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## Research to support the Duty to Review the Implementation of the Mental Health (Wales) Measure 2010

Qualitative evidence on the views of service  
users, carers and practitioners

### Part 4 FINAL REPORT: Mental Health Advocacy



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#### **Opinion Research Services**

Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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A Research Advisory Group comprising practitioners from statutory and voluntary sectors guided the project and we are grateful for their support and advice throughout.

At all stages of the project, ORS' status as an independent organisation engaging with service users, their carers and practitioners as objectively as possible was recognised and respected. We are grateful for the commission, and we hope this report will contribute usefully to thinking around the implementation of the Mental Health (Wales) Measure 2010 and will ultimately contribute to improvements in services for people living with mental health problems in Wales.

## **Glossary of acronyms**

ACT	Acceptance and Commitment Therapy
ADHD	Attention Deficit Hyperactivity Disorder
BDI	Battelle Developmental Inventory
BME	Black and Minority Ethnic
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CPA	Care Programme Approach: the main way of assessing and identifying the care needs of people with a mental illness receiving secondary mental health services in Wales up to 2012. Replaced in Wales by CTP in 2012.
CTP	Care and Treatment Plan introduced by the Measure and operational from 2012
CAVAMH	Cardiff and Vale Action for Mental Health
DoLS	Deprivation of Liberty Safeguards
DNA	Did Not Attend – referring to service users who do not attend appointments
EMDR	Eye Movement Desensitisation and Reprocessing therapy
IAPT	Improving Access to Psychological Therapies
IMCA	Independent Mental Capacity Advocate
IMHA	Independent Mental Health Advocate
LD	Learning Disabilities
LPMHSS	Local Primary Mental Health Support Service
MHDO	Mental Health Development Organisation
OPMH	Older People's Mental Health
OT	Occupational Therapist
PAMH	Powys Agency for Mental Health
PTSD	Post Traumatic Stress Disorder
UAP	Unified Assessment Process

# 1 Introduction

- 1.1 Opinion Research Services (ORS) was commissioned by Welsh Government in June 2013 to undertake qualitative research to support the Duty to Review the Mental Health (Wales) Measure 2010.
- 1.2 Information and data were gathered by Welsh Government from a range of sources to inform the Review including this study, regular submissions from health board/local authority services, health board primary care satisfaction surveys and third sector surveys. Welsh Government was responsible for coordinating all inputs to the Review and for final reporting to Welsh Ministers.
- 1.3 This study by ORS provides qualitative evidence on the views of service users, their carers and practitioners on the implementation of Parts 1 to 4 of the Measure. The findings are presented in four separate reports; one for each part of the Measure and an overall summary report in Welsh and English versions.
- 1.4 An interim report<sup>1</sup> published in 2014 presents the background and methodology for this study in some detail. This report presents findings from qualitative interviews conducted between July 2014 and April 2015 involving participants with direct experience of Part 4 of the Measure.

## Part 4: Mental Health Advocacy

- 1.5 This part of the Measure introduced an expanded statutory scheme of independent mental health advocacy (IMHA) for patients subject to compulsion under sections 4 and 5(2) and 5(4) of the Mental Health Act 1983. In addition, Part 4 of the Measure expanded the IMHA service to individuals receiving care and treatment in hospital for a mental health problem who were not detained under the Mental Health Act 1983 but were voluntary (or informal) patients. The advocacy aims to assist inpatients in making informed decisions about their care and treatment and to support them in getting their voices heard.

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<sup>1</sup> <http://gov.wales/docs/caecd/research/2014/140410-support-duty-review-implementation-mental-health-wales-measure-2010-en.pdf>

- 1.6 Statutory duties around Part 4 commenced on 3 January 2012 for compulsory patients and on 2 April 2012 for informal patients.

### **ORS Role and Commission**

- 1.7 Welsh Government identified their requirements of the qualitative research project in relation to Part 4 as follows:
1. To report on service users, their carers and practitioner experiences of the new Independent Mental Health Advocacy (IMHA) services introduced under the Measure
  2. To report on service users' perceptions of the impact of the new Independent Mental Health Advocacy (IMHA) services on their care.
- 1.8 The findings from the research presented in this report adhere to these requirements.

### **Ethical Considerations**

- 1.9 For this project the qualitative work with service users could not begin until the project team had:
1. Determined whether an ethical review was needed for the study and if so, had achieved Research Ethics Committee approval
  2. Gained permission to proceed from the health boards via their Research and Development sections.
- 1.10 Examination of the Research Ethics Committee decision tool<sup>2</sup> clearly identified the project as 'evaluation', meaning that it was not subject to full ethical review. All seven Health Boards gave their permissions to proceed. In addition, The Government Social Research Ethics Checklist was completed and guided the project throughout.
- 1.11 All ORS staff involved in the project were fully trained in the principles of medical and social research ethics and, in particular: potential participants' rights to clear and full information about the study; the importance of informed consent; the right to withdraw from participation at any time and recognition that potential harm to

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<sup>2</sup> <http://www.hra-decisiontools.org.uk/research/>;  
[http://www.wales.nhs.uk/sites3/Documents/952/RES\\_Defining\\_Research\\_Sept\\_2013.pdf](http://www.wales.nhs.uk/sites3/Documents/952/RES_Defining_Research_Sept_2013.pdf)

subjects takes many forms, including inconvenience and emotional stress. Each participant was required to read full information about the project and to sign a consent form before taking part.

#### **Methodology – Part 4 Qualitative Interviews**

- 1.12 Our methodology encompassed individual face-to-face or telephone interviews with service users and carers along with focus groups and interviews with practitioners.
- 1.13 We encouraged participants to engage with the issues and express their opinions and feelings in their own words. Focus group sessions lasted for up to two hours and interviews for about half an hour to an hour.
- 1.14 Although qualitative approaches cannot be certified as statistically representative samples of public opinion, the meetings and interviews reported here gave diverse groups of people the opportunity to be involved. Because the recruitment was inclusive and participants were diverse we are satisfied that the outcomes are broadly indicative of opinion based on direct personal experience. The outcomes reported in this report are, therefore, reliable as examples of the reflections and opinions of a range of informed people on the implementation of the changes introduced by Part 4 of the Mental Health Measure.
- 1.15 We relied heavily upon statutory and third sector organisations to recruit service users and carers and 16 interviews were eventually achieved. (see Appendix 1 for profiling information).
- 1.16 The recruitment of service users to this stage of the project was the most challenging in the whole study. ORS contacted staff within a wide network of statutory and voluntary organisations throughout Wales and circulated information and handbills to aid recruitment over a period of eight months.
- 1.17 The service user participants all had direct personal experience of being supported by an Independent Mental Health Advocate during a stay in hospital as an informal or voluntary patient. In a few cases, their status changed from detained to informal/voluntary



during their stay. All of them had stayed in mental health units in NHS hospitals.

- 1.18 Verbatim quotations are used throughout, in indented italics, for their vividness in capturing points of view. ORS does not endorse the opinions in question. In this report the quotations are ascribed to five categories of participant: 'service user', 'carer', 'IMHA Practitioner', 'MHDO' and 'Practitioner', which includes all other types of practitioner, including nursing staff and consultants.
- 1.19 This Final Report presents the sentiments and judgements of participants about mental health advocacy; its implementation, management, examples of good practice and issues arising. The views expressed by participants might or might not be supported by available evidence; that is, they may or may not be accurate as accounts of the facts. ORS cannot arbitrate on the correctness or otherwise of people's views when reporting them. This should be borne in mind when considering the findings. Where possible any such issues are flagged up in the report.

## 2 The Findings: Part 4

- 2.1 This chapter draws upon the interviews conducted with service users and their carers and with practitioners, including IMHA providers. Findings under each of the two specific review questions (as in the original Welsh Government project briefing document) are presented in turn. A summary of the key findings under each question precedes a detailed commentary.

### **Review Question 1: Experiences of Advocacy**

Report on service users', their carers' and practitioners' experiences of the new Independent Mental Health Advocacy (IMHA) services introduced under the Measure.

### **Summary**

- 2.2 Service user participants found out about the IMHA service in a number of ways: from nursing staff; from other patients; via posters and leaflets or directly from advocates themselves. Most felt it should be easier to find out about the service and their legal rights to it and suggested that patients (and carers) should be informed at admission and throughout the hospital stay. More awareness training by health boards for hospital staff was called for, and especially for staff within general and independent hospitals.
- 2.3 Service users said it was easy to get in touch with IMHAs and they were given enough time with them. Some received IMHA support under both detained status and informal status during their stay which was considered to be a positive change under the Measure.
- 2.4 Practitioners identified people they thought were missing the opportunity for IMHA support and these included people in general hospitals and independent hospitals; people with dual diagnosis; young people; older people and people living with dementia and their families.
- 2.5 Several service users felt that the role of the IMHA was too restricted; that they should have more influence over clinicians or

that they should be able to help with practical matters like housing and finances that affected patients' mental health. The benefits of the same person acting as IMHA and community advocate were highlighted and some participants suggested that health boards should be mindful of this potential when commissioning providers.

