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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 3 FINAL REPORT: Assessments of Former Users of Secondary Mental Health Services



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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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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
DBT	Dialectical Behaviour Therapy
DNA	Did Not Attend – referring to service users who do not attend appointments
DVLA	Driver and Vehicle Licensing Agency
DWP	Department of Work and Pensions
ECG	Electrocardiogram - a test that records the heart's electrical activity
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
PDSI	Physical Disability and Sensory Impairment
PTSD	Post Traumatic Stress Disorder

QTC	The calculation of the measure of the time between the start of the Q wave and the end of the T wave in the heart's electrical cycle.
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 report¹ published in 2014 presents the background and methodology for this study in some detail which are not repeated in the final reports. This report presents findings from qualitative interviews conducted between July 2014 and April 2015 involving participants with direct experience of Part 3 of the Measure.

Part 3: Assessments of Former Users of Secondary Mental Health Services

- 1.5 'Part 3 of the Measure is concerned with assessments of former users of secondary mental health services. The aim is to enable individuals, who have previously been in receipt of secondary mental health services to refer themselves directly back to secondary services for assessment. This allows assessments to take place without individuals necessarily needing to go to their GP or elsewhere for a referral, therefore improving access'².

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

² Source: Welsh Government, Code of Practice to Parts 2 and 3 of the Mental Health (Wales) Measure 2010

1.6 Statutory duties around Part 3 commenced on 6 June 2012.

ORS Role and Commission

1.7 Welsh Government identified their requirements of the qualitative research project in relation to Part 3 as follows:

- To report on the experiences of service users, their carers and practitioners in relation to Part 3 (arrangements for assessment of former users of secondary mental health services) and to consider, for example:
 - Is the relevant discharge period for Part 3 proving to be appropriate?
 - How well have service users been informed of their entitlement to assessment following discharge?
 - The experience of reassessment.

1.8 The findings 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 tool³ 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

³ <http://www.hra-decisiontools.org.uk/research/>;
http://www.wales.nhs.uk/sites3/Documents/952/RES_Defining_Research_Sept_2013.pdf

from participation at any time and recognition that potential harm to 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 3 Qualitative Interviews and Focus Groups

- 1.12 Our methodology encompassed individual and paired face-to-face or telephone interviews with service users and carers along with focus groups and interviews with practitioners. We also conducted longitudinal interviews with a sample of service users. Four case studies from these interviews are presented in Appendix 1 and their comments are incorporated where relevant throughout the report. These case studies provide insights into individual patient experiences of Part 3.
- 1.13 We relied heavily upon statutory and third sector organisations to recruit service users and carers and 31 interviews were eventually achieved (see Appendix 2 for profiling information).
- 1.14 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.
- 1.15 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 3 of the Mental Health Measure.
- 1.16 Verbatim quotations are used throughout, in indented italics, for their vividness in capturing points of view. ORS does not endorse the opinions in question.

1.17 This Final Report presents the sentiments and judgements of participants about the assessment of former users of secondary mental health services; the implementation of Part 3, its 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 3

- 2.1 This chapter draws upon the interviews conducted with service users, carers and practitioners. Findings under each of the specific review questions are presented in turn and in the order in which they were presented in the original Welsh Government project briefing document. A summary of the key findings under each question precedes a detailed commentary.
- 2.2 Service users and carers related their individual experiences of self-referral and assessment over the period 2011 to the autumn of 2014. This report is concerned with Part 3 of the Measure; it does not present opinions in relation to discharge, nor does it comment extensively on patient outcomes. It should also be noted that service users and carers involved in this study had direct experience of accessing or trying to access services under Part 3. The report does not include commentary by relevant service users who did not try to gain access for whatever reasons.

Review Question 1: Discharge period

Report on the experiences of service users, their carers and practitioners in relation to Part 3 and consider, for example:

- Is the relevant discharge period for Part 3 proving to be appropriate?

Summary

- 2.3 Service user participants were divided in opinion concerning whether the three-year self-referral period was appropriate. Whilst about half of them thought that three years seemed about right; others felt that it should be longer and some said that people should be able to self-refer at any time and that digital record keeping made this possible.

Comments

I think three years is fair enough if you still have the option to go back to your GP as well. (Service user)

I'd say the three year period is adequate. It's going to be different

for everybody of course but for myself, I cycle with my times into hospital every year and a half to two years, so it's possible that I might want to get in and see someone from secondary services quickly, and then at least I'd already be on their books and have the option to get in straight away and not have to go through a GP. I think that would be useful. (Service user)

Three years isn't long enough. They should keep our records on file for a longer period ... It would make me feel more secure. If I was able to click back into care I'd be happy that that's there. (Service user)

I think it should be five years not three. Because sometimes clients will struggle on for up to three years following discharge and then they pop out of the system after three years and then they have to go back through the process of going to the GP and the GP gets told, 'no the client is not suitable for reassessment'. (Third sector practitioner)

I don't think that seems very fair to be honest. I think there should always be some sort of facility there to provide something. At the end of the day, you can go through your GP, but how long is that going to take? (Service user)

Some people have lifelong episodic occurrences like me ... there are so many different levels of severity. Are they trying to say that if they're OK for three years then they don't need to be in the system anymore? I think you should be able to self-refer at any point. (Service user)

I suppose you could have the right for re-referral for life actually – With computerisation you're not having to keep lots and lots of physical files anymore. (Service user)

Review Question 2: Information on Part 3 entitlement

Report on the experiences of service users, their carers and practitioners in relation to Part 3 and consider, for example:

- How well have service users been informed of their entitlement to assessment?

Summary

2.4 Service user participants revealed a mixture of experiences concerning how they became aware of the Part 3 provisions. There was some indication that good practice was being introduced, with practitioners giving clear and full explanations in meetings with patients and then confirming these arrangements in discharge letters. Having meetings with patients and giving clear verbal explanations was considered to be highly important although not required within the current code of practice. The findings show that there is still some way to go in communicating effectively with patients and ensuring that all involved at discharge –practitioners as well as service users - are fully aware of the legal rights of the patient to self-referral and assessment.

Comments

Introduction

2.5 By mid 2015, the Measure had been in place for three years and by this time all patients eligible to self-refer, under the Code of Practice, should have received written information about Part 3 provisions at time of discharge. The people who were discharged before the Measure, were not aware but were eligible. All of our participants apart from two were discharged after the Measure was introduced.

Awareness of Part 3 entitlements

2.6 Several participants said that they had not been informed of their entitlements under Part 3 at time of discharge and particularly those discharged in the early days of the Measure (2012 to 2013).

Nobody told me about my entitlement to assessment to re-enter

secondary care. So I had to go to the GP. (Service user)

I went via the doctor, not knowing that I could go back through the service ... Once I got there they told me I could have gone straight back to them. I should have been told this before. I had no idea.

(Service user)

I've only had a couple of patients (who wanted a re-assessment) ...

I have a feeling they're not aware of it. (GP)

They were unaware that they could try to re-access. (MHDO)

- 2.7 Some participants said that they had not even been informed that they had been discharged or had not fully understood:

We went back to his GP to try and get the medication, but the GP said he had to go to a psychiatrist. The GP wrote to the psychiatrist three times before we actually got anywhere. This was two years ago. We ended up talking to the crisis team and they told me that (patient) had officially been crossed off the care list... the GP didn't know that (patient) had been discharged either. (Carer)

I know there were some informed but there were a lot of people saying they didn't really understand because they weren't told anything, so we had a big mixture. (MHDO)

- 2.8 However, practitioners in one area suggested that people claimed not to have been told because they were aggrieved at being discharged:

Well it's an issue of misrepresentation by patients. So (health board) did a patient survey about a couple of years ago and we were horrified that virtually none of the patients knew anything about the Measure and the fact they'd been discharged, which wasn't true, because they'd all had the briefing over the previous year: the Measure's coming in, you're going to be discharged, you can re-refer yourself or get your GP to re-refer you. And it was just a mantra, as the clock was ticking down ... It doesn't go down with a certain sector of our population who are then dying to come along

to talk to people like yourself and say how terrible the mental health services are. (Secondary sector practitioner)

- 2.9 A few participants, however, said that some people were unaware of their entitlements under Part 3 owing to illiteracy or anxieties:

But letters were coming in and they didn't read the letters, they didn't understand the letters, nobody warned them that the letters were coming anyway. I think they should have been told face to face and it should have been explained to them... Surely somebody should have noted their literacy level. They shouldn't have been sent out in batch. There was a rush for 'we need to comply – they need to have a care and treatment plan; if they haven't got one by this date, we're in trouble. Therefore, we're just going to have to discharge them'. But the reason they're in the system is because they're fragile people. (MHDO)

People don't know how exactly to go about it. It may be said to people, but when you're in a meeting situation and you're being told things you don't want to hear – you don't take it on board. That's why you need something written you can take away. Then you've got a guide you can look back to. I think most people aren't getting letters, and that's what provokes concern. (Service user)

- 2.10 Even when patients were aware of their rights to self referral and re-assessment, it seemed that the services themselves were often unaware and staff in some CMHTs persisted in telling service users to go to their GPs for referral:

My mum phoned as well, but they said they wouldn't talk to me because they said I was discharged, so if I wanted to see them again I would have to get an emergency referral from the doctors. (Service user)

I tried to re-refer (in August 2014) but they said I had to go to my GP and go through the whole rigmarole again. My (primary care) CPN was absolutely livid with them because apparently you are allowed to re-access within three years. (Service user)

There's been a big increase in discharge of these patients because they can always come back under the Measure if they want to. But that doesn't seem to be something that's working terribly well, with patients being told they need to get a letter from their GP. The service is not as reactive as intended when people re-apply. (GP)

Some team members including medics insist that Part 3 patients be screened by a GP before they will agree to see them. In practice such patients end up having to be seen by CPNs. There needs to be clarity about part 3 of the Measure and agreement that all team members will comply with it. (Secondary sector practitioner)

- 2.11 Participants also observed that some GPs remained unaware of the Part 3 provisions; indeed, some of the GPs involved in this study were uncertain of the process (both interviewed in 2014):

Am I correct under the Mental Health Measure that a patient/client who's been seen within the last three years is allowed to just ring up the CMHT and re-refer themselves? (GP)

My impression is that that's not terribly easy for them to do always. I haven't got confidence that it's going to happen ... I'm not sure whether I should be saying you were seen a couple of years ago why don't you just ring them up? I don't know whether I should be giving them support to give them a ring or whether I should be doing it for them via a single point of access letter. Do we have confidence that if they ring up they'll be listened to? (GP)

- 2.12 One participant who had not received the information about Part 3 when discharged in 2012 had received the information in a letter following a second discharge in 2014. Another participant who supported two different clients to seek re-assessments (one in 2012 and the other in 2014) noticed an improvement in access arrangements between the two cases. These and other findings suggest that the procedures around informing patients about Part 3 were being imbedded in practice over time:

It does say that this time. Obviously the first time I didn't even get a

letter. (Service user)

I feel that in the second case there was less banging of heads on walls – it didn't get to the point of waving the Measure around in the air. The awareness has definitely been raised in the last two years.

