT commissioning IMHA from its own advocacy provider (150 miles away) for its local residents					
<b>F</b>	Commissioned by PCT based on historical activity. LA commissioning IMCA and other elements of advocacy	IMHA only although will allow some generic mental health advocacy activity	No	No	No	Yes in 2011
<b>G</b>	Five providers commissioned by 4 PCTs, including a jointly commissioned service for specialist mental health services	IMHA services for local boroughs commissioned by independent PCTs, which jointly commission the IMHA provider for national specialist services and this is led by one of the PCTs	No	No	Generic impact assessment undertaken, not specific to IMHA	Yes in 2011
<b>H</b>	Seven PCTs commissioning 5 IMHA providers with 3 out of 5 IMHA providers commissioned by one PCT	Four of the IMHA providers are local and one is a national provider commissioned by 2 PCTs	No-pilot IMHA service commissioned to determine local need	No	No	In 2011 for one area

**Table 18: Summary of the IMHA commissioning arrangements in the case study sites**

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