- 2.6 IMHA practitioners highlighted their approaches to support minority language groups; people with limited capacity or other communication needs. Although the IMHA service was generally able to support Welsh speakers, participants highlighted difficulties when involved in meetings with non-Welsh speaking mental health practitioners or those with non-British cultural backgrounds.
- 2.7 Even IMHA practitioners who said they had spare capacity felt the existing IMHA network would be unable to meet the potential demand from all in-patients with mental health problems. IMHAs and hospital practitioners stated working relationships were, at times, difficult. Fully understanding the IMHA role was considered to be key to improving these relationships.

## **Comments**

### **Awareness**

- 2.8 Service users were asked about how they became aware of their entitlement to an IMHA. For some, the information was given freely by members of the nursing staff either as part of the admissions process or at other times during their hospital stay:

*When I was admitted I was told about advocacy but wasn't made aware of how much that entitled me to. My nurse in charge (later) told me that if I needed any help at all that the hospital couldn't help me with I could ring up this person. (Service user)*

*Well, I already knew, but at the point of admission they told me. They are quite good in that way. (Service user)*

*I found out I was entitled to get an IMHA in my first month in hospital; the nurses told me about it. They asked whether anyone wanted to see an advocate, and if they did then they would arrange it. (Service user)*

*When I was in (hospital) ... you get a visit from an advocate in your first few days—whether you need them or not—to make you aware of the presence, which is amazing. (Service user)*

*(I was told about the advocate when) I was being read my rights under section by a staff nurse. In the psychiatric unit I was only under section for three days and the rest of the time I was a voluntary patient. (Service user)*

*I think it was in the information that came when she was admitted. (Carer)*

- 2.9 A few service users said they could not recall whether they were made aware on admission and suggested that the advocacy service should be introduced at a time when the patient was able to understand or benefit from it:

*I don't really have a memory from the first week. (Service user)*

*The problem is that you don't know where your state of mind will be at any given time when you're in the hospital but usually I think it's better to wait a while to actually come down from what you're suffering with, to feel more lucid and rational and be able to hold a proper conversation, rather than someone come and visit out of the blue. Perhaps it would be better to be informed then that you have the right to an advocate and be able to see what an advocate role was. (Service user)*

*The time that you need your advocate most is probably the time when you couldn't hold a conversation with them or retain the information they're giving you. It's probably up to the nursing team to determine when it's time to introduce you. (Service user)*

- 2.10 Others were made aware by hospital staff only in response to direct enquiries or complaints:

*I had an issue that I wanted to complain about. I explained what had happened and they recommended that I see an advocate. (Service user)*

*I phoned a lawyer. I thought they were holding me against my will and they said, 'we can't help you but you can phone an advocate' ... I went to one of the nurses on the ward and said I need the number of an advocate. She was happy to give it to me but she didn't understand why I wanted to talk to one. (Service user)*

- 2.11 Several service users became aware of the advocacy service via leaflets or posters on the ward:

*There were posters up on the ward ... although I wasn't sure if I was entitled to it because I was voluntary. (Service user)*

*There was a noticeboard in the ward full of absolutely everything, including things about the advocacy network. (Service user)*

*It was a poster on the wall on the corridor as you come into the ward – it was amongst different services that were helpful like Hafal. It said you are entitled to a free and impartial IMHA ... I probably saw the information on the first day but I didn't write it down till half way through my stay. (Service user)*

- 2.12 Others became aware through word of mouth from other patients or by seeing the advocate on their ward rounds:

*I was advised by one of the other patients – and they gave me her card. (Service user)*

*A lot of the people that came in after me, I was telling them to get in contact with her ... that she was a person that people could turn to. (Service user)*

*The IMHA was on the ward a few days a week – pretty regularly. (Carer)*

*Being approached by the advocate gave me some reassurance, because I had never seen any adverts about advocates before that. (Service user)*

*Presence on wards is a good way of raising awareness. Word passes round word of mouth patient to patient. (IMHA Practitioner)*

2.13 Other service users had been aware of the IMHA service before their latest hospital stay: one from their nursing course; two because of previous hospital stays and another through their contacts with a community advocate. In one area, third sector participants said that the IMHA service had undertaken outreach and awareness-raising work; had distributed leaflets in projects and spoken to the Mental Health Forum.

2.14 Most participants felt that information should be easier to access and that making patients aware of their entitlement to an IMHA and the role of the IMHA should be embedded in admission procedures. This should happen both in acute and general wards:

*When I was admitted I wasn't told.* (Service user)

*Nobody (in the hospital) said that you can talk to an advocate.*  
(Service user)

*I think when you are admitted to the hospital at the start, you should be informed of everything they do, rather than going in and one day being asked whether I wanted to see the advocate, and not knowing what that is.* (Service user)

*One thing that bothers me is that I know that not all wards are informing people about their right to advocacy and even to the fact that people who have a diagnosis have a right to advocacy in general wards.* (Service user)

*I had been to (community advocate) and found out a number of little things so when I went yesterday I asked in the office. I mentioned IMHA and one of the nurses said 'well she can have one if she wants one'. She hadn't been offered. You go in the ward; you expect to see a noticeboard with things on it - there's nothing.*  
(Carer)

*Although the posters made it clear about the service, it wasn't something that the staff publicised and it wasn't clear that the person coming around the ward was an advocate.* (Service user)

*The young people I've spoken to are under the impression that*

*they are only eligible to see an IMHA if they're on a psychiatric ward. (Practitioner)*

*All the posters get taken down for infection control so you can't keep posters up. It's pointless. (IMHA Practitioner)*

*Build it into documents for admission as a prompt for staff – and do that in every hospital – even general hospitals. Ask the question: does this person have any form of mental illness? It's happening with detained patients. We have worked with our health board to make them do information for voluntary patients. So that's about staff making the decision to refer to us but in general hospitals ... at the moment, there's nothing as far as I'm aware. (IMHA Practitioner)*

- 2.15 In one health board the practice of informing patients at admission had been implemented and a member of the management staff highlighted their best practice approach and the positive results arising from it:

*We collect the offer of IMHA at the point of admission on the patient particulars – there's a box on the form and the admitting practitioner has to ask the question, 'do you want an IMHA?' This box has to be ticked. So when I came into post (in 2013) 28% were being box ticked and I went onto the ward and asked why? They said that patients when they come in might be too distressed. In that case they lack capacity but they said they didn't think of that. So we've been working with the staff and now (2014) we're up to 97% across mental health services as a whole. I get the figures in every month with the names of the patients and I can find out which patients haven't been offered (an IMHA) and I can follow that through. We can't do that on the general wards because the IT system doesn't support that. We are very behind with our IT systems talking to each other and that's where we need an awful lot of investment. (Practitioner)*

- 2.16 In one area the award of the IMHA contract to an organisation based at some distance had meant that patients had to make appointments to see the advocates. This was considered to be a less satisfactory arrangement than weekly ward rounds:

*The service, which used to have regular weekly visits by advocates to the ward, where people would see them and could get to know them and/or access them freely, now relies on a patient asking for access to an advocate and the staff having to ring the advocacy service and fit into their schedule for appointments. This puts an onus on the patient knowing about advocacy and then relying on staff to broker this arrangement which I know is probably the way it works mostly, but feedback from both patients and staff indicates the weekly visits to the ward certainly were much better. (IMHA Practitioner)*

- 2.17 IMHAs said that many hospital staff knew little about the IMHA service; were not aware of their obligations to inform voluntary or informal patients or did not appreciate how the service could support patients. They also said that staff were making judgements over whether or not to inform patients about the service:

*Generally staff are very good at referring formally but don't seem to realise that they should be doing the same for informal - and the informal, in general, we'll pick up on the wards. (IMHA Practitioner)*

*Staff don't realise their obligations to inform people of their right to an advocate. People who lack capacity – consultants don't see the need for an advocate. The biggest issue is just getting people to be aware of their statutory obligation and to do it. (IMHA Practitioner)*

*Where consultants have referred and have seen the results, they are the ones who will refer again. Problems are where staff don't know. (IMHA Practitioner)*

*The nursing staff may say, 'an advocate may be able to help you' or, 'it's a service if you'd like it' but actually patients need to know that this is their statutory right. (IMHA Practitioner)*



*Staff often make a bit of a judgement as to whether they think it would be right for that person. I've had staff comment to me and to my colleagues and say, 'well they don't really need an advocate - they're more than able to represent themselves'. I mean, that comes back to staff - not just nursing staff but also administrative staff, strategic staff, planners ... All sorts of people in the health board need to understand what people's statutory rights are. (IMHA Practitioner)*

*But actually from the minute you're detained or as an informal patient, but particularly where people are detained under short-term sections 4-5-2 and 5-4; from that very point you are entitled by right to have an offer made to you of an IMHA. That's not to say that the IMHA service will attend or it will be appropriate or that actually the person themselves wants it. The fact is, it's got to be very clearly built into that pathway. (IMHA Practitioner)*

- 2.18 IMHA practioners said that patients were not being repeatedly informed about their rights to an IMHA although this was in the code of practice:

*As an advocate myself, my role is to provide the support for the patient; I don't need to be telling staff on a daily basis that they should be revisiting our role. You'll actually quote the code at them and the code states that you must revisit this with patients, they're like, 'I don't know about that' and, 'I've told them two hours after they were admitted' (when they were stressed and ill). So we have highlighted that IMHA needs to be revisited after maybe two days, five days and as the code clearly states it should be revisited throughout the person's stay in hospital ... but the staff are not making patients aware on a regular basis. (IMHA Practitioner)*

*We need someone to ensure that that's happening because I hear from modern matrons that, 'oh we'll look at this once a month to see how many people have ticked that box', but I don't know they're actually asking them or asking them in the right way. (IMHA*

Practitioner)

- 2.19 The relationship between staff and IMHAs was considered to be vital to raising awareness. So too was having a visible IMHA presence on the wards or raising awareness via community advocates:

*I know that the staff on our wards respect the jobs that we do and actually us being on the ward for that one patient actually reminds them that they may have to mention IMHA to a number of other patients. But obviously we have leaflets on the wards; we provide also a drop in service for community advocacy ... therefore, again, if the patient is maybe talking about debt issues or about some other issue, that advocate will say, 'well, do you know about our IMHA service?' (IMHA Practitioner)*

- 2.20 The challenges in increasing awareness amongst patients and staff in general hospitals were highlighted:

*It's the part that's around the general and community hospitals, where nurses are rehabilitating people ... and when mental health comes around it's the last thing on their mind ... so even when I did a secondment for nine months raising awareness around Part 4 of the Measure on general and community hospitals their feeling was, 'well, she does mental health or she had a bit of training in mental health she might be the one to attend', rather than, 'actually, oh do I need to know this, should I attend this training?' (IMHA Practitioner)*

*And, fair play, the commissioners are on board with this and they acknowledge that there's an issue with general hospitals especially. (IMHA Practitioner)*

- 2.21 Practitioners speculated that the service was not being promoted within general hospitals owing to resource shortages or that the pathways and monitoring for general hospitals were currently ill defined. Some IMHA practitioners said they would be unable to

cope if the general hospitals came on board and suggested that priorities should be set at a strategic level:

*If you were to advertise an advocacy service which covers community based general hospitals you need to resource it in order to meet demand. (Practitioner)*

*Obviously we know that when they're admitted to the mental health unit that there is a pathway; that things need to be completed during the period of time, but as far as being admitted to a general ward we have no idea and I think that's where Welsh Government has fallen down because when we've looked at how we monitor the service that we deliver we've had a little of, 'make it up as you go along ...' (IMHA practitioner)*

*I would love to understand some thinking behind the informal in general and community hospitals ... I totally get the informal patients in a mental health hospital and I think its fantastic and I think it's encouraging that the Welsh Government wants to support people that are in general hospitals and are having their mental health assessed, but how was it agreed that it would be a positive step forward to extend the measure to incorporate those? I would love to really understand the thinking behind that. (IMHA Practitioner)*

*I think the fact that general and community hospitals are not utilising their role allows us to do the work that is being provided for us in the acute units and in the independent mental health hospitals ... (IMHA Practitioner)*

- 2.22 Practitioners in one area said that referrals were relatively higher from the smaller community hospitals because staff were well informed of the IMHA service:

*We are busier in (area) and (area) because we're getting a lot more general hospital referrals – these are areas with much smaller hospitals so it's easier; there are not so many agency staff in small hospitals and staff are much more aware of the IMHA role. (IMHA*

practitioner)

*I've done a lot of work on the general wards with the IMHA and the IMCA service. The practitioner that's involved with DoLS teamed up with (the IMHA service) and went on the wards with a very short poster and ten minute presentation to the general nurses and we've had 70 referrals in the last three months from (two community hospitals). (The IMHA service) has said you've got to go in. We saw the gap there. I wouldn't say it's brilliant but we are making inroads, which ... is really good. (Practitioner)*

- 2.23 Many practitioners recommended more training for hospital staff about the IMHA service but also highlighted challenges which included cancellations at short notice owing to staff sickness and work pressures:

*Training is always the first thing to go (IMHA Practitioner)*

*It's fair to say that I think our training on the Measure, the advocacy side, has been light and we're going to have some joined-up training. (Practitioner)*

*We would like to go out and train them more or raise awareness of mental health advocacy to staff within hospitals but quite often they don't have the time to attend training. (IMHA Practitioner)*

*So it is about a cultural change and I don't think we've addressed that at all. We have just focused on implementing a legislation without necessarily thinking about the lead in time and the preparation work that you have to do with people who are delivering services as well as the people who are receiving services in terms of how they understand what that change is about. (IMHA Practitioner)*

*There should have been a lot of work done in preparation for this, and I'm not actually sure how possible it is afterwards. I think afterwards it ends up more like beating people with a stick because they're not implementing something that they should be. (MHDO)*

*Yes, we've had some resource to follow the Measure but it's not enough to change this culture of working and services need to be allowed the time and the resource to take people out of that environment and, if you like, retrain them and I have to say that's from Band Three nurses right through to psychologists and psychiatrists and, you know, there are issues at all of those levels in terms of how the Measure has been implemented. (IMHA Practitioner)*

- 2.24 IMHA practitioners were also very clear that the obligation to increase awareness of Part 4 amongst clinical staff belonged primarily with the health boards and Welsh Government and not with IMHA providers. They also felt that the teaching of the Measure – including Part 4 entitlements - should be included within undergraduate programmes:

*Health boards are always saying about difficulties of getting information to staff but we have third year placements and until they come to us they've not heard of any of it. And they themselves admit that this is stuff that they should be trained in ... (IMHA Practitioner)*

*You've got to look at how nurses and doctors and clinicians and psychiatrists and psychologists are trained; it's got to be embedded there and then it's got to go right through the system in terms of going right to those people who've been in service for a very long period of time. (IMHA Practitioner)*

*I think we can do as much as a service as we can in terms of trying to encourage people to meet with us; encourage people to attend the training, to release staff; to all of that but actually health boards and Welsh Government have got the authority to say to people you will embed this in your training. (IMHA Practitioner)*

*You know, we don't have any authority. You know the bit that we did around the general hospitals ... we were asking modern matrons; we were asking staff nurses; asking the community*

*hospitals, can we come and deliver this training and they're like do we really need it? Or they don't get back to you – it's not an issue for them. It's got to come from the other level; it's got to come from up there - the Director of Nursing, for example, has got to take this on board ... What are we going to do with nurses who've been on the psychiatric unit for the last 25 years who are going, 'I've always done this job; I know how to do it, don't tell me how to do it' ... and then you've got the clinicians ... I think there is a particular problem around professionals at that level that we've got to deal with and that's got to come through not just the health boards but the Royal colleges as well. (IMHA Practitioner)*

### **Access to Advocates – Positive Comments**

- 2.25 Throughout the study we spoke with people who decided not to access IMHA support. They said that they preferred the support from family or, in the case of one individual, from their integrated team of mental health professionals:

*The thing is my husband always came in with me. So I didn't feel I needed to take up the offer. (Service user)*

*I told them I was glad to get their details, and I told them I might be in touch if I was in hospital for a longer length. As it turned out, I didn't need to do that, because everybody was involved. My CPN and my therapist were up on the ward to have a meeting with the resident psychiatrist. It was all good and joined up – we were all singing from the same song sheet. There was no need to get the advocate involved. The fact that everybody was working together was what made the difference. (Service user)*

- 2.26 Participants who decided on IMHA support said that once initial contact was established the advocates were easy to contact either face to face or by telephone. Access was either by self-referral and appointments; direct one to one contact during ward rounds or via nursing staff. Non IMHA advocates also advised nursing staff to refer to the IMHA service:

*I got in contact with the advocate by saying, 'yes' when they asked me if I wanted to see him. I got to see him instantly practically – within a day. He was on the ward already. (Service user)*

*Well they normally came round once a week and everyone knows about them really. They come and introduce themselves ... and ask if you want any help. They're quite helpful. You've got to try and catch them when they're around. They had loads of patients to see really – but there wasn't a problem if you wanted to see them. (Service user)*

*I was actually ushered into a room one day by a nurse to talk with the IMHA. I talked to him for about an hour and a half about how he could help me and what he's there for. (Service user)*

*One of the nurses would come in and say the advocate is coming today, and write everybody's name on a list. (Service user)*

*Sometimes hospital staff tell us or the community advocates say you should be referring this to IMHA, which happens regularly to be fair. Our older person's advocate particularly will say, 'this should be referred to IMHA because the mental disorder is paramount'. (IMHA Practitioner)*

- 2.27 Where the IMHA's office was actually in the hospital, contact with patients was considered to be particularly easy:

*Our service has an office within the psychiatric unit at (x) Hospital so we actually get people who come to our door ... so people can come in and we'll sit them down and we'll introduce ourselves, say who we are and what we do. (IMHA Practitioner)*

- 2.28 Service users generally found that getting hold of their IMHA outside of their normal visiting times was easy; some advocates gave out direct contact numbers. Response times to requests to meet were considered to be quick: within the same day or next day at the latest:

*It was OK to get through to the advocate. I spoke to the receptionist*

*and the advocate got back quite quick – within a couple of hours and said she'd be in the next day. (Service user)*