(Third sector practitioner)

Sources of information about Part 3

- 2.13 A majority of service user participants said that they received information from the services that discharged them and some participants observed that services varied in their effectiveness in communicating the information:

They said if ever I need their help I just have to ring them up and they will reassess my situation and support me again. That was the home treatment team. (Service user)

It's not being communicated effectively, but I wouldn't say it's never being communicated. There also seems to be great variability between the CMHTs. (Service user)

We give those young people as part of their CTP when they're going to hospital a letter to say that they are entitled to refer themselves to adult services when they're 18 if they're 15 when they're discharged. (CAMHS)

Letters are sent up to four weeks after discharge – we don't have proof that they've been told they can self-refer. This is an issue we're addressing. (Practitioner)

- 2.14 Some participants found out about Part 3 via voluntary services or through their involvement as service user representatives. Also, mental health charities like Mind and Hafal were working with patients to raise awareness of their legal entitlements under the Measure:

I found out about the right to re-referral from a voluntary organisation: One Voice Wales. (Service user)

The psychiatrist said about my entitlement to reassessment. I also

found out about the entitlement to reassessment because I follow a lot of the information services on social media, and blogs. There was a patient service and representation meetings and I know the local participation officer, so I know some of the jargon and I know some of the terms. (Service user)

It was through the patient's council and it was through a consultation session taking place when I was volunteering that I found out that I could refer myself back in. (Service user)

The manner in which participants were informed

- 2.15 As mentioned already, some service users said they were not informed at all about their Part 3 entitlements by the service that discharged them. Of those who said they were informed, some said they received letters; some said they were only informed in a meeting with a practitioner and others said they had verbal notification which was followed up by letter:

After I saw the psychiatrist I did not get a discharge letter. (Service user)

I didn't get a letter. I didn't know I could refer myself back in. (Service user)

I think most people aren't getting letters and that's what provokes concern. (Service user rep)

People shouldn't have just been given letters. Consultants should have sat with people to tell them what was going to happen. (MHDO)

I did get a discharge letter and I've still got it in my medical file. It said something like 'if (patient) needs to see the team again there is a window of opportunity in the next three years.' (Service user)

I believe my discharge letter said something about if I had any trouble I could engage with services again via someone on duty at the mental health resource centre. (Service user)

I had a letter from my psychiatrist. It was just a basic letter saying I

could see my GP. (It said) that I no longer needed full psychiatric care. The letter definitely did not say anything about being able to re-access the service. (Service user)

They said they'd discharge me and I said, 'that's fine because you're not doing anything for me anyway'. He explained about the Measure and I knew about it anyway... I got a letter following discharge and he went through it (Part 3) very well. (Service user)

The psychiatrist didn't send a letter directly to me. He would have informed the GP. I understood what the psychiatrist was saying and I had heard a little bit about the Measure. He said I could re-access; ring up the lady on reception and request something if I felt the need. (Service user)

I attended the regular three month appointment and it was discussed there and then – the fact that there was no improvement or detriment to my wellbeing – therefore, under the Mental Health Measure they would look to discharge me and I would have the opportunity to return within three years. And the way that it was closed was excellent - you look after yourself and we'll see you when you're next in crisis. (no letter received) (Service user)

In my role as a service user representative on the CMHT, I know that there is a big issue about the whole discharge process and great unhappiness. There isn't a full standardised thing in place. There should be letters in place, along with an information pack ... I'm congratulating a lot of people who are being discharged, but a lot of them are seeing it as a negative thing, because they've lost that key worker. They are concerned about what will happen to them. I don't think a lot of people understand the re-referral process. (Service user rep)

- 2.16 Service user and practitioner participants agreed that best practice involved meetings as well as written notice and suggested that the Code of Practice should be changed to reflect this. Some said that

service users should be involved in their own discharge decision, in accord with the principles of the Measure:

If it was in there that you actually had to sit down with a client or service user and the family and explain to them the reasons why they are being discharged I'm sure a lot of them would understand if they had that face-to-face rather than just having a letter.

(Secondary sector practitioner)

For me the way to do it would be to make that discharge process part of that review of CTP. (Secondary sector practitioner)

If it's a CTP review the client should be central to that. But that depends which team it is doesn't it? (Secondary sector practitioner)

- 2.17 The quality of patient letters was a matter of some discussion amongst third sector practitioners and in at least one area a voluntary organisation had worked with CMHT managers to produce a more informative letter and had held discussions around holding discharge meetings to provide people with information about community services and their entitlements:

(The original letter) ... didn't actually say that you could re-access and finished with the Samaritans' phone number ... even the word 'discharge' isn't very nice so the whole format was very medical but it did have some good points – indicators of feeling unwell; if this happens you can do this, this and this ... It was quite an unpleasant letter to receive ... It's being worked upon to make it more informative, slightly more informal and not so medically orientated – more personal ... It could be quite harsh for somebody who's been in a CMHT for 15 years to receive a letter and hear that they no longer have that access to a safety net and for it to be worded in a formal, medical way. It should be a well thought out process and it should be done holistically – that's what the Mental Health Measure says. (Third sector practitioner)

We have got these little discharge leaflets that we give people when we have them in for review ... here's a leaflet that will explain

in the future if things change how to get in contact with us.

(Secondary sector practitioner)

- 2.18 Several participants said that they were given other information to support them at time of discharge and some suggested that receiving information about community support services and well-being advice, might limit the number of self-referrals:

They gave me lots of advice when I was discharged. They told me to eat well, exercise, not stay in and to go out with my mates.

(Service user)

... they said there was a national help line if I wanted to talk with somebody. (Service user)

So my psych knew of this organisation and suggested I referred myself to it. It was certainly beneficial. So once again at my own expense I continued with this. (Service user)

We talked about accessing other support, talking therapies.

(Service user)

When I was discharged they did give me leaflets ... for charities and the local mental health support group. (Service user)

There were some contact numbers for services that could help me on my discharge letter. (Service user)

The day service were told they could only take people with care plans. They hung on to people longer than they should have done – they gave information and took people to other projects – they worked really hard. (MHDO)

- 2.19 The idea of having a discharge plan in place when transferring to primary care was suggested by several participants. However, the quality and amount of information or support provided was variable and many participants had nothing at all on discharge:

As long as that support is in place when somebody is discharged and as long as that person is aware of what support; where they can go - there could be quite a good success rate ... but it's still a

variable system in this area. (Third sector practitioner)

I haven't been told about any other organisations I could go to outside the health services. All I know about is the day centre. I didn't get much information at all. (Service user)

The GPs or psychiatrists didn't give me any information about voluntary services and didn't put me in touch with the primary mental health service either. (Service user)

There was nothing like that (advice or signposting). It was almost as if I had been given a complete cure and I was now cut off because I didn't need any care. (Service user)

The psychiatrist said something about if you need a change to your medication your GP can always send you back to me. I didn't find it terribly reassuring, no. (Service user)

- 2.20 A service user representative suggested that the following information should be provided in writing at time of discharge:

Firstly, some information on why you've been discharged and if you're managing very well, or if you're stable, and if you've made progress. Also, if they feel that you don't require the same level of secondary services as you did formally. Information should be very clear and very basic. They should also give information about other support and services that would be able to help – like the third sector and drop-ins. They should also give information on the primary mental health service, as they are running free access courses. (Service user rep)

- 2.21 Several participants highlighted the difficulties in accessing support services like mental health day care or outreach following discharge from secondary services:

There is a gap between being discharged from CMHT and then where to go if you need support – very much so. I'm working with people who are in that situation. There is a big problem: if you are called for an examination (at DWP) and you are no longer under

the care of the CMHT then it is seen as an indicator that you are quite well and are fit for work. This is a genuine fear for many people. Also, in (area), there is very little provision for people who are not referred by the CMHT to outreach or activities ... so you can fall by the wayside as you are not picked up by other services. I know of people who have begged their psychiatrists to keep them on lists and maybe only see them once a year, just so they can keep their CMHT status. (Service user rep)

Review Question 3: The assessment

Report on the experiences of service users, their carers and practitioners in relation to Part 3 and consider, for example:

- The experience of reassessment.

Summary

2.22 Service user participants were divided equally between those who had mainly positive experiences and those who had mainly negative experiences of their assessments. There were several factors that influenced their satisfaction. The approach and attitude of the assessors was considered to be important and participants valued having the time to express themselves, feeling comfortable to do so, being taken seriously and being listened to. They appreciated professionalism and thoroughness and were pleased when they were given hope or achieved an outcome with which they were satisfied.

2.23 Participants were disappointed with their assessments when they felt intimidated; were treated in an off-hand way by their assessors; were rushed; were subjected to a 'tick-box' approach to assessment or when asked to relay their whole history of mental health leading to too-long interviews. Participants were also disappointed with their assessments when outcomes did not meet expectations or where participants gained the impression that re-access was only available to people in acute need.

- 2.24 Practitioners highlighted the extra pressures placed upon them by Part 3, particularly having to repeatedly undertake assessments for people who did not meet their criteria.

Comments

The assessment process

- 2.25 Participants' assessments lasted for anything between half an hour to two hours and involved from between one practitioner to a whole team of people – psychiatrists and CPNs in the main, although one participant saw a psychologist. A few participants were unsure whether their interviews were actually assessments as they had not been told and a few said they did not know who had interviewed them. Some said they had worked through a questionnaire whilst others said they had been asked for a detailed history:

It was just with one person and she wasn't a consultant I believe. I wasn't sure if she was a CPN as I wasn't told. (Service user)

It was like a questionnaire, asking how you're feeling and everything. I know it was a lot of forms and a lot of tick boxes. It was a screening process – trying to get what therapies would be recommended for me. It was quite long really, but I dealt with it... (Service user)

I saw three psychiatric nurses and they had me in the room for about an hour and they went right through my case with a fine tooth comb. Why I don't know, because it was all in the notes. My mother was with me so I wasn't alone thank goodness, otherwise I would have found it intimidating. It was as if my notes weren't there ... They told me that they would refer me to see a psychiatrist and then nothing happened. (Service user)

- 2.26 One participant who suffered from recurring critical episodes described their typical assessment:

I think there is still an assessment that's done, but because of the state of my health it's quite quick and goes through quite quickly,

so the priority is to get me into hospital and to engage with secondary services again. (Service user)

Assessments – positive experiences

- 2.27 The personal skills of the assessors were considered to be highly important; participants mentioned empathy, understanding, caring but more than anything they valued being listened to and being taken seriously:

I was quite fearful as those things can get quite personal. She was quite caring in that way, so that was good. (Service user)

The interviewer was empathetic, he was understanding, he seemed that he wanted to ascertain what all my problems were and provide solutions and basically there was no time element – it took as long as it took. At the end of the interview I felt fine. (Service user)

She listened a lot – she asked very personal questions but they were questions that had to be asked. She took about an hour – it was supposed to be less than that but she spent as long as I needed. (Service user)

I was pleased to have seen him and I felt that he had taken my concerns very seriously. He wasn't in any way trying to brush me off or to diminish my concerns. (Service user)

- 2.28 Some participants were reassured by the thoroughness of the assessment:

It was very thorough and he was asking all the necessary and appropriate questions, such as why I was feeling this way and what was contributing towards it – all the questions a nurse should ask. He also asked about medication etc. He did a very thorough and proper assessment. At the end he told me that it would be discussed at the next team meeting, which happens weekly, and then I would know if I was going to see the psychiatrist. (Service user)

What was good about the meeting was that I felt anything that had been left out would have been put in and whatever they've got now they've got in my notes, they've got everything; there's nothing left out – it is a complete set of notes of my illness right from the word go. They listened to me. (Service user)

- 2.29 Inevitably feeling hopeful that something would happen or having an outcome with which they were satisfied led to participants being satisfied with their assessments:

He felt quite happy after the assessment, because he felt that the doctor had taken the time to listen to what had been going on, and the doctor offered him further appointments and information about his diagnosis. He offered to liaise with the drug team too. He's now a lot happier and settled with his consultant. (Third sector practitioner)

I felt hopeful after the assessment. I felt that they might be able to help me. I remember coming out and thinking I might get somewhere. (Service user)

All I remember is that I wanted CBT. I expressed that it was one of the things that I hadn't had. She took that on board and that ended up being one of the therapies that I had. (Service user)

She looked back at my notes and said "if this helped before, then let's do it again". I was listened to and I came away with what I wanted. (Service user)

Assessments – negative experiences

- 2.30 Some participants reported that they had experienced a poor attitude from their practitioner and this was a major negative for them. Some said they felt intimidated and challenged at a time when they were feeling unwell and seeking help:

She (psychiatrist) didn't say much, but she asked what was wrong now, said she would chase up the therapy and said that maybe we should change my meds, did that, and then said see you in a month's time. I feel that her attitude was disgusting. (Service user)

I felt very paranoid about it, and that nobody understood the way I was feeling... I was crying and I was getting very muddled up and confused... They didn't reassure me that I was being looked after in the meeting. (Service user)

The assessor was heavily pregnant and I thought she was going to be going off soon. I sensed that she was a little bit uninterested. She felt a little bit distant. (Service user)

Yes, it was absolutely awful. The meeting was meant to take 20-40 minutes, but it took longer. He more or less blamed me for that, and told me that it was taking longer than it should have, but he was asking the questions. He also kept missing questions and having to go back ... I felt absolutely rubbish. He just confirmed in my mind that I was rubbish. (Service user)

My impression of the assessment was that during the first ten minutes it felt like we were being challenged about why we were there. It felt a little bit like we had bothered them and we had wasted their time. Once we got into the conversation and started discussing his health, their attitude did change, and they were quick to agree that he needed to be taken back into the CMHT to get more help. It went from an encounter that lacked empathy to a more respectful one. (Third sector practitioner)

She was acting as though I was wasting her time. She didn't empathise with me at all, it's like she was trying to keep me out. Even though I was feeling ill, I had to exaggerate how ill I felt otherwise I wouldn't have got anywhere! I shouldn't have had to do that. (Service user)

- 2.31 One participant felt that she was not taken seriously by her psychiatrist/assessor because of her young age:

With me, I felt that they brushed me under the carpet as someone who is eighteen; she's just going through a bit of a difficult time, feeling a bit depressed, it's just the teenage years. It felt like they were trying to get rid of me. I've been struggling for years, but they

just didn't listen to what I was saying. I've been with them on and off since January (2014) and it isn't until now that I've got this new psychiatrist who is making a difference. (Service user)

- 2.32 Some participants questioned the need for long assessments for patients under Part 3 given that full records were on file:

Because at the time that they have the assessment, they are unwell, they find it borderline between stressful and unnecessary. Why can't I just come back? You know all about me – you know who I am. I've been around the system for years. Why do I have to go all through this again? (Third sector practitioner)

- 2.33 One participant who had lived elsewhere in the UK where she had received good support from mental health services felt that limited resources was a significant impediment to the success of Part 3 for patients in Wales. This was echoed by many others throughout the study. She suggested that patients were only readmitted when in crisis and described her own experience of assessment under Part 3:

Everyone's very nice but I get the feeling that there are just no services here. Like I phoned up just before Christmas when I was depressed and it was, like, 'are you going to kill somebody else? Are you going to kill yourself? No? Well go away then'. So I just get the feeling they really are over-stretched rather than not trying to listen to people. I just think it (assessment interview) was very rushed and you're fine, go away but that wasn't said. It was about half an hour but he filled in all the bits of paper on the thing and just kept asking questions – you know, 'have you ever thought about harming anybody' ... and I know they have to do risk assessments but it was less about what I thought I needed and more about them ticking all the boxes on the computer. (Service user)

- 2.34 Having unsatisfactory outcomes, sometimes involving very long waits for support; limited support or no support at all, inevitably led to dissatisfaction with the assessment process for some:

At the end of the meeting, I thought that something would happen but nothing did. Not only that but instead of me being referred to the psychiatrist ... while the mental health unit was being moved to a new building, they lost my case; they lost me off the computer. When I rang them up they had no record of me whatsoever.
(Service user)

They then offered me an appointment at some point in the New Year (this was November), which wasn't good enough for me as November and December are difficult times of the year for me – which I told them. They told me to ring the crisis team if things got worse. I rang the crisis team two days before Christmas Eve because I had a meltdown ... and they gave me some sleeping tablets ... I rang the psychiatrist and I was told I would be having an appointment in early February and I had a letter saying my appointment isn't until March 2nd. (Service user)

The GP referred her to the psychiatrist. I then got a phone call from a social worker ... we meet her, she does an assessment. The social worker then recommends my wife go to see the psychiatrist. The psychiatrist turns that down and says I'll write to the GP and amend the medication – he's not even prepared to see her. So where the hell are we going? He hasn't even got the courtesy, time, call it what you will to see her. Basically, don't worry, we'll get back to you; all the promises in the world and then sod all happened.
(Service user/carer)

- 2.35 This participant felt that under the Measure, efforts to standardise practice in the best interests of patients via the Measure were not succeeding:

So far from the rigid, formal framework, you've got people doing what the hell they like. (Service user/carer)

Follow up letters or reports

2.36 According to the Code of Practice⁴, mental health service providers are required to provide written reports to individuals following assessment which set out 'whether any services have been identified that may improve or prevent deterioration in the individual's mental health'. Most of the participants said they did not receive a letter or report following their assessment or that they could not remember having received one. A few participants did receive letters but nothing that could be described as assessment reports:

I went for an assessment with a social worker. She sent a letter saying I didn't meet their eligibility criteria – that my anxiety disorder wasn't sufficiently serious to receive secondary care services. (Service user)

I received a letter saying I had an appointment to see a psychiatrist. (Service user)

After the assessment he sent me a copy of the GP letter the next week. It just said he'd be seeing me in a year and would discuss having a CPN in the meantime. (Service user)

Review Question Other: Self-referral

Report on the experiences of service users, their carers and practitioners in relation to Part 3.

- Other findings – The experience of self-referral

Summary

2.37 Participants were generally supportive of the principles of Part 3 and service users commented that they were reassured at discharge that they would be able to re-access the service if needed. Whilst a few participants involved in this study were

⁴ Welsh Government, Code of Practice to Parts 2 and 3 of the Mental Health (Wales) Measure 2010

pleased with their experience of the process, most of them found that securing an assessment was far harder than anticipated and identified various barriers.

- 2.38 In many cases the services seemed to have no knowledge of the person's rights under Part 3 and several of these were sent back to their GPs for referral, suggesting that the Part 3 entitlements were not yet ingrained in the working culture. In some cases the services simply did not respond – even to numerous requests.
- 2.39 Some service users and carers reported that they felt services had been intimidating or disrespectful during self-referrals or communicated in ways which they thought were inappropriate, like telephoning people who were not able to use the telephone when ill and having limited times when the duty officer was available to accept referral requests from service users.
- 2.40 Some people lack understanding of their own condition or capacity to make decisions for themselves when they fall ill. Many service users, carers and third sector practitioners considered it appropriate, therefore, that referrals should be accepted from their carers or third sector support workers and that the code of practice should be changed to allow this.
- 2.41 Practitioners highlighted the extra pressures placed upon them by Part 3, particularly having to repeatedly undertake assessments for people who did not meet their criteria.