*She was absolutely fantastic. Everything I wanted help with she was literally a phone call away and she would be there the next day or even the day that I rang her. She kept in weekly or fortnightly contact with me anyway to see how I was but every time I needed her I'd send her a text or give her a phone call and she'd make an appointment for that week or an appointment for the Monday or the Tuesday. (Service user)*

*There was a time when I had to ask somebody to ask her to phone me back and she did phone me back so, yes, she was definitely very accessible. (Service user)*

### **Time Spent with Advocates**

- 2.29 The time that service users spent with IMHAs varied widely: some said they saw the advocate whenever they were on the ward which could be weekly or fortnightly and others said they saw them from once to four times during their stay in hospital. All, without exception, said that they were given enough time; were not rushed and that the frequency of contact was appropriate to their needs. For instance, one person said that they only needed one short meeting because they were 'generally happy about how the ward is run':

*I thought the meeting with the advocate was good, because he answered my questions. The meeting was for about 15 minutes, which was fine for what I needed. (Service user)*

*Last time I was in hospital I spoke to my IMHA once on the phone and once in person – I was only in for two weeks. I thought for the issues raised that it was enough. We had the meeting in the room for 45 minutes, which was more than enough time to cover it. (Service user)*

*I saw him maybe three times. It was enough, fine for me. (Service user)*



*We were talking for ages – it was long enough. She didn't do the slyly looking at her watch or anything. She was very good. (Service user)*

- 2.30 A few people said they saw the same advocate during the one hospital stay under both detained status and informal status. This was considered to be a positive change under the Measure:

*Say, I see someone who is obviously an IMHA because they were detained under the mental health act ... then if they become an informal patient they're still entitled to an IMHA – as long as it comes under the remit of the IMHA then it works really well. (IMHA practitioner)*

### **Access Difficulties – people missing out**

- 2.31 Some practitioners were concerned that people were missing the opportunity for advocacy and that the levels of referral varied markedly by hospital or area. Whilst interviewing people for other parts of the Measure, we came across people who said they had been in hospital for their mental health but who had not been offered an IMHA and had not been made aware of their rights to one. For example, one young person had been in hospital on three occasions, for about a week or two each time; they had seen CAMHS staff but had not been offered an advocate. Another person had been a voluntary patient in 2013 and had not been made aware of the advocacy service and another participant who had an advocate whilst detained in 2013 had not been offered one on their more recent stays in hospital:

*There's a lot of success stories of people that do access them but a lot of them don't get that face to face meeting – they might not even be aware that they exist. (Service user)*

*The patient who probably needs us most is the patient who doesn't ask and hasn't been informed. (IMHA Practitioner)*

*I was speaking to somebody - they asked for an IMHA and they didn't have one, they were short staffed. (Practitioner)*

- 2.32 In one area, practitioners said that if the IMHA service was included in care pathway policy documents, then busy clinical staff would be more likely to implement Part 4 on their wards:

*We've had experience recently around development of an integrated pathway for acute care which is from the moment someone enters a unit to the minute they're discharged and everything in between ... Now we've gone back to the policy just to see that statutory advocacy and community advocacy are not implicit in this document ... When you're a nurse on a ward you have so many things being fired at you left right and centre ... they are actually in an environment where there are already so many rights, laws, regulations, particularly around the Mental Health Act; they're inundated with it but if it (IMHA) was built into pathways and policies ... (MHDO)*

- 2.33 A particular issue concerned access to people staying in general hospitals – and particularly the larger ones. Two service users who were interviewed for other parts of the Measure said that when staying in general hospitals they were not offered the IMHA service. One was in hospital for three weeks and 'was denied an advocate' and the other said:

*The second time I had a psychotic episode was when I got pregnant again – his heart stopped... It all got too much, because I couldn't cope with the stress of it all. I was in the mother and baby unit at (area) and I felt intimidated and very vulnerable and alone. (Service user)*

- 2.34 Other practitioners made comments about IMHA support in general hospitals:

*The Measure has benefited so many more people but still there are issues with low take up in general hospitals. (IMHA Practitioner)*

*Often in general wards, the emphasis is simply on discharging the person; moving the person somewhere else and so I think things like advocacy aren't seen as very important. And I think they are far*

*more vulnerable in general hospital settings than in a mental health setting because we think of the big picture, whereas medics and nurses just want to deal with the disease or illness and get them out. (Practitioner)*

- 2.35 Particular issues were highlighted concerning access to patients staying in general hospitals short-term. For example one IMHA mentioned the challenges of timing their own support with the visits of psychiatric liaison on paediatric wards:

*Quite recently I've met with the nurses on the paediatric ward and talking to them about children accessing mental health support and they're saying 'so, when the psych liaison comes up at ten to six at night or nine o'clock in the morning to do a psych liaison assessment, you're going to be there?' ... So the nurses were saying I don't want to tell the patient because in a sense I'm telling them on the one hand but on the other hand I'm saying you can't have it because you aren't actually going to be in here long enough and that's a big, big issue ... I tried to explain to the nurses in the general wards, well when you think psych liaison is on you should be thinking IMHA ... but obviously we have a different response time to psych liaison. (IMHA practitioner)*

- 2.36 Participants mentioned other groups of people who they believed were missing out on their right to the IMHA service. These included people with dual diagnosis; young people; older people on general wards or older people's units; people living with dementia and their families and people in independent hospitals:

*I think that the area where this is falling apart a little bit is in dual diagnosis and substance misuse because it's very, very closely tied with mental health but I think often it's these people that aren't getting the advocacy that they need ... Now this was a mental health setting and there were a lot of people with mental health diagnosis but there were no posters up; there were staff members there who were quite hostile to the idea of advocacy and when I*

*kind of brought it up, they said, 'that's not the kind of thing we do here', whereas actually I've found out since then that it's a legal right ... and not something they can choose to do or not to do ... I think the sensitivity they need to work with people with mental health problems would absolutely translate to substance misuse.*  
(Service user)

*We have young people's units at (hospital) and it's been a battle to get in there and change the culture of staff. ... We've got them actually now to agree that a young person is told that they can have an advocate and that they're referred to us but it's not explained to that young person what an advocate does. It's been 15 months; it's been a battle and this week has been one of the first times we've had a young person phone us saying, 'I want an advocate'. (IMHA Practitioner)*

*So you go to an independent hospital where some of them are informal, some of them are on a Section 3 and the staff say well why are you involved because they have an advocate? It's about training and making them aware and being honest about what we can actually do for a patient as well because although there might be an advocate involved, they are not an IMHA and there are certain things an advocate can't do that an IMHA can do under statute. Unfortunately, as a patient in an independent hospital if you're being told you've got an advocate; you don't need them (IMHA) are you going to challenge that? And you're entrenched in the independent hospital sometimes for many, many years. (IMHA Practitioner)*

*It would be nice to know if individuals who are in older people's hospital and maybe CAMHS have the same right to an advocate<sup>3</sup>.*  
(Practitioner)

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<sup>3</sup> This quotation reveals a level of uncertainty by this practitioner as to patient eligibility under Part 4. The Measure, in fact, created statutory duties to ensure IMHA help and support is available for all inpatients with mental health needs.

- 2.37 A few participants also felt that the IMHA service should be extended to people in the community:

*In an absolute ideal world; if funding was no barrier, I'd like to see it extended to people who are (not in hospital) as well because I think there are people with quite disabling conditions ... and it seems to me that sometimes we wait for people to get to crisis point before we offer them the help they really need and I think to make sure their voices were heard and they were happy with their treatment plans before it got to being in an inpatient setting or perhaps to help people to access secondary mental health services because there are people who struggle with that. (Service user)*

### **The IMHA Role**

- 2.38 IMHA practitioners explained their role at length during the study and also highlighted typical working practices in relation to their advocacy role:
- Having a thorough understanding of the individual rights of each patient
  - Explaining the role of the IMHA to the patient
  - Always being patient-focused; listening to them, helping them to understand and make decisions; developing their confidence and skills to communicate
  - Being flexible - in response to patient need
  - Attending ward rounds with or without the patient
  - Meeting with a range of professionals (doctors, social workers, nurses) at ward rounds or separate meetings to arrive at answers from professionals for the patient
  - Preparing patients for meetings with clinicians; empowering them to communicate without their direct support at ward rounds
  - Communicating with the client in the mode of choice: by telephone or meetings
  - Approaching patients directly on the wards; taking referrals from staff

- Working intensively over short periods with people on acute wards where the turnover is quick, supporting them with their medication, discharge planning and any other matters
- Supporting people of limited capacity by spending time with them; accessing records or speaking with relatives on their behalf
- Ensuring an independent approach by, for example, using independent interpreters - not those employed by the health board
- Meeting defined response times: *so what we've got now are two response times in our contract so we've got a same or next working day response for anyone within holding power of the Mental Health Act and then we've got five day response for everybody else.*

2.39 Several service users suggested that the role of the IMHA was too restricted; that they also needed help with practical matters, like housing and finances that affected their mental health whilst in hospital. Others mentioned the advantages to patients where the same advocate was able to act as IMHA and community advocate:

*IMHAs don't deal with benefits, finances, debt or anything like that. So then I put my community advocate hat on. Now if I wasn't a community advocate I would just refer him to one. But because we cover both, he gets a completely seamless service. We have a lot of people who say that they prefer to be speaking to the same person. (IMHA practitioner)*