Comments

Access experiences

- 2.42 Participants generally supported the principles of Part 3 and many highlighted the existing or potential benefits: giving confidence to practitioners and service users around discharge; enabling speedy reaccess and empowering service users:

For service users, I think it's positive ... it's allowed people to have that entitlement to care and there are some people coming through who are saying, I want to be assessed again and there's a confidence about that; that it is an entitlement – we can discharge

people knowing that they can come back. There can be less concern from both parties with that knowledge. (Secondary sector practitioner)

I think the right of re-referral is about patients' own expectations of being able to manage without the service, so they've a right to come back to us if they're panicking without it and also to provide a throughput ... rather than a huge caseload (Secondary sector practitioner)

When you're referred by a GP, they sometimes decide inappropriately. They can put people down as urgent when they're not urgent, or vice-versa. (Service user)

I think that having direct contact with secondary services is more useful personally than having to go through a GP and then to go back into secondary services. In my experience there's more security being able to directly contact secondary services if there is any trouble. I do know people who have been benefitting from the home crisis teams recently. It seems to be an effective alternative than having to go back and see a CPN or a psychiatrist on a regular basis. (Service user)

I am confident that if I was in crisis where I didn't have capacity or I was manic I would be able to go to a CPN. What happens after that point I really don't know. But it would be better than attending a GP surgery ... (Service user)

I do like the empowerment and where if you feel that you aren't coping or aren't managing you can get in touch. I think it would be better to be monitored more regularly but if they are going to discharge you it will be good that you are able to personally get in touch ... (Service user)

The overall feeling about the Measure—for a lot of people in my field including myself—is that there is nothing wrong with it in principle. The ideas and aims of the Measure are great. The difficulty is the practical applications of it – which is at times

influenced by staff and attitudes, and at other times is influenced by money. (Third sector practitioner)

- 2.43 Almost without exception, service users and carers involved in this study found the process of self-referral more difficult than they expected or were given to understand at time of discharge. Many said that knowing they could self-refer had reassured them about discharge but that the actual experience of self-referral had been challenging:

I thought I would be able to get back in quite easily. I didn't think I'd have any problems because the social worker was ... really forceful when she spoke to me that I would have absolutely no problem at all in getting support. (Service user)

When I first heard about the self-referral system I thought it was an excellent idea, but in practice it just didn't work. (Service user)

- 2.44 As already mentioned, securing access to an assessment is one thing, but actually re-accessing the service is another and many felt that limited resources and restrictive access criteria meant that in reality, very few were allowed to reaccess.
- 2.45 However, the whole process worked well for one participant, leading from depression to a successful outcome and to discharge with his consent, a second time:

I think the self-referral system is very good. With my second depression, not having to go through my GP really helped. All I had to do was make a phone call and give my name and explain the situation – then they took it from there. It's quicker when you don't involve the GP – it sped things up a bit ... When I spoke to reception, I said that I was self-referring. They fully understood where I was coming from ... And they referred me back to the lady I was with before ... She was absolutely superb. It (Part 3) has worked for me - very much so. She was really very, very good ... It was reassuring to know that I could come back into the service again. It was good that I had a number to ring to be reassessed to

enter the service. (Service user)

- 2.46 Other participants also highlighted best practice particularly in relation to reaccess following crisis:

I think people's experiences aren't consistent. For instance, I've got a friend in the bipolar group who referred herself back in and she did get a response and an assessment and got a relatively short course of CBT and she's happy ... for people who get ill very quickly it is a useful service. But it is patchy. (Service user)

I'm more reassured than I was in the past because this (home treatment team) didn't exist for me. I knew nothing about this as a system so I feel I have phone numbers in front of me that I could phone – they've given me two or three numbers that I can call for the crisis team and there's an all Wales helpline called CALL. (Service user)

- 2.47 For most participants access to assessment was problematic. One participant described his experience of a service being seemingly unaware of Part 3 and also highlighted something that was frequently mentioned by service users; that 'primary' and 'secondary' were terms commonly used by practitioners without explanation, when speaking to patients:

I was about three or four months in and I had a few things that went wrong – it's like a peak and trough thing ... but when I phoned back to get an appointment to see him – I phoned the mental health team – they said, I'm sorry Mr (x) you're back in primary care. And I thought what's primary care, secondary care – you don't know these things, you know. They said – you've nothing to do with us – you can't see anybody because you've been discharged – go back to your GP. (October 2013) I went bonkers ... I lost the plot with them because I was desperately in need of seeing somebody ... (Service user)

- 2.48 Others also described confusion surrounding their rights to self-referral and assessment:

When I referred myself back in first time, they didn't respond at all – so it's been really hard and then they started to say I wasn't really discharged so I couldn't refer myself back in. So I was in some sort of limbo. It was quite confusing because I had had a discharge letter in October 2011. It almost seemed that they were changing their story. (Service user)

I rang them in November 2014 as I felt my condition deteriorating and I spoke to the duty officer. I told her I wanted to come back into the service and she told me I needed to go to my GP to re-enter the service. I told her about the letter that said I could access the service again within three years and she told me it wasn't as simple as that – she said I had got things wrong. I was on the phone for half an hour having to argue and justify why I needed to come back into secondary care. (Service user)

I was feeling very poorly again. I tried to access the service three times by writing a letter (May, June, October 2013) to the team of psychiatrists – I had no response ... I've tried ringing them too. The receptionist says that she will get a member of the team to ring and you never hear from them. I went in person twice too and the same thing happened ... the service was absolutely zero. What can I do? The Measure was put into place by the Welsh Government and the psychiatrists aren't responding. The mental health services are under so much pressure that it just doesn't work. I haven't had an assessment – I haven't got that far! (Service user)

In my case it was ineffective, it simply didn't work. I don't think it's been ingrained in the working culture yet, but this is law and this is serious. I've heard this off several people. (Service user)

We then approached the CMHT directly for the reassessment (in July 2012). After our first request we were told that it was not possible and that they didn't know what the Measure was. We returned with a second request in August 2012 and we got a similar response – this was from the secretary of the CMHT. At the end of

August 2012 we put that in writing to the CMHT and we were told that it wasn't possible as the patient was on the books for an OT but the OT was refusing to see him at that point We kept on going and they finally accepted him for the assessment in October 2012. He was then reassessed in December 2012 and was taken back under the care of the team. It took over six months, and there were a couple of occasions where he had severe depression – he was incredibly low in motivation and he just wanted to give up.
(Third sector practitioner)

- 2.49 This practitioner said that the above case was quite typical. He also said that some services were responding to self-referrals better than others. This was echoed by a few other participants:

Out of the four CMHTs we deal with, two are okay about Part 3 and two are lagging behind – it's a mixed bag. I think a lot of it is down to the attitude of the secretarial staff – they often try and push you back if you ask for a re-referral. That could be the instructions they're getting from above though. (Third sector practitioner)

I know that this particular CMHT had troubles and that senior executives at the health board were aware of it. It seems to me that they got into a state of learned helplessness – it was their routine, they just can't see people until they can see them. Their reaction is to send people to their GP. (Service user)

- 2.50 One participant who tried to self-refer said he was only taken seriously when his GP referred him:

I was OK until October last year (2014), when I knew I was becoming really unwell. I rang and told them I was getting in serious trouble and they told me they couldn't see me for six weeks. I asked, 'what about Part 3?' and they told me that they didn't think I had an urgent need. They told me to ring my GP. By the time I got a GP appointment—when I was even more unwell—the GP told me that he couldn't prescribe me anything as it was too specialist. The CMHT told me to go to the GP; and the GP told me

to go to the CMHT – it was like ping pong. The GP referred me and the CMHT told me, ‘yes we have had a referral from the GP, so perhaps it’s a bit more urgent than you said.’ They put in an appointment in two weeks, which was still four or five weeks after I initially contacted them telling them about my trouble. (Service user)

- 2.51 Several participants mentioned further barriers to self-referral. A few said that they had problems using the telephone and although this was in their records, the services chose to ring them with their appointment times:

They told me that they phoned me in August and left an answerphone message, which wasn’t much help to me. Also, I know that there’s a note on my file that says that I don’t answer my phone when I’m unwell – I’ve seen it. They didn’t send me an appointment; they sent me a message on my answer phone. I didn’t get the message and they recorded that as another DNA. This was the period when I had to wait, and I kept getting more ill. (Service user)

- 2.52 One participant said that to visit the service in person to request an assessment was also difficult when he was ill; this was echoed by another participant who also mentioned the physical barriers to self-referral:

My one criticism of this self-referral system is, particularly in a rural area – one of the problems you have with accessing the medical centre is the distance you have to travel. Plus if you don’t drive there’s the lack of regular public transport to get there and of course some mentally ill people have their licences revoked by the DVLA ... I kind of feel if a potential relapse happened in a mentally ill person, they might not necessarily make contact by telephone or visiting a centre of treatment until a tipping point has been reached, by which time it’s sometimes too late to prevent a psychotic episode occurring. (Carer)

- 2.53 Restrictions placed by services on the timings of assessment requests were mentioned by two participants, one of whom said:

They will only take the assessment request from the duty worker, who is only available between 1pm and 5pm. I only visit this person in the morning as they have an issue with alcohol and substance misuse. The best time for us to have an appointment is 8 or 9am when they haven't had an opportunity to become under the influence - I left the issue with them (CMHT) and asked what could be done. I was expecting a call back from them, but I didn't hear anything. I was off for a couple of weeks in September, so my manager rang on my behalf. My manager was told that they had no record of the phone call. I rang again when I came back to work in October, and I pretty much got the same response from the duty worker – he wasn't with me, so they couldn't accept it (referral). (Third sector practitioner)

- 2.54 This same participant also suggested that the attitude of practitioners to requests for assessment could be a barrier in itself for vulnerable people and that having advocacy support at the time of the referral would be helpful:

The duty social worker was quite challenging about why the patient needed to be reassessed. They wanted to know what's changed. They were quite pushy, and there was no acknowledgement that there's an automatic right to reassessment. I think he (patient) would struggle to articulate why he needed to be reassessed. He might well have got angry ... However, about halfway through the call the duty worker clocked who I was and agreed to make the referral. He was seen then a fortnight later and was retaken back into the service. I felt quite uncomfortable that me personally being involved oiled the wheels. On the one hand it was positive but on the other hand it was negative as it shouldn't matter. (Third sector practitioner)

- 2.55 Other participants felt they needed support to reaccess services under Part 3:

I'm glad my advocate was able to ring, because I didn't feel like ringing. That was the anxiety and stress for quite a few days really... With the anxiety, you need to know where you are with things, which is why it was affecting my health... I knew I needed to see someone. (Service user)

When I'm unwell there's no way I could be phoning the CMHT ... if there's somebody you've got a relationship with it's much easier. (Service user)

You have to be quite together to ask for reassessment in a way – to ring and then getting knocked back. (Service user)

- 2.56 Another person said that his low level of trust of secondary services meant that he was disinclined to self-refer unless in crisis:

I have so little confidence. My friends in the third sector want me to refer myself back into the CMHT but my trust and confidence in that CMHT is that poor, I do not wish to present myself to them. I think it's likely that I will be sectioned before I return. ... I don't have the trust in the organisation to actually provide the service that I may require because they haven't in the past and I'm not confident that I would be able to persuade a jaded CPN (to put me forward for assessment) ... (Service user)

- 2.57 Participants often said they had to wait too long for their assessments and described how they coped whilst waiting. They particularly mentioned frequent GP appointments, taking prescription drugs and using voluntary services:

I had an assessment in there ... about a month after my GP referred me... It was a bit hard, because I wasn't in a very good place back then. I've had to keep using the services of Mind as I wasn't well enough to do things myself... (Service user)

I remember waiting ages, which is why I decided to go back on the

pills again. I remember thinking it was so long...it seemed like forever. (Service user)

I phoned up and I spoke to one of the receptionists and I explained that I had been discharged from secondary services in the last year and that I wanted to see somebody...when they located my records they phoned me back on the same day ... Then they told me they will be in touch to give me an appointment with a psychiatric nurse. This is where I consider the problems to lie: the length of time it all took. It took a couple of months before I saw the psychiatric nurse. Then it was several weeks more before I actually saw the psychiatrist – and I think that's quite general. I hunkered down and waited. (Service user)

There was a two month lag between them saying he could have an assessment and him actually getting the assessment. He felt it was typical of how the system generally treated him. He felt that he was unimportant. He felt that he had no respect from the CMHT. He thought the whole process of trying to re-access was impersonal and reflected how he had been treated. He felt that the mental health team didn't think his problem was serious enough. He didn't have any other support – I was the only person involved with him. He was under medication from the GP. We were going back to the GP regularly. The GP had already done everything they could. (Third sector practitioner)

The speed of the service needs to be improved. If somebody's re-referring themselves they at least need reassurance. If they are in need of help the longer you leave it, the worse you get ... They should maybe ask people if they are willing to be seen over the next couple of weeks or if they need to be seen soon. (Service user)

- 2.58 One participant said that she had to contact the crisis team whilst awaiting her assessment:

I rang the crisis team two days before Christmas Eve because I

had a meltdown and they offered me an appointment for the next day. I went there and saw a nurse and a doctor. (Service user)

2.59 Another participant was admitted to hospital:

I saw somebody on Tuesday. They then told me they weren't going to discuss my case till the Monday and I actually ended up in hospital as a result because nobody came back to me ... If you're feeling desperate 24 hours is a hell of a long time ... I do believe you can have emergency ones but you're not going to get that if you just walk straight in. The only way to get an emergency assessment, to the best of my knowledge, is if you have the backing of your GP. (Service user)

Impact of Part 3 upon workloads

2.60 Practitioners highlighted the difficulties from their own perspective and how pressures from Part 3 had impacted their own practice and were adding to their workloads:

I think the problem is now with people re-referring themselves, I think we're assessing more than actually delivering therapeutic work. At (CMHT), at some point it feels like a crisis unit, you know. GPs want people seen there and then ... (Secondary sector practitioner)

But you've got to tell someone they can come back and they're the kind of people, because of what the situation is, that they're going to bounce back every time. So it just seems a waste of resources and you're kind of inviting more waste of resources by doing so. (Secondary sector practitioner)

2.61 Some suggested that so many were trying to reaccess because no ongoing support was provided at time of discharge. One participant highlighted the provisions he wanted following his experience to try and reaccess the service:

The self-re-referral thing wasn't working, the assessment system wasn't working and I wasn't listened to. As a result, I was nearly hospitalised for the first time in eight years ... I'm now discharged. I

saw a psychiatrist in May of this year (2014) and I told him I was happy to be discharged on the proviso that we draw up a proper care plan with proper relapse signals that is written down. I wanted it recorded and I wanted a copy. I was reassured that I would receive a copy and I still haven't received one (interview was in October 2014). (Service user)

The role of family/carers

- 2.62 The important role of carers and other family members in supporting people to reaccess secondary care was acknowledged by some participants. In the main, service users and carers felt that secondary services should accept referrals from close family members and carers when people are too ill to do this for themselves. Many said that this should be with service user consent. However, some also acknowledged the sensitivities and difficulties for staff in taking referrals from family members and concerns over confidentiality were often mentioned, sometimes by service users, but most often by mental health practitioners:

At the moment it is the individual themselves that has the right to re-refer, the problem is that for a number of people that may need to be re-referred, they themselves may lack insight into it. (Third sector practitioner)

It is very difficult because at the end of the day unless you are sectioned under the mental health act you have a choice as to whether or not you access services, you can't force somebody to access services unless they are detained, so I think it is going to be tricky and difficult giving carers the right, but at least they can have a right to inform services that the person may need an assessment. They can't force them to have an assessment but you know they could strengthen it in that way. (Third sector practitioner)

- 2.63 Participants mentioned the difficulties faced when carers tried to speak to the services regarding reaccess:

If somebody is seriously ill, they often don't recognise it themselves

so you need a carer or family member to refer them back in but the CMHT don't take any notice of the carer or family member. That is a major issue and it's made a lot of people more unwell. If they could be referred in by a carer or family member, they would recover quicker rather than waiting till they have a crisis. (MHDO)

I think if they trusted my husband's view then there may have been a different outcome. It might have been quicker if they took it a little bit more seriously. Maybe if they had listened to him it wouldn't have gone on for so long. I wouldn't have had to burden all the people I had to burden. (Service user)

Some carers, who've come to the carers' group ... they have some bug bears with certain professionals because of the way they've perceived they have been treated in the past. Their issue is that if their loved one is going through an episode and doesn't have capacity they're scared. They've rung up the CMHT and they can't get past the receptionist. They're asking for an assessment which could lead to either them being back in secondary mental health services or sectioned, which will have an impact on their long term relationship with that client, but a lot of carers can't even get past the receptionist. (Third sector practitioner)

I think carers should be allowed to get an assessment as long as the person has consented. (Third sector practitioner)

- 2.64 A mother described how she was treated during an assessment for her son under Part 3, highlighting her opinions on the professional's attitude to her as a carer:

I feel as though I'm fighting a losing battle. I don't feel like they are listening to me. I was told not to speak yesterday and I had to put my hand up when I wanted to speak and the psychiatrist said, 'No, not now.' I need to know that (son) will be looked after if anything should happen to me. I feel that (son) needs a CPN as he needs somebody else to talk to other than his mum. I feel like they've left him alone because I'm looking after him. I got the impression that I

was an interfering mother from this psychiatrist – that’s why I was put in the naughty corner! (Carer)

- 2.65 A few participants highlighted the extra strain on carers following discharge from secondary services and how this could impact on their own mental wellbeing:

What they don’t realise is when they put people back to primary care when you’re not well the carer’s got to take over their benefits and their finances. And that can lead to the carer having a mental illness. They’re taking over from the CPN. They’re doing everything – the carer’s got to take over all of that besides the caring role. (MHDO)

- 2.66 A few were guarded about how far relatives or carers should be involved in re-access:

That’s a very difficult one, as it depends on the relative... Sometimes the relatives and carers underestimate the ability of the individual to be able to manage perfectly well. There is a tendency to wish to wrap up somebody with a mental illness in cotton wool and be very protective... I think giving relatives/carers that power (to refer under Part 3) could open a floodgate. I, as a mental health sufferer, have strongly resented interference in the past from my mother. I felt very unhappy that her words were taken over mine. However, other people have very good and close relationships ... (Service user)

They took the GP referral more seriously than my self-request for help. They also took my family and work colleagues more seriously as well...It made me feel like my voice wasn’t heard and other peoples’ were. (Service user)

- 2.67 A particular issue repeated many times during the study was that practitioners did not value the ‘lived-with’ experiences of carers and made decisions based on how patients presented during their short interactions with them rather than taking the carers’ experiences on board:

The GP referred someone and so did a family member – the assertive outreach team went to see this person and they spoke to him for five minutes and said he was quite calm (MHDO).

- 2.68 Several participants suggested that third sector mental health professionals should be eligible to refer people under Part 3:

Some people who are chaotic – it's difficult if they are discharged to get an assessment and might lose out on access back in, in contrast to people who are more proactive and capable. (Third sector practitioner)

I occasionally have clients who are eligible to be re-assessed by the CMHT because they're within the three year time frame and they'll say, well, can you ring up for me as my advocate and they'll say, no the client has to write in or ring up themselves and I think that's rather silly. Because I think if my client's authorised me to act on their behalf and I have a consent form signed by the client, then what difference does it make who makes the phone call? (Third sector practitioner)

- 2.69 The issue of the capacity of individuals to self-refer owing to dementia or learning disabilities was also raised and services were adapting the rules to ensure that people were able to reaccess:

Well I suppose 3 and 4 are interesting from a dementia and learning disabilities perspective because again they were constructed with an adult psychiatric sort of focus – so, you know, the right to ring up and request. So we accept care homes or family members ringing up. (Secondary sector practitioner)

One of the issues we have with older people is that our psychiatrists are reluctant to see people who self-refer, unless they've seen a doctor first. Now the reason for that is because, of course, they could have an acute confusional state which is due to something physical which hasn't been treated. So we've had all sorts of discussions over that and often what happens is CPNs have to go and screen them first. Well it just causes resentment,

that it's seen that there's people in the team who will say; I'm not seeing that person because they haven't seen their GP. So everyone else has to kind of run around and see them instead.
(Secondary sector practitioner)

Review Question Other: Outcomes

Report on the experiences of service users, their carers and practitioners in relation to Part 3.