*Community advocates are being asked to work with people who have previously been in hospital – having the same advocate in both would be beneficial. (Practitioner)*

*We have had referrals from mental health advocates for matters concerning housing or benefits because they are only able to help with the patient's needs whilst in hospital but other matters were affecting their mental health. We could go to housing with them or something so I think there's something of a gap there. When young*

*people are in hospital the advocate (IMHA) can't help them with things they need help with. (Practitioner)*

*I was hopeful that it was something that would help me – I was having issues with housing and I was hoping they would help me with that and I was hoping that they'd be able to help with the communication issues with my psychiatrist. You know, there had been a lot of frustration and arguments and upset and I was hoping she'd be able to help me with that. Well with the housing, she said that wasn't actually within her domain but she did actually refer me on to a housing worker. (Service user)*

- 2.40 Some participants felt that the health boards should be mindful of the potential for cross-over between IMHA and community advocacy roles and also the potential for continuing support with the same advocate following discharge. The provision of more seamless advocacy support would also be facilitated by commissioning local providers who were more likely to be already known and trusted by local service users. Participants suggested additional advantages in terms of reducing travel times for IMHAs; familiarity with local mental health services and addressing local language needs. A service user also called for service user involvement in the commissioning process:

*I would like to see service users lots more involved in the commissioning process. Bigger organisations come in without knowing anything about the local doctors and nurses. Local knowledge and relationships are critical. In the commissioning process they say they can't do that because they've got to open it up to ... competition ... You come out of hospital and you are dealing with different advocates. That makes the service less effective. (Service) had a Welsh speaking advocate who couldn't speak Welsh! It makes a difference to have a first language speaker ... They (IMHA providers) need to be continually scrutinised. (Service user)*

- 2.41 Two participants said that they would prefer the IMHAs to have more power:

*It would be better if they had more authority. What they can do is support you to say what you want or speak on your behalf. But there is no requirement on the service to do anything about it. They can be there when something happens, like an interaction between you and the service, and you complain and they support you - their witness has not been taken seriously because they are not 'professionals'. (Service user)*

*It would be nice if they had more power because in a way in the ward round everybody seems to have so much power except the service users and their advocates. Advocates can speak up for them but they can't really change anything. But what they can do is at least make people listened to and help people articulate. I'd love them to have more influence. I'm all for advocacy – I think it's really, really important. (Carer)*

### **The IMHA Role: communicating with patients**

- 2.42 Inevitably, the need to support people whatever their communication needs is central to the role of any advocate and IMHA practitioners highlighted approaches for minority language groups; people with limited capacity or other communication needs:

*We're doing a lot of work in the community with BME groups now and one of the things we're doing is work in the communities to see how best we can design our literature to see how somebody on a ward would be able to understand it. So that's a big piece of work we're doing at the moment. It's not always best to have it translated because of low literacy levels. (IMHA Practitioner)*

*A translator would be brought in to attend the ward round and we would obviously arrange to meet the patient and the translator before the ward round to do the normal prep that we would do going into that meeting. But it's not just about spoken language it's about other forms of communications: Makaton, British Sign*



*Language, story books, picture cards, facial gestures, non-instructed advocacy observation.* (IMHA Practitioner)

- 2.43 Practitioners mentioned particular concentrations of BME communities throughout Wales requiring translators including Somalis, Chinese, Polish, Portuguese, Chinese and Asian. In most areas, IMHA practitioners said that demand for translation was low, although increasing for people from Eastern Europe. Although translators were easy to come by, they were expensive at about £50 per time and required some administration to source and organise.

- 2.44 Levels of demand for services in Welsh varied, of course, throughout Wales. IMHA providers in South and South East Wales said they had limited demand and would use translators or team members to meet any needs. They also highlighted a particular need from older people with dementia:

*If they've got dementia, if they've been Welsh speakers as children, they'll revert back to speaking Welsh so we use specific Welsh speakers for them now. It happens more often than you would expect especially in Rhondda and Swansea.* (IMHA Practitioner)

- 2.45 In the more Welsh speaking areas, particularly in West and North West Wales, first language Welsh speakers on the IMHA teams were usually able to cover the demand to support patients. However, participants pointed out that in meetings or ward rounds with consultants and other practitioners, Welsh speaking patients and IMHAs would need to resort to English to be understood:

*It's very difficult; there just aren't enough Welsh speaking staff and I don't think there are any psychiatrists who speak Welsh. Psychologists? You may as a second language in the West but not as first language Welsh speaking.* (IMHA Practitioner)

- 2.46 Participants thought that this was an issue which required intervention at a strategic level to encourage Welsh speakers to train and then practice in mental health:

*The Royal College and the Deanery have got to address this issue. They have got to try and encourage people who train - Bangor is the heart of psychology ... I think there's a fundamental issue around junior doctors as well ... It always seems that mental health is the last ones to have junior doctors allocated and those are doctors in training, they are not psychiatrists and psychologists. We need to incentivise people to stay in North Wales, to use those natural skills they have in terms of their culture and their language ... we do need to have more emphasis on people staying locally, to deliver services. (MHDO)*

- 2.47 Participants explained why it is so important for patients to be able to communicate with mental health staff in their language of choice:

*I think when you're ill it makes a huge difference. It's not so bad if you're fine - you're out in the community you're OK - but when you're ill, you're in a different place; you might be in a ward in a hospital, wherever, it's a strange place, you're not 100% sure what's going on, who are the people all around you, and if you have someone within all that mix that speaks Welsh to you it's just comforting ... you've got someone there who you can turn to. (IMHA Practitioner)*

*I think if you're distressed you want to go back to where you come from naturally don't you? (IMHA Practitioner)*

*It's less of a struggle to formulate sentences – you don't have to bother translating it for somebody's benefit. (MHDO)*

### ***The IMHA Role – capacity and resources***

- 2.48 The need for quality, trained IMHA staff was highlighted and proper resourcing of the service to allow the necessary time for interactions with patients:

*My opinion is if you want quality staff then you have to pay. You have to know as much as the other professionals in hospital because otherwise you can't challenge them. (IMHA Practitioner)*

- 2.49 Whilst some IMHA practitioners thought they had sufficient resources to support more people, this was not the case for all. Even those currently with spare capacity felt the existing IMHA network would be unable to meet the potential demand from all in-patients with mental health problems. The distances travelled by IMHAs in some areas were considered to present an additional challenge to providers:

*We are very busy but I don't think we're receiving the level of referrals that we should be receiving, there's still scope for us to receive more work but how would that affect staffing levels? At the moment across (area) we've got nine fulltime approved equivalent advocates ... we're not receiving everybody that should be provided with an IMHA so if the full level of referrals was to materialise I don't think that nine would be enough. (IMHA Practitioner)*

*There's no way you can provide an advocate for every single client that needs it. It's great saying that every mental health patient, whether they're voluntary or detained, has a right to an advocate but you can't provide it. (Practitioner)*

*(IMHA provider) has put in their notice on the contract because there's not enough funding. They were finding that the funding wasn't adequate I think because of the rurality ... you've got advocates running up and down which is doable if the advocates are actually in the area. I think what (provider) was trying to do was run it from (centre) which makes it very difficult. (IMHA Practitioner)*

### **Working Relationships: Hospital Staff and IMHAs**

- 2.50 Practitioners highlighted examples of positive working relationships between IMHAs and clinical staff and observed that fully understanding the IMHA role was crucial to those relationships:

*One of our consultants, Dr X, she does a lot of the elderly care and once she became aware of our service she was quite forthright with her referrals and she'll phone us and she'll say, 'I'm not sure if this*

*person fits your service'. So we'll then have a conversation with her on the phone or in person, so if it doesn't fit the IMHA service, it may fit our community work. (IMHA Practitioner)*

*Within (health board) CAMHS has had positive engagement with the advocacy services and build referrals into key protocols. (Practitioner)*

*They (acute units) know us ... I'm invited to go to patients' meetings ... we get lots of phone calls from other professionals asking our advice on points of legislation – social workers, nurses, doctors ... Now clinicians understand that this is not our opinion – we're just there to give clients the information to make their own decisions. It may not be a helpful decision or a wise decision but it's their right to make it. (IMHA Practitioner)*

- 2.51 IMHA practitioners often commented that advocacy was improving standards of nursing. However, several said that their relationships with hospital staff were at times difficult and that their role could at times challenge hospital working practices and cause friction:

*We've had experiences in the past when we've had consultants who might have had a bad experience of advocates. At the end of the day, the advocates can be very challenging to professionals if they're not doing what they're supposed to. We have one consultant will tell you that he vehemently hates advocates and doesn't want us involved with any of his cases. When we do get involved we are finding so many things that they're doing wrong and they think it's a personal attack but it's not – it's making them act within the law ... and telling them that they need to address it. (IMHA Practitioner)*

*Oh I'm sure some of the consultants do feel that but there is also an element where they welcome the challenge and they like to have us. (IMHA Practitioner)*

*(Part 4) is a very positive aspect of the Measure and introducing the broader element of advocacy to all patients in hospital*