- Other findings – Satisfaction with outcomes

Summary

- 2.70 Although the focus of this report is upon the assessment process, it is useful to follow up with some outcomes. The majority of our service user participants were able to reaccess services whether for a short period or in the longer term. Levels of satisfaction with the outcomes both for those who reaccessed and those who did not varied from highly satisfied to those who still felt in need of further support.
- 2.71 Some of the GPs that we interviewed felt strongly that GPs should receive better support from secondary services to manage patients discharged from secondary services and suggested group sessions and training.

Comments

- 2.72 About two thirds of our service user/carer participants reaccessed secondary services; most of them re-entered following assessments but some were taken back into secondary services without one. Just under a third did not gain access. This section presents comments from participants under these two main categories:

Participants who re-accessed secondary services

- 2.73 Most were glad to be back in secondary services and some were positive about the support they were receiving:

This psychiatrist actually listens to me. He's working on a new

diagnosis for me. He understands that my problems are more severe. ... He's sat me down and said it's not depression; it's more serious than that. He's sent me to DBT. (Service user)

They had decided that my CPN would come to the house as many times I needed, and that they would try and sort me out from home, so I didn't have to be taken in by the hospital. The psychologist had to assess my tablets as well. They also rewrote the care plan about what I felt needed to be done and when I felt I needed to be admitted to hospital. We started doing a bit of CBT. (Service user)

I am glad that I am back in the service. I've had my meds properly sorted now, which has made a big difference. (Service user)

My care coordinator managed to get me to see a new doctor, and he's lovely. At the end of the first session he said 'we can make you better'. No one has ever said that. I've got the two care coordinators who have put a care plan together for me and the first one I have ever had where I feel that I have a significant input in it. I think I've got there now, but it hasn't been the route it's supposed to be according to the Measure. (Service user)

- 2.74 However, some were guarded about the support they were receiving:

I've had a lot of trouble recently because a couple of months ago I was having a really bad time, and it was a crisis really. My mum phoned up (CMHT) and was wondering if someone could see me in the house, or if I could get an appointment earlier, or anything to help me in the meantime. My mum phoned up day after day, and just nothing happened. Because I was having episodes, they said the only things we could do were take me to the hospital if I hurt myself or phone the police. (Service user)

I don't really know what to expect. I used to have a one to one and I could talk to her all day long. With my CPN I feel that I have to keep to the medical things. I have to watch the clock as we only have a set time... My meetings are a bit formal and a bit medical.

(Service user)

So he's going to see me in a year's time and they're going to discuss a CPN so it's not really changed anything going back.

(Service user)

He is back with the CMHT, but I don't think he feels that he gets a great amount of support from them. However, he prefers to be under the banner of the team just in case he has a crisis. It's like a safety net, which is slightly beneficial for him. He's got the crisis team in case of emergency. (Third sector practitioner)

He's never had an assessment at all – no...He's never been told what was the matter with him. Yesterday this new psychiatrist ... wouldn't tell me what he thought it was. (Carer)

- 2.75 In some areas psychiatrists discharged high numbers to primary care where they would see them in clinics under the same arrangements as in secondary care, but without providing them with care and treatment plans. Several participants were confused and upset by these changes because their discharge from secondary mental health services also meant discharge from the support services that, they argued, had been keeping them stable. This is because local authorities were restricting support from day centres and advocacy to people in receipt of secondary mental health services. Following discharge, from the local authority support services, the mental health of some of these service users declined rapidly, resulting in them returning to secondary sector psychiatric care within a few months and ultimately involving the services in more intensive support than prior to discharge.

The day service was told they'd have to discharge them and they would talk to them. But by that time you're somebody who's anxious and depressed. They might take on the fact that they are discharged, but the rest isn't going to register. Some have become very unwell and have come back in and have had to have care plans. There will always be a percentage there where that was the

best route – they've moved them on and they've coped ... and there will be those that are just hanging on by a thread somewhere else. (MHDO)

I had to stop going to the day centre, because the local authorities don't provide day centre care to people who don't have a psychiatrist or a CMHT. Even though I was discharged, the psychiatrist had written in the care plan about me going to the care centre every day. Maybe he didn't know that if he discharged me that I wouldn't be able to go there. When I was discharged I felt like I was shut out from everything. I only had the day centre, and there's nothing else out there for me. There are no drop-in centres or anything, where you don't need a psychiatrist. Because I have been discharged I've got nothing. They've just abandoned me. (Service user)

Participants who did not re-access secondary services

- 2.76 People were coping with the support of family, third sector organisations, their GPs or private therapy but some would still have liked more help from specialist services; a few were hopeful that they would be accepted back into secondary care in the future:

Right now I am getting support from my family, with the GP monitoring my medication. I would like to get moral support and talking from the services. I want support from someone outside my family, because the mental health workers are professionals and they understand my situation. My family's been very good to me, but they have their own lives to lead. I don't want to burden them. The system has let me down a little bit. (Service user)

I am learning from it (bipolar group) ... It's been so helpful. (Service user)

I have basically been coping on my own since then. If I can get in to see a GP—which is really difficult—I will get a change of pills. ... I have mentioned getting more talking therapy to my doctor a few times and he said he'd see what he could do. He said he was going

to refer me on, but I heard nothing. This was about nine months ago – something should have happened by now. Either it got lost, or he didn't bother. I did get the GP to write to the Council about my housing situation, but they didn't do anything about it – even though they got the letter. The GP also said he would get me a gym membership on the NHS, but nothing ever came of that either. (Service user)

They give me the pills to fight the symptoms, but they don't sort the problem out. (Service user)

We accept the fact that they've washed their hands of us. It's so sad, because with a little bit of help of somebody we could be a hell of a lot better. (Service user/carer)

I've gone outside of the NHS these last few months and just got enough money together to do private psychotherapy. That's an hour a week and that's the minimum therapeutic level I think. There's nothing like that available on the NHS, certainly not for any length of time. It's probably just as well that I can check in with the GP once in a while and then the psychiatrist just becomes a crisis worker. (Service user)

I've heard that there's now a very good psychiatrist in place so I hope that he will accept me. I'm trying to get my drinking under control because I know they can't assess you properly if you've had a drink. (Service user)

- 2.77 For a few participants, discharge had been a positive move forward. For this person, the assessment reassured them that they were making good progress outside of secondary care:

I'm not back in a CMHT system ... I went to see the psychiatrist back in the summer and told him what was going on and he said, 'I've never seen you so strong' and that I was coping with it really well. He said he had no concerns about me and what I was going through was a perfectly normal reaction to what was happening to me. He said that he didn't think I needed to see him. I did ask him

to put me on the list for counselling, which would take a year minimum. He thought that they probably couldn't help either, so he gave me the information for the primary mental health courses on stress. (Service user)

Outcomes for GPs

- 2.78 It is worth mentioning the impact on GPs of discharge and Part 3 as highlighted by them in this study. Most believed that they were seeing more patients and this was impacting on their workloads. Some were concerned over GPs' abilities to respond to the needs of patients previously under secondary care:

This has added to the workload ... not hugely but we may not be doing as much as we should be to respond and I think it's something that's getting more in the last six months or a year so I think it's a burden that will pick up. (GP)

There are issues in our local - and even a more regional level - about workload on GPs, particularly ECGs and blood results and certain anti-psychotics and getting letters saying 'please do the bloods and the ECGs and if they're okay then start this' ... That needs to be done at psychiatry, you're prescribing the drug, you need to know how to look at the ECG and prescribe it appropriately. But at the moment we seem to be working well. We're doing ECGs, we're measuring the QTC, we're prescribing the medication, if there's issues we're liaising with them but... we still feel very distant ... So there's enough people coming here without the hordes they're bumping off from secondary care to us as well! (GP)

I think it's very confusing for GPs because they feel that they need more specialist care for this patient and they're getting told, no. (Third sector practitioner)

- 2.79 Although support was available for GPs from psychiatrists, it was thought that they were not always easy to access:

The hospital consultants are fantastic, if you managed to actually

speak to one ... that's what's missing; it's that direct link. If you could have a contact in the hospital who you could speak to, you'd be fine. But it's finding that person, it's getting through the admin, it's getting through the secretaries... it's just so time consuming. And I don't think it's fair that secondary care expect this doctor to do that. (GP)

- 2.80 It was feared that people might slip through the net and become ill without their GPs being aware. The need for regular follow up support was considered to be necessary for both GPs and for patient care:

So you get patients discharged on quite heavy medication - we were always providing the medication with the understanding that they were being monitored and checked regularly by the CMHT. There's been a big increase in discharge of these patients because they can always come back under the Measure if they want to. There's certainly an increase in discharges so you have people on psychotics who are not being followed up by secondary care so there are the issues of responsibility for the general health aspect of it because there are tendencies to get diabetes and heart disease when you're on these medications. That's been a boundary level of responsibility as to who is supposed to be checking for those. You can phone up and talk to the psychiatrists ... I think it's more my worry about ... These are people who've been in touch with services for a long time and feel part of the family with the mental health teams and felt they were there and supportive and then they get discharged and unless practices are proactive about that I worry that there are going to be issues ... people getting ill without anyone being so aware. (GP)

I suppose we do need a clear plan post discharge because we've done a lot of work reducing benzodiazepine but I struggle with the ones that have been initiated by a psychiatric team and we're not quite sure if the psychiatrist really wants us to carry on with them; whether they think it's really important or whether it's fair for us just

to reduce them. (GP)

When they are discharged, there should also be a plan for their medication, so we have a clear idea of whether they are going to be on it forever, or if they should review it or reduce it in the future. (GP)

There have been real problems in relation to Part 3 because we've had some real battles with how patients at that level are most appropriately managed. (GP)

- 2.81 One GP felt that aside from support, they should have more training to help them cope with these patients:

Well... you know... getting us all together, so you know, if we did have teaching sessions, or if we did have like a sit-in session... so if psychiatry was a rotation that was compulsory for GPs well maybe that wouldn't be unacceptable. (GP)

3 Issues for Consideration

- 3.1 This section summarises suggestions for Part 3 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 Code of Practice for Part 3 of the Measure.