*increases support for people's rights. (Practitioner)*

*A lot of the nurses said like she was a busy body – just putting her nose in where it wasn't really needed but it was almost like they did not want outsiders interfering with what they were doing. (Service user)*

- 2.52 Hospital practitioners in one area highlighted their issues with the IMHA service around communications generally; IMHAs' understanding of the context under which clinical decisions were made and personality clashes:

*The feedback that I got about advocacy from members of the team is that they feel that there is not enough communication between the advocate and the actual professional ... They were saying they never came and approached nurses ... I know they're there representing the patient but they feel there is almost a block, you know; they don't have any input at all. So one of their questions was what is their training and role? It feels very much sort of them and us and I have felt that myself as well. (Practitioner)*

*There's different styles of advocacy, so we've had some great advocates in the past... but when advocates exceed the bounds of their authority on a regular basis, it becomes quite challenging and when it takes two senior psychiatrists to take a deep breath to stop situations escalating in the ward round, you know that there's something seriously amiss and we had to have a meeting to try to address it. (Practitioner)*

*In principle, advocacy is fantastic because it holds us to account and we all have blind spots and it's useful to have that accountability and reflection, but not when it's done in a hostile manner. (Practitioner)*

- 2.53 A practitioner highlighted a case which illustrated their frustration with a particular IMHA's approach:

*The advocate was acting like an agent provocateur, reminding over and over again that someone who was potentially detainable under*

*the Mental Health Act had the right to leave at any time they so decreed. And we would have to say; actually, you're informal up until that point that we decide to assess you under the Mental Health Act, starting with a 5.2 which lasts up to 72 hours, and we had to say this like four or five times in the same interview, with the advocate saying; no you can go at any time, you're informal, you can't threaten them with a section, just to keep them in hospital. And we were bending over backwards to try to prevent a Mental Health Act assessment on someone which would be really damning for the rest of their life to come on a section. So do you want to go onto a Mental Health Act assessment and section in due course or will you agree to stay informal? And it got very frustrating; she was doing that over and over again. (Practitioner)*

- 2.54 Lack of understanding remained an issue which was considered to hamper working relationships and practitioners on both sides admitted that it was taking some time to fully understand the IMHA role:

*I think we had more problems than most - It's a very interesting role that isn't a natural fit of how mental health services have been run before .... they're there to represent the patients' views and I think it would probably be fair to say, well, 'Why aren't they working with us' but it isn't their job to work with us ... and that did cause a lot of tension with people not understanding quite why you couldn't have a quiet word with the advocate to go and explain ... I think there was a lot of confusion when it first started. (Practitioner)*

*And I think that's also part of the issue that quite a lot of the managers and what have you don't quite understand the role of an advocate. I had an example quite recently when I had a manager of a unit who didn't quite like how the IMHA had dealt with a case but I don't think that manager understood the role of the advocate and so I went and I had a long discussion, probably for an hour, and in the end she understood ... (IMHA practitioner)*

*And I think that there has to be a consequence to not actually fulfilling the legislation but actually you've got to have allowed people the time to understand what that is, give people the time to do the required training, absorb that training and then implement it. Share good practice, move people around. When you've got a system that's pressured all the time with limited or no resources or reducing resources as is the case probably in (area of Wales) in terms of mental health, you can't expect people just to pick that up and run with it. It just won't happen. (IMHA practitioner)*

- 2.55 IMHA practitioners in one area highlighted the importance of their role in supporting patients who had consultants with different cultural backgrounds:

*Sometimes they (consultants) don't understand local colloquialisms the people use, so ... I've often stopped a meeting where the consultant has said, 'oh you mean this' and the client has said 'oh no, no, no I don't mean that' and I've had to explain what the client means because the consultant is from another culture and actually doesn't truly understand. (IMHA practitioner)*

*The actual culture itself can be problematic at times as well ... we've worked with clients where the consultant has been very strongly of the view that the man is the head of the home and the woman should be submissive to that ... when our advocate was going in to the meetings with the wife it was a constant reference back to, 'but your husband said this, your husband said that ... you should do this' ... So it's really important that people have a very strong advocate who's able to see and raise those issues. (MHDO)*

### **The IMHA service and CTP**

- 2.56 Several IMHA practitioners highlighted their role in supporting people with their care and treatment plans whilst in hospital. They also commented that CTPs were not being prepared in some hospitals – particularly in independent hospitals – or that the quality

of CTPs was poor and patients were typically not involved in their preparation:

*We will contribute to them if the patients want us to ... We'll tell them that they should be having a CTP. We might give them an example of how we can support them. We might say, 'well, when you have your review of your care and treatment plan, we can support you' and they might say, 'what's one of them?' So then we'll say, 'well you should have had this' and we'll give them that information. (IMHA Practitioner)*

*CTPs are predominately produced for a patient: 'here's your CTP please sign it'. And we'll say, 'Oh! When did you have that meeting? Why wasn't the client involved and why are you producing this CTP for this client?' So we can ask those sorts of questions. They're not happy because it's so much easier to write the CTP yourself than to meet with the client ... Personally I have helped a client read a CTP once their care worker had left it with them ... so I sat with her and then we made notes to ask the worker ... (IMHA Practitioner)*

*There was a patient involved with us and in that advocate talking with the patient about what the problem was, one of the discussions was, 'have you got a Care and Treatment Plan?' The patient hasn't, so the advocate has come to us on behalf of the patient and said, 'we want a care and treatment plan'. (Practitioner)*

## **Statistics**

- 2.57 In one area, practitioners said that they were confused about how best the IMHA service should be monitored to ensure standardisation across Wales:

*The way that we count them is still an issue. Do we count the number of contacts there are from an IMHA with the patient? If they were to come off section and become informal would that count as a second IMHA offered? So we have places in Wales that are double counting each time that happens and places that are single*



*counting. Our numbers are significantly higher but we do have a good system where we are counting very well. Detailed figures are split into ages and learning disabilities are identified. (Practitioner)*

### **Review Question 2: Service Users' Perceptions of Advocacy**

Report on service users' perceptions of the impact of the new Independent Mental Health Advocacy (IMHA) services on their care.

## **Summary**

- 2.58 IMHAs supported service user participants in various ways: providing information; working with them to prepare for ward rounds and meetings and accompanying them to meetings, CTP reviews and ward rounds. A few service users asked their IMHAs to access their records or speak to staff on their behalf.
- 2.59 Service user participants all acknowledged that the IMHAs made a positive difference to their stays in hospital and particularly appreciated having an independent, professional person 'on their side'.
- 2.60 They enjoyed their interactions with the IMHAs, often highlighting their personal qualities and their ability to reassure and calm them down; to listen and understand them; to accurately represent them and to make them feel safer, particularly when they were feeling vulnerable, frightened, unwell, confused or forgetful. They valued the way in which the IMHAs could make things happen for them and how they had been empowered through their relationship with the service.
- 2.61 Participants highlighted various positive impacts from their involvement with IMHAs which ultimately made their hospital stays easier and the treatment more beneficial:
- Reassuring patients and lessening their anxiety, meaning they could settle and participate fully in hospital treatment
  - Answering their questions about hospital rules

- Helping to mend patient / consultant relationships by advising the patient of how best to prepare and communicate and take more control of the relationship and treatment
- Improving self-esteem
- Shortening the hospital stay and helping towards a sustained recovery
- Reassuring a carer that someone was on her daughter's side and advocating on her behalf.

## **Comments**

### ***Support Received***

2.62 Service user participants highlighted the various ways in which the IMHAs had supported them. Some mentioned being given information, including information to help them understand their rights. Most said that they were supported to communicate with clinicians; they worked with IMHAs to prepare for ward rounds and meetings and were accompanied by IMHAs to meetings, CTP reviews and ward rounds. Being able to contact the IMHA when they were concerned about anything was considered to be another benefit. A few service users said that they asked their IMHAs to access their records or speak to staff on their behalf, although most had no need of these options.

### ***The Patient / IMHA Relationship***

2.63 Every service user participant who had received support from an IMHA was satisfied with the service and, no matter how transient the relationship, they acknowledged that the IMHA had made a positive difference to their stay in hospital. All said that they would recommend the service to other people.

2.64 Service users particularly appreciated having someone that was on their side and independent from the clinical staff.