Discharge arrangements
<ul style="list-style-type: none"> • Ensure that GPs are trained and fully supported to care for former secondary sector patients. Allocate a named individual consultant or other team member to facilitate speedy access to advice.
<ul style="list-style-type: none"> • Institute systems for regular GP check-ups with former secondary patients.
<ul style="list-style-type: none"> • Introduce discharge, supervision, monitoring or recovery planning as appropriate to the needs of the individual patient.
<ul style="list-style-type: none"> • Ensure that support services like outreach, advocacy and day centres are available to patients following discharge from secondary care services to support mental wellbeing and stability.
Communications and Information – Part 3 Provisions
<ul style="list-style-type: none"> • All relevant service users and their carers to be informed of their discharge and their entitlements under Part 3 of the Measure and to be helped to understand this information. <ul style="list-style-type: none"> ○ Discharge letters to be written in clear and simple language giving full and clear explanations. ○ Individual meetings with patients to discuss discharge - ideally at CTP Review. ○ Communicate with patients in ways appropriate to their needs: for example people with limited capacity; limited literacy skills or living with anxiety.
<ul style="list-style-type: none"> • Continue to inform practitioners and GPs about patient entitlements under Part 3 and the Code of Practice stipulations.
<ul style="list-style-type: none"> • Provide patients with clear advice and signposting information at discharge; also about the Local Primary Mental Health Service.
Referrals
<ul style="list-style-type: none"> • Ensure that duty officers and reception staff are fully aware of service user legal entitlements under Part 3. Staff to be trained on responding to self-referral requests.

<ul style="list-style-type: none"> • Offer flexible access for self-referral taking full account of the likely barriers faced by vulnerable service users: most appropriate times of the day and modes of contact – telephone, in person, by letter etc.
<ul style="list-style-type: none"> • Respond in a timely manner and efficiently to self-referral requests. Treat all requests with respect.
<ul style="list-style-type: none"> • Change the Code of Practice to include carers and third sector support staff as relevant sources of referral.
Assessments
<ul style="list-style-type: none"> • Follow up assessments with written reports or letters to service users including reasons for decision; advice and information.
<ul style="list-style-type: none"> • Where possible arrange for the assessment to be with at least one person who has worked with the service user and is familiar with their case.
<ul style="list-style-type: none"> • Treat patients with compassion and respect and aim for service user involvement.

Appendix 1: Case Studies

The case studies here concern people with direct personal experience of discharge and self-referral. The real names of the participants have not been used. The case studies are derived from interviews with service users only; and do not, therefore, encompass the reasoning and opinions of the practitioners involved in their cases.

Findings from these case studies have been included within the main body of the report and are intended to provide additional evidence to highlight the experience of individuals under Part 3 of the Measure.

Case Study 1: Mark

- Three interviews (June 2014, October 2014 and April 2015)
- A man in his late twenties living with severe anxiety and OCD - taking Sertraline for depression and anxiety.
- Discharged from his psychiatrist in Spring 2014 – applied to re-access shortly afterwards.
- Following discharge attended two courses run by LPMHSS.

The Discharge Decision

Mark initially felt that the discharge marked a positive change and an opportunity to open a new chapter in his life. He felt that the care and treatment planning had helped him to make positive changes including pursuing his interests, volunteering and attending a social centre. The decision to go to university was a major positive step. Discharge had been discussed with the psychiatrist prior to the actual discharge meeting and although worried about this, Mark was reassured by the part 3 entitlements:

I remember at the time feeling a bit anxious about being discharged, but I felt that the whole three year thing was a safety net, just in case. My doctor informed me about being able to go straight back into the service.

As part of his discharge planning two short primary care courses were arranged to help him to self-manage his anxiety and panic attacks. However, soon after discharge, and well in advance of the first of these courses (by six months), Mark suffered a setback and tried to access immediate support from psychiatric services:

I went into a massive panic ... I tried to implement some of the things I had learned, but I hadn't had the (group therapy) sessions at that point ... I just wanted to sit down with somebody ... I just wanted to somehow offload everything that was going on with my head with somebody that was understanding, but not burdening my parents.

Re-accessing Secondary Care

Mark's parents telephoned the service on his behalf on several occasions and invoked the Part 3 conditions (Mark had anxieties around using the telephone) only to be told that he would have to wait for group therapy and nothing else was on offer; this was confirmed by letter. This led to six months of waiting and being unwell, which Mark feels could have been avoided if he had been seen by a mental health practitioner straight away:

I wasn't really normal for months afterwards and ... it was just like, well you've got (group therapy). You'll have to wait for that ... I just had to sit it out. So I cancelled all my volunteering things ... didn't go out for a bit and was just in the house and stuff for a while ...

He met the psychiatrist months later but by this time he was feeling a lot better and had already attended the first course. By this time he no longer felt he needed to re-access the service but wanted the flexibility to speak to a mental health practitioner when he needed to. At other times he felt sufficiently supported by his family and his GP.

Mark acknowledged the value of undertaking the two group courses:

It was just reaffirming some of the things I'd learnt in the past really - new ways of looking at them as well – they covered the mindfulness in that one more than I had done before – so just being more aware of that really – the way my thoughts were and stuff.

However, in spite of the courses he suffered another panic attack before starting university. He telephoned the service and received a letter advising him to ring back in ten days' time at a specific time of day. He missed this appointment as he was busy at university but he and his parents kept ringing:

It felt like I had missed the boat – It felt like it's my fault now because it's been over ten days. I'm just sitting, waiting at the moment, it's like in my head, I don't know. It's my caller ID coming up and they're thinking well, it's over ten days ... I just keep ploughing on and I've got all the advice that's going on in my head as well from the (group interventions) and doing my reading and

things like that.

When asked to reflect on his experience he said that the Part 3 changes had made little impact and voiced his frustrations at his own personal barriers to access and the unresponsiveness of the service:

... I didn't realise at the time how hard it would be to reapply because that's the time when you need it the most but that's the time when you're least able to do anything about it.

... when you do phone, you'd think that if you phoned five times you'd expect somebody to answer.

I got the impression that if I turned up at the door then somebody would have seen me but I wouldn't have been able to get myself there at the time.

He believed that the service only responded to crisis. At the time of the last interview he was coping with his enduring problems of low mood, lethargy and academic stress with support from his parents, the GP and a mentor arranged by the university:

It was a bit of a pain really trying to re-access it when I needed it ... Because of that experience, it puts me off a bit, you know, re-accessing it. I think if it was more the anxiety and the panic attacks; the psychosis side of it, then I would, but at the moment, just being like down I'm just dealing with it I suppose.

Good Practice

- The care and treatment planning had helped Mark to move on in his life.
- Group courses were arranged as part of his discharge planning and to help him self-manage his problems.
- The discharge decision and Part 3 entitlements were fully explained by the psychiatrist in person

Areas for Improvement

- Staff to respond appropriately to people seeking re-access under their legal entitlements.

- Timely response to telephone calls.
- Provide flexible and short term access to past service users.
- Adopt a person-centred approach when fixing appointments: (Mark was anxious about using the telephone and attending meetings)
- Reduce waiting times for therapeutic interventions especially when they are part of a discharge plan.

Case Study 2: Dafydd

- One interview with participant (February 2015)
- A man in his early sixties living alone; long history of depression which became worse following a stroke in Spring 2012
- Was discharged first in November 2012; self referred to re-access in spring 2014 and discharged again in October 2014.

The Discharge Decision

Before discharge Dafydd was receiving medication and support from an OT, who was also his care coordinator who he described as:

Very, very good ... and the main reason was that she was CBT trained so she was able to listen to what I had to say.

At the time of discharge he did not feel he was fully recovered; the depression was not lifting:

I sat down with the psychiatrist eventually and ... I said I'm feeling a little bit better but the medication isn't having any effect and the psychiatrist said to me, well maybe you've always been depressed and I came to the conclusion then that I wasn't going to get any better so they discharged me.

He received a discharge letter that informed him of his entitlements under Part 3 and contained advice about keeping well by eating healthily, taking exercise and socialising. He said he did all these things but was not getting better.

Re-accessing Secondary Care

Dafydd 'struggled on' until the spring of 2014 when he fell back into another deep depression and self-referred to the service that had discharged him, asking to see the same OT as before:

It helps very much indeed. You can just make a phone call and give your name and tell them I had depression in the past ... it's quicker, yes. Because if I went to the GP, he would then get in touch with mental health ... so I suppose it speeded things up a bit. I mentioned the word to the receptionist that I was self-referring, that I had a letter.

The OT undertook an assessment – Dafydd could not remember how long he had to wait for the assessment but said that he was:

Feeling pretty desperate and I felt I wasn't going to get any help

By the end of the assessment, however, he felt more hopeful. No letter or report followed but the Home Treatment Team was put in place for daily visits 'to make sure I didn't jump off a bridge'. He was taking his medication and seeing the OT at the same time; to start with twice a week; then once a week and then once a month by which time he said he was 'really starting to improve'. With a change of medication, which finally 'took hold' and the support of the OT and his family, he claims that he came out of this depression completely:

I feel I really stepped forward a great deal. From the medication, from this lady OT, in particular and from my family who have been very supportive. I've really made progress. Much more than I have for a very, very long time.

He was at pains to stress the importance of CBT:

The bottom line is there aren't enough CBTs in the business. Not enough funding for the training. I said to her, you've more or less saved my life – she knew how to listen.

Dafydd was happy to be discharged again. This was discussed with him in a care and treatment plan meeting with the OT following which he received a letter confirming the Part 3 arrangements and advising him to contact the OT directly to request an assessment should the need arise. He was given the telephone number of the OT for direct, personal access:

I know that if I do slip into depression I can ring this lady.

Good Practice

- Speedy, seamless self-referral to the practitioner of choice
- Intensive support by Home Treatment Team and OT.
- The discharge decision and Part 3 entitlements were fully explained in person and by letter.

- Dafydd was happy to be discharged knowing he could self-refer within three years should he need to, directly to his trusted practitioner.

Areas for Improvement

- The need for CBT therapists and practitioners with listening skills.
- Timely management of discharge and following support

Case Study 3: Tom

- Three interviews (June 2014, January 2015 and April 2015)
- A man in his early fifties living alone; history of anxiety disorder and epilepsy
- Discharged in 2013 following eleven years of 'a very caring and consistent (secondary) service'

Discharge

Tom was discharged to primary care following the replacement of his social worker with a new one. He received a letter about a week after discharge informing him of his entitlements under Part 3.

This is the case study of someone who wanted to get back to the same position of support and care that he had for eleven years and which, he argued, kept him stable. Before discharge he had a care plan:

This care plan said that if Mr X is left to his own devices his housing will break down and there will be problems in his life. I didn't think much of it at the time but looking at that today he was proved right because my housing has broken down. I had a social worker, an advocate, a support worker coming in and it was all managed by a brilliant social worker who put my care together and whatever I needed, I only had to ask.

He felt that being outside of the secondary care system meant that support, like advocacy and other support agencies were no longer open to him as they required referral from a CMHT and believed strongly that discharge from secondary services should be managed more carefully:

What I'd like to see is an alternative mental health team within secondary care that deals with stable but serious long term patients; those who are not too critical who need monitoring for 12 months to two years to see if they really do need our services – a recovery team in other words – rather than total discharge. Let the patient decide that they don't need the service anymore.

Re-accessing secondary care

Tom contacted his MP shortly after discharge who requested assessments of his mental and physical health needs and as a result the PDSI (Physical Disability and Sensory Impairment) team became involved. A social worker from this team referred him to the CMHT for assessment and he described his experience of assessment which he said lasted an hour or two. He took a housing officer with him *'because after the discharge, I didn't trust the CMHT'*:

... but they influenced the whole assessment: you don't need us, you're alright. You've got a housing officer; you've got third sector – things like Hafal. You don't need us. They were trying to find ways not to accommodate me.

On the plus side, he said it was easy to get the assessment. However, at the end of the assessment, he felt:

... awful because I felt they hadn't listened. Because the Measure had just started and they said this is the way they were delivering services now ...

He received a letter following this assessment which told him he did not meet the criteria and advised him to access third sector support which he considered to be 'passing the buck'. He admitted that his attempts to access third sector support were limited:

They might do some therapies, but they're not going to help me with issues that I'm struggling with

Tom moved to another town to try to access the service there and received an assessment at the CMHT following a referral from his GP. He subsequently received a letter saying that he did not meet their criteria either:

I was angry because now I was in general housing, the local housing had withdrawn their support. Now I'm getting no help from PDSI and no help from mental health. My health has deteriorated. My mood is as low as it's ever been. I've got flies in my kitchen because I've been that depressed I haven't been bothered to clean the place and every time I approach local CMHTs, I don't meet their criteria.

I feel a bit of a failure because this is about as high as you can get with housing and I haven't cut it. My mental and physical health has let me down.

He complained that having a dual diagnosis had complicated the problem and he would like the teams to work together rather than passing him back and forth:

The mental health team are saying it's epilepsy that's the problem. The physical disability team are saying, 'oh no, it's definitely mental health'. So I'm being passed backwards and forwards ... and all I'm asking is why can't you two work together? What's the problem?

His GP referred him directly to a Tier 0 talking therapies service where he was assessed and told that he did not meet their criteria because his anxieties were too high and who, he said, were surprised that he had been discharged. Tom was unaware of the LPMHSS service; his GP did not refer him to them for assessment so he was unaware whether he would be able to access any short term help from them.

By the time of the second interview in January 2015, Tom said that he was seeing a psychiatrist every three months but was not in secondary care. He had asked for an assessment to re-enter the service but a CPN had informed him that there was no point; that he would still be ineligible to re-enter and made an appointment for him to see the psychiatrist. He understood from his advocate that the mental health service was monitoring him. Tom complained that rather than putting any support in place, the psychiatrist 'just talks to me' and had put him on a tablet to relax him at night:

By the time of the third interview in April 2015 Tom had just come under the care of a vulnerable adults team run by the local authority; he had been referred to them by the PDSI team. Although happy to have the support to set and meet goals in his life, he was concerned that this support was time limited to about a year. He was awaiting an assessment from his social worker '*who's got a background in mental health so she's pretty much ideal*' and had been told that if they detected any signs of mental ill health that '*they can get me back into the mental health team*'. He was pinning his hopes on this in spite of

the fact that the psychiatrist had recently confirmed that he did not have a mental health diagnosis.

Having complained to the health board, they were investigating his grievances about discharge and being bounced between teams.

He felt very strongly that the Measure had been the cause of the drastic change in his circumstances:

This Measure, instead of helping people to be independent is destroying them. It's taking their confidence; it's taking their well-being.

Good Practice

- Ease of accessing assessment
- Discharge arrangements and Part 3 entitlements were explained by letter
- Assessment was followed up in writing
- Psychiatric monitoring post-discharge
- Vulnerable Adults Team working towards recovery

Areas for Improvement

- Manage patients with dual diagnosis by teams working together
- Carefully manage monitoring of patient prior to agreed discharge to primary care

Case Study 4: Fiona

- Two interviews (September 2014 and April 2015)
- Fiona, a 53 year old woman, under mental health services for 27 years owing to recurrent depressive disorder and complex PTSD and a history of breakdowns which disrupted her working and academic life. For most of this time she was under primary care but for three years prior to discharge was seen by a clinical psychiatrist and attended a statutory sector mental health day care centre for four days a week.
- Discharged to primary care in April 2013. Discharged from day centre in December 2013.

The Discharge

Fiona found out about the decision to discharge her to primary care and the provision for re-access in a discharge letter and a leaflet which arrived from the Clinical Director.

The crazy thing is, until the letter dropped on my doorstep, we had nothing. That was the first we'd heard that there were any changes. I brought this up with my psychiatrist, and it wasn't signed by my psychiatrist; apparently, they as a team refused to sign these.

She felt the letter and leaflet were contradictory and confusing, since at the time she did not understand the terminology of 'primary' and 'secondary' and although she was to be discharged to primary from secondary care, she was to continue to see her psychiatrist:

We are writing to inform you that due to forthcoming changes that the government has asked us to make (in line with the new Mental Health Measure) you may notice a different title on your outpatient appointment letters. Please be reassured that this is all that has changed. A new clinic will be called Primary Care Psychiatric Liaison Clinic. You are still under the care of the same consultant psychiatrist as before. In the future if you are discharged back to the care of your GP and need further treatment we enclose a letter about how you will access these services if needed ... many people discharged from mental health services are unsure how

they can re-access services should they need to. Therefore this leaflet has been produced to provide you – the person being discharged – with clear information on the process and procedure.
(Discharge letter)

On the one hand it was saying 'now you've been discharged from secondary care nothing has changed; you will still see your psychiatrist' ... but they didn't say I wouldn't be eligible for this (day) service any longer because it's a secondary sector service.

Over several months the day service helped to prepare Fiona and other service users for 'discharge' from the day centre by mentoring and supporting them to access community services. Fiona described what the day centre service meant to her:

If you've got a mental health problem it's essential that you have that supportive and genuinely caring environment. For the first time in my life I felt accepted, I felt cared for, I felt like I belonged in a community ... Being at (day centre) kept me stable ... the staff give over and beyond, they treat you like a human being. You're like an equal when you're here ...

Assessment and Re-access

Fiona had been in primary care for about six months when in the early summer of 2014 she had a breakdown and came under the care of the crisis team, which followed on from an interview with her psychiatrist. She was visited by the team for three weeks awaiting the return of her allocated CPN. She commented that she had not been made aware in the discharge letter that contacting the crisis team was an option. She also said that she continued to have a good service from the crisis team which was at odds with the experience she had heard from others:

I had to ring them at 4.30 this morning ... and they were once again very good - spent 20 minutes calming me down through listening by which time I was able to get myself a cup of tea and return to sleep.

She had an assessment with two members of the CMHT and two crisis team staff, after which she was told that she would be in secondary care 'for a long time'.

There were four people in the room; I was terrified because I didn't know what was happening. I was terrified that there wasn't going to be a safety net, as in the support here that I needed.

She was not aware of having received a report of her assessment. However, she was pleased with her care and treatment plan:

I can't fault the care and treatment plan. One of the CPNs said we didn't realise how seriously ill you were. It's a shame that it got towards this breakdown before that ... They basically looked at my needs holistically for the CTP. They looked at the routine medical stuff; they look at your diet and exercise. I had to come up with four things that were priorities. As much as they are there to support me, I've got to stay in touch with my emotions and expressing them in an appropriate way. I've got to understand what's going on there. That's what the occupational therapy team are trying to do with me ...

At the time of the second ORS interview, Fiona had been seeing her psychiatrist weekly for nine months for therapy; her CPN every three weeks; was receiving support from occupational therapy and attending the day centre five days a week: a far more intensive regime than prior to discharge and one that she said was costing the Welsh Government far more than before discharge. She was also reading books about her condition and had attended a mindfulness course.

Fiona said that she felt totally involved in the CTP process and in setting her short, medium and long-term goals:

The goal-setting was helpful insomuch as it gave me a structure.

She believed that the fact that she had highly trained, professional people on her case had made a 'huge difference' to her life and being able to access emergency support around the clock was particularly appreciated. She was 'pretty confident' that she was going to be cured.

Good Practice

- Ease and speed of re-accessing secondary service during crisis
- Thorough assessment followed by regime of high support from a range of mental health practitioners and specialist day centre
- High involvement in preparation of CTP and goal setting to recovery
- Ongoing access to the crisis team
- The value of mindfulness and intensive therapy

Areas for Improvement

- Use plain English/Welsh when communicating with service users; avoid jargon and give face to face explanations.
- Involve service users in discharge decision
- Ensure that day centre services are still available to patients following discharge from secondary care mental health services.

Appendix 2: Part 3 Profiling information for service users and carers/relatives

	Total: 31 Service users: 29 Carers: 2	
Age	SUs	Carers
16-24	1	
25-34	4	
35-44	5	
45-54	14	
55-64	3	
65-74	2	2
Gender		
Female	14	1
Male	15	1
Working status		
Working Part Time	2	
Volunteering	6	
Student	2	
Ethnicity		
White British	29	2
BME		
First language		
English	29	2
Welsh		
Other		
Physical illness/disability		
Limits a little	6	
Limits a lot	8	1

Appendix 3: 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.

	ABMU	ABU	BCU	C&VU	CTU	HDU	PT
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	✓	✓	✓	✓	✓		✓