*It was nice to know that there was somebody who was more on my side, rather than the psychiatrist telling you what you have to do and what you can't do. (Service user)*

*It's important to have an independent advocate because they're*

*disinterested. I just generally think that mental health advocacy is a very, very important role in a society where so many people are uncertain and afraid about what happens to them if they can't understand and it's very important to have an independent voice because doctors do act sometimes very authoritatively and the advocacy service must exist to stop that sort of practice going on.* (Service user)

*It's nice to talk to someone you don't see all the time – you don't know each other, so there's nothing between you. It's easier if it's a stranger – you're going fresh to them.* (Service user)

*(The service is) like a voice for people who can't find it themselves or don't know how to go about it.* (Service user)

*It's nice to think that you can chat to someone apart from the doctors and nurses. It's just like a comfort blanket really because they know more about the mental health services than you do. I'm not saying the doctors and nurses aren't on your side but if you've got any problems ... They were at hand to put another point of view and work around things. So I think they are beneficial in the hospital.* (Service user)

*I felt there was someone there who was on my side. The hospital situation is very difficult because you're suddenly put with a load of practitioners who don't know you and they sometimes make assumptions about you based on the reasons given for your referral.* (Service user)

- 2.65 Service users said that they enjoyed their interactions with the IMHAs; often highlighting their personal qualities:

*She was actually really friendly and helpful and I did like speaking to her.* (Service user)

*The advocate that approached me was quite calm and relaxed – friendly.* (Service user)

*I find it easier to speak to an IMHA than a doctor. You know the*

*doctors are fine but it's probably to do with my background (with authority and things) ... (Service user)*

*He was a very charming man and he was very gentle and very easy to talk to. He didn't patronise me at all and he reassured me that things were going to be OK. I was feeling anxious because I was on a section. Potentially I was there for a month. (Service user whose status changed to voluntary)*

*She came along smiling. She introduced herself and her role. We made an appointment and we had a chat and it was pretty good, you know. (Service user)*

*Her nature was really nice, she was calm, she wasn't imposing, she didn't talk over me; she let me say what was on my mind. Her voice was nice. (Service user)*

- 2.66 Participants appreciated the way in which the IMHAs were able to reassure and calm them down. Being listened to; really understood and accurately represented were highly beneficial, particularly when people were feeling vulnerable, frightened, unwell, confused or forgetful:

*I knew I was vulnerable and I knew that having an advocate could only be a benefit. I believed they were going to be an extra part of my brain when I was forgetting things. I didn't think that everything was coming out logical or coherently so it was nice to have an advocate who was able to fill in the gaps when I'd forgotten. It was a good reminder. (Service user)*

*She took it seriously, she was really helpful, said she would arrange a meeting with the social worker and the nurse. (Service user)*

*It was professional and quite warm in a way – made me feel at ease. (Service user)*

*They listen to what you say, and they represent what you say – not what they think you mean. I find that sometimes doctors write down*

*what they think you mean. (Service user)*

*Someone who can help you when you may not have the courage to speak up yourself, or feel at a loss of what to say or how to go about saying things. Sometimes you feel perhaps a bit intimidated by management and not quite knowing what you should say. I've seen a few people who need encouragement to speak up and feel nervous about going above the nurses to speak to management about what might need to change. (Service user)*

- 2.67 Two participants said that the IMHAs made patients feel safer:

*It can be pretty traumatic being in hospital even if you are there as a voluntary patient. (Service user)*

*I think advocates are brilliant and people should be encouraged to have them. I think for somebody who doesn't have a carer or a carer who's not particularly strong or doesn't know their way around the system, an advocate is almost vital. It's a safety net kind of thing. (Service user)*

- 2.68 Service users often commented on the professionalism of the IMHAs; of their thorough knowledge of the hospital system, medication and terminology and their business-like approach:

*Seeing him a few times while I was there was very, very reassuring – very amicable and business-like. It was as though we were wanting the same result so it was the best possible outcome. (Service user)*

*When my advocate went on holiday, she asked me if I was happy to see somebody else when she was away. They are all equally qualified and equally competent. (Service user)*

*The IMHA was somebody who was passionate about their job and their role and generally trying to help you. So that was nice. (Service user)*

*I think advocates are very important for people like me that didn't know anything about the mental health system before. (Service*

user)

*She was amazing at her job. (Service user)*

*It's a familiar face and you know what's there on offer and you can talk to them as friends while you're getting help from them as a professional. (Service user)*

- 2.69 Participants also appreciated the way in which IMHAs could make things happen for them. One service user said that hospital staff 'take you more seriously when you are with the advocacy service' and others supported this view:

*When it's brought in formally from someone things do start to change. That's where their role comes in as quite important. You feel better because you feel like you are being supported and they are making a difference. (Service user)*

*If there's something playing on your mind and you have questions that you need to ask. It can be very simple things. Say if you've approached a staff member and you haven't been given an extra pillow you can make those requests .... Little things like that can make a world of difference. (Service user)*

- 2.70 Participants spoke of how IMHA support could be empowering:

*Everyone else there were just psychiatrists. They'd speak to you, and you were treated and made to feel like every day you are in hospital, you are a patient, you are ill and you have to do what we say. When spoken to by the psychiatrists, you feel really out of control, you're stuck there. Whereas when I spoke to her she didn't speak to me so much like a patient. She spoke to me differently. It felt like I was in control more. (Service user)*

*The advocates give you a range of options and ask you what you would like to happen. It's refreshing when you are given those kinds of options. I've been involved in psychiatry since the age of 18 and in the past it has been something done to me – not with me. I like being asked what I want out of something. (Service user)*

## **Impact – Individual Case Studies**

2.71 In this section, brief case studies highlight the particular benefits derived from the service as identified by five individuals.

2.72 Participant One said that meeting the IMHA had changed her experience of hospital ‘quite a bit’. She had been highly anxious about being in hospital and self-referred to the IMHA service shortly after admission in the belief that they could arrange her discharge. However, she was reassured by her IMHA, meaning that she was able to settle down to treatment free from anxiety:

*She calmed me down and made me realise that it wasn't so scary being in there and that it wasn't going to make me worse. I was in there to make me better. I was having panic attacks about what was going to happen so she kind of dismissed all that for me. After I saw her I wasn't so freaked out by being in there and I'd run out of rant and rage. She was like, 'there's no padded cells; they don't lock you in your rooms' ... She was reassuring so I thought, 'I might just survive this'. (Service user)*

2.73 Other participants also spoke about the IMHA putting them at their ease. Participant Two said she was troubled by two conflicting pieces of information from the clinical staff and asked for an IMHA. She had only one meeting with the IMHA because the meeting cleared up the issue in question and she was otherwise satisfied with the hospital staff. She said that the meeting made a big difference to her:

*I think my advocate made things a lot clearer, because some things were mismatched: some people said something; and another said something else ... I'm glad that I did it – it put my mind at rest and made me understand a few things. I felt like I achieved what I wanted from that meeting. My worry and concern had gone away. I think this service is useful. (Service user)*

2.74 The only criticism was that, given the choice, she would have preferred a female IMHA:

*I think there should be an option to see a male or female advocate – that would be helpful. I'd have probably preferred to see a female. (Service user)*

- 2.75 Participant Three felt that the IMHA had helped her to communicate more effectively with her psychiatrist:

*I was incredibly agitated and wound up at the time, that the psychiatrist really wasn't listening to me and I was worried about the direction my treatment would take but just knowing that I'd have someone to advocate for me and make sure that my views would be heard and just to sit in on the interview with the psychiatrist - that was something that put my mind at rest ... Without having that, things could have been really quite different and even though I was a voluntary patient, it could very easily have gone the other way and there was a point in which a temporary section was placed on me during the early days and I agreed to remain informal otherwise they would have sectioned me. (Service user)*

- 2.76 She described the IMHA's approach:

*It went very well, she was very reassuring; she was very calm. I found it very helpful because she didn't get me riled up – she acknowledged the complaints I had and told me what I could do about them but she didn't kind of impose her own agenda and, looking back, I think that was very helpful because I think at the time it would have made things worse if she'd said, 'oh God, yes the psychiatrist, what an awful person ...' (Service user)*

- 2.77 This participant also acknowledged that involvement with the IMHA sat well within her own intention to take control of her life:

*A lot of it as well has been me taking responsibility for my own life. That's why I like the approach of advocacy really. Because for a long time I'd fallen into the role of being a professional patient or service user. So I was having these cycles of intensive treatment and then going out into the real world and thinking, well what can I do? I can't do this myself ... I'd lost confidence in my own ability to*



*manage my life and the more I've started to do that, the more confidence I've gained. I put things into place now that are really sustainable things because having that really intense support might be necessary in the short term but it's never going to be sustainable long-term. And it's not fulfilling either. (Service user)*

- 2.78 She described how her involvement with the IMHA had directly influenced her treatment in a positive way:

*I mean following that meeting I was able to get the treatment I needed and that treatment has absolutely turned my life around and it's funny because that psychiatrist now I have an absolutely superb relationship with – she's treating my ADHD which is a massive deal; she's put me on DBT therapy, which I'm still receiving which has been hugely, hugely helpful. And I think that really things could have very easily gone the other way. It was a crossroads in my life, that period, and I think that if I'd had a bad experience as well as being in hospital overall, I think that things could have spiralled and I could have ended up having further admissions. As it was, that short period of hospitalisation actually achieved a huge amount.*

*It was just at the time when I'd got into a paranoid way of thinking - so I think that having somebody who made sure my rights were being observed and who was witness to that, really made a difference to my mental state and it really helped me to approach the psychiatrist more calmly and more rationally. I think that if the relationship had continued to deteriorate things could have gone incredibly differently for me because I think the foundation of making changes to my life was to do with getting the appropriate treatment and the advocate really helped with that. (Service user)*

- 2.79 Participant Four felt that knowing that there was someone to represent him and sort out his problems with clinicians was reassuring and calming:

*It definitely did help in the hospital. Put me at my ease really. I*

*know doctors are very busy so now you've got IMHAs there I think they take the burden off the doctors. They can write a plan out for you. It was good to know that there was someone on the outside that if there was something I wasn't agreeing with while I was in hospital that I could turn to and she was always there – because there were some disagreements whilst I was inside. But when I managed to speak to my advocate she sorted things out. She helped me with loads of stuff really. (Service user)*

2.80 He explained his trust in his IMHA:

*She was very, very approachable – I'm not somebody who can just tell all my problems to someone. It was almost like she had an understanding of where I was coming from. She knew how I felt – she was very understanding and I was able to open up to her quite a lot where in the past I haven't been able to do that sort of thing. She was like a very close friend of mine – it almost became a professional friendship. I knew that I could rely on her – she would always pull through and get things sorted out. She was someone I could turn to and rely on. (Service user)*

2.81 Participant Four also explained how his IMHA had helped him feel good about himself. He felt that without the IMHA, who was also a community advocate, he would not have recovered and pointed out how she helped with a number of issues aside from his treatment:

*At the end she actually said she was proud of the progress that I made which was a big morale boost – knowing that someone was proud of me made me feel better about myself ... because when I first went in I was a wreck, a complete mess.*

*If I didn't have the advocacy when I was in there – I'll be honest with you, I'd probably still be in hospital. She helped me with my legal case, getting out of hospital, getting a place – she was always there to talk to about other things. It wasn't just hospital things – she'd talk to me about my well-being and about occurrences in my life – she had her own knowledge and experience which she was*

*passing on to me. She helped clear these things up for me and ensured that I did carry on with my day to day life without having all these problems niggling at me. (Service user)*

- 2.82 Participant Five was the mother/carer of an autistic adult daughter who was admitted to hospital under section under circumstances that they both found distressing. The section was subsequently lifted by the psychiatrist and she became a voluntary patient.

- 2.83 The mother said that she liaised with the IMHA because her daughter would have been too frightened to see him on her own:

*Because she finds it so difficult with new people. He was very good but she didn't find it easy to communicate with him but if I was there as well she felt OK. (Carer)*

- 2.84 She described how the IMHA supported her daughter:

*He went to the ward meetings with her; he negotiated with the care coordinator. He gave her information – he was on her side. He told her he was there to speak up on her behalf. He explained the situation – the options she had. He was there for her. He was very, very definitely there for her. He was with her every step of the way. The IMHA was very respectful; he was very gentle. He was really, really lovely. (Carer)*

- 2.85 She also said that the IMHA helped her as a carer to cope with the circumstances of her daughter's case:

*(The IMHA) made a difference to me too - the fact that I knew there was somebody there that was on (daughter's) side - that really was listening to her – because it really was such a horrendous situation. (Carer)*

- 2.86 She made a suggestion that the IMHAs should have training in autism and felt that this would have improved the service for her daughter. She also compared the IMHA with their community advocate who had 'expertise in the autistic spectrum' and was, therefore, able to put her daughter more at ease:

*It would have helped had the IMHA had training on the autistic spectrum. I don't know if they do have that training – generally all round there needs to be more awareness. We were an hour (with community advocate) - she just felt so safe with him.'* (Carer)

### 3 Issues for Consideration

3.1 This section summarises suggestions for the Independent Mental Health Advocacy service raised by service users, carers and practitioners throughout this study. These suggestions are for consideration by Welsh Government along with the various additional sources of monitoring information being collected for the Review.

3.2 It should be noted that many of the suggestions are already included within the Guidance for Part 4 of the Measure.

<b>Commissioning</b>
<ul style="list-style-type: none"> <li>Where possible, commission local providers to: reduce IMHA travel times; capitalise on local knowledge and Welsh language expertise and enable seamless interface between IMHA and community advocacy services.</li> </ul>
<b>Implementation of Part 4</b>
<ul style="list-style-type: none"> <li>Implement Part 4 provisions in all clinical units throughout Wales.</li> </ul>
<ul style="list-style-type: none"> <li>Include the IMHA service in acute care pathway development.</li> </ul>
<ul style="list-style-type: none"> <li>Standardise monitoring systems across Wales.</li> </ul>
<b>Information and Awareness</b>
<ul style="list-style-type: none"> <li>Increase awareness amongst clinical hospital staff of the role of IMHAs and the legal rights to the service of inpatients with mental health needs.</li> </ul>
<ul style="list-style-type: none"> <li>Include a requirement in admission procedures for verbal and written information on patients' rights to the IMHA service; the role of the service and how to access it - to be adopted in all mental health units, general hospitals and independent hospitals. Information to be given to patients and their carers.</li> </ul>
<ul style="list-style-type: none"> <li>Display posters and leaflets about IMHA on hospital wards. Signpost patients and staff to online information about the service. Ensure that patients are informed as appropriate throughout their hospital stay.</li> </ul>
<b>Access</b>
<ul style="list-style-type: none"> <li>Improve access for people with dual diagnosis and people with dementia and their families. Include training for IMHAs in specialist needs such as autism.</li> </ul>
<ul style="list-style-type: none"> <li>Consider extending the IMHA service to the community.</li> </ul>
<ul style="list-style-type: none"> <li>Patients to have the choice over male or female IMHAs.</li> </ul>
<ul style="list-style-type: none"> <li>Ensure adequate resources to meet demand the for the IMHA service.</li> </ul>

## Appendix 1: Part 4 Profiling information for service users and carers/relatives

	Total: 16 Service users: 14 Carers: 2	
<b>Age</b>	SUs	Carers
16-24	3	
25-34	5	
35-44	2	
45-54	4	
65-74		2
<b>Gender</b>		
Female	8	2
Male	6	
<b>Working status</b>		
Working Part Time	3	
Volunteering	1	
Student	1	
<b>Ethnicity</b>		
White British	14	2
BME		
<b>First language</b>		
English	13	2
Welsh	1	
Other		
<b>Physical Illness/disability</b>		
Limits a little	1	
Limits a lot	4	

## **Appendix 2: Mental Health Practitioners involved in the study**

Mental Health Practitioners working in each of the seven Health Boards in Wales participated in interviews or focus groups throughout the study in relation to the four parts of the Measure. Their job roles are presented below.

### **Primary Care Practitioners**

Three focus groups – one in each of three Health Boards involving 29 practitioners:

Strategic Leads and/or Programme Managers and County Managers for Part 1 of the Measure; Nurse assessors and practitioners; Senior Nurse OPMH; Community Development Workers; Operations Manager; Psychologist; Psychiatrist; Team Leaders; Mental Health Development Manager; Managers of CAMHS Primary Mental Health Support.

### **Secondary Care Practitioners**

Four focus groups – one in each of four Health Boards; qualitative interviews and written responses involving a total of 41 practitioners:

Heads of Adult Services, Children's and Family Services and Children's Services;  
Team Manager, Assistant Managers, Heads, Clinical Psychologist and Occupational Therapist for older adults services; Team Leaders/Managers, Assistant Head; Community Services Manager; Occupational Therapist and Student Nurse in specialist learning disabilities services;  
CTP Trainer; CTP and Audit Officer;  
Team Leader, CPNs, Occupational Therapist, Social Worker, Integrated Manager in CMHTs;  
CPN Lead for Forensic Team;  
Prison in-reach Nurses;  
Service Improvement Partnership Lead and Part 4 Lead;  
Manager, Assistant Head of CAMHS;  
Service Improvement and Partnership Lead;  
Psychiatrists;  
Member of Home Treatment Team;  
Adult Social Services Manager;

Day Centre Nurse Manager;

Social Work student.

### **Voluntary Sector Practitioners**

Representatives from the following organisations were involved in practitioner focus groups and interviews (20 participants). It should also be noted that voluntary sector staff participated in many of the service user/carer sessions and were invited to share their opinions. A further 19 were involved in this way. In the end, 39 staff from the following voluntary organisations were involved in the study:

Advocacy Support, Cymru; Barnardo's; Cais (Parabl); Cardiff and Vale Action for Mental Health (CAVAMH); Conwy and Denbighshire Advocacy Service; Flintshire Advocacy Service; Gofal; Gwynedd and Ynys Mon Advocacy Scheme; Hafod Care; Mind; Hafal; Gwent Association of Voluntary Organisations (GAVO); Interlink; Eiriol; Mental Health Matters Wales; Patients' Council; Powys Association of Voluntary Organisations (PAVO); Tros Gynnal Plant; Unllais; Vale Council for Voluntary Services; West Wales Action for Mental Health; YMCA

The table below presents a distribution of practitioner type by Health Board area.

	<b>ABMU</b>	<b>ABU</b>	<b>BCU</b>	<b>C&amp;VU</b>	<b>CTU</b>	<b>HDU</b>	<b>PT</b>
LPMHSS	✓		✓		✓		
Primary CAMHS	✓			✓	✓	✓	
Memory clinics		✓		✓		✓	✓

CAMHS	✓			✓	✓	✓	
CMHT				✓			✓
Crisis							✓
Learning Disabilities		✓				✓	
Forensics				✓			
Older People's Mental Health		✓		✓		✓	✓
In-patient							✓
Prison in-reach				✓			
Third Sector	✓	✓	✓	✓	✓	✓	✓
Advocacy organisations	✓	✓	✓	✓	✓		✓