

Inquiry into the Covid-19 outbreak on health and social care in Wales

Hafal's Preliminary Response

Note: Hafal's immediate concern — and the reason why we are making this preliminary response - is to ensure that during the Covid-19 outbreak patients and families affected by serious mental illness can access a sufficient service and so are kept safe. It will also be important to hold the national leadership of health and social care in Wales to account, together with local delivery by Health Boards, local authorities and others, and to learn lessons: we will make a further response to the Inquiry on this in due course.

1 About us

- **1.1** Hafal is a charity and company limited by guarantee which speaks for people in Wales with a serious mental illness (including schizophrenia, bipolar disorder, and other conditions involving psychosis or loss of insight), their families and carers, and for a wider group of vulnerable people for whom we provide services.
- **1.2** Hafal is governed by our Members about 1,000 people who are mainly service-users and carers who elect our Trustees who are themselves mainly users and carers. We manage services in all 22 counties of Wales and also facilitate 232 carers support meetings each year. Together these services support over 6,000 service users and carers every year. Many of our 420 staff also have experience of mental illness or as carers.
- **1.3** Hafal has put in place local and national plans to manage the impact of coronavirus on our services, ensuring vital support is maintained while also keeping everyone as safe as possible. We are also delivering **Hafal's Promise** our pledge of lasting contact and friendship across Wales, and we have seen a 100% rise in the number people taking us up on our Promise within the last month. Read more about Hafal's response to the pandemic here.

2 Response

2.1 Hafal is concerned that people with a serious mental illness are being let down and put at risk. We understand that services have needed to be scaled back but patients need to know what minimum service is on offer is how they can access it; and that service needs to function effectively. We note that the Welsh



Government has published advice on the general mental health and wellbeing of people during the pandemic but this is not the subject of this response.

- **2.2** On 8 April 2020 Hafal launched a survey to gather feedback on the impact of the recent coronavirus outbreak on people's mental health in Wales, and their experience of mental health services. The survey, which was completed by over 300 participants from across the country, reveals that while the mental health of 74% of respondents has been negatively affected by the coronavirus outbreak, nearly two thirds (63%) had been unable to access their GP in the previous two weeks.
 - Almost half of respondents (46%) had not been informed about what is happening with mental
 health services in their area, and 37% had services cancelled within the previous fortnight. 14% had
 experienced difficulties in getting hold of their Community Mental Health Team, and 44% had not
 been informed about what they should do or who to contact if their mental health deteriorates or
 they experience a crisis.
 - Responses to the survey included:

"I booked an 'emergency appointment' (in January) for the middle of March, this was cancelled by telephone, until further notice, three hours before I was due to be there."

"My review was cancelled. I had a lot I wanted to discuss and don't know when it will be rescheduled."

"My partner's ECT has been cancelled because of this Covid-19. He has become very low and is depressed and suicidal. Spoken to the CMHT but they said it can't be helped it's the virus?"

"My CPN has left. I don't know who my new one is and not heard from anyone."

Read more about the survey here.

2.3 Hafal's Chair Mair Elliott wrote to the Health Minister in April expressing our concerns, stating:

"As Chair of mental health charity Hafal I am writing to you urgently to express my grave concerns about the safety of the most vulnerable mental health patients and their carers and families in Wales during the coronavirus outbreak and to seek your assurance that their safety will not be compromised.

"We are witnessing the almost complete disappearance of CMHT support, early discharge from inpatient units, and closure of inpatient units with major reconfiguration of services seemingly focused on dementia beds.

"We need a guarantee that services will keep patients and their families and carers safe in these difficult times."

Read more on this correspondence here.



- **2.4** We are concerned that the Welsh Government has not instructed or advised Local Health Boards and local authorities on what **minimum service** should be maintained, and it has not set out any **national standards** for minimum service delivery aside from conformity with the law (which should hardly need stating to public bodies).
- **2.5** The Welsh Government has told us that local contingency plans by Local Health Boards should include details of what will be provided as a minimum service. We have not seen these plans and nor of course have patients. We are sceptical about whether the plans do in fact set out what minimum service will be provided: our impression is that local planning has revolved around suspension and closure of services and has not included any clarity about what basic services will remain in place.

3 Actions which would help right now

- The Welsh Government should set out national minimum standards for what service must be maintained for people with a serious mental illness during the pandemic
- Local Health Boards should publish their contingency plans now and give guidance to people with a serious mental illness on what services are available and how to access them
- National standards and the local availability of services should be revised regularly flexing with the demands of the pandemic on the NHS and others and people with a
 serious mental illness should be advised accordingly

4 Contact

Head of Communications

Hafal

Hafal Head Office Unit B3, Lakeside Technology Park Phoenix Way, Llansamlet Swansea SA7 9FE

Web: www.hafal.org



Inquiry into the Covid-19 outbreak on health and social care in Wales

Further evidence from Hafal

Hafal's Preliminary Response to the Inquiry can be <u>downloaded here</u>; this further evidence should be read with reference to that initial response.

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2. Freedom of information request

- **2.1** In June 2020, Hafal wrote to each Local Health Board to request a copy of their business continuity plans in relation to the provision of mental health services during the present crisis.
- **2.2** The plans are very varied and difficult to compare. This demonstrates the key issue: no template was provided by Welsh Government, so the plans vary widely according to LHB area. In other words, the quality of plans for continuing to deliver mental health services during the pandemic depends on where you live in Wales.
- **2.3** The plans focus substantially on withdrawal and redeployment of services with little consideration of what will still be provided: this amounts to simply dropping services rather than

carefully scaling them down leaving sufficient support in place to keep people safe. It is little wonder then that there was no clarity given to patients about what support would remain in place - the "planners" did not know themselves.

2.4 Hafal Members believe the LHBs should have been provided with clear standards by the Welsh Government. For example, as a minimum the plan should have been required to meet the following criteria for planning mental health service delivery:

Plan details continuing care and support for the following:

- > inpatients, including both voluntary inpatients and those held under the Mental Health Act
- > those in care homes and supported housing
- > those supported in the community by CMHTs, CAMHS, or other specialist services.

Plan specifies:

- > how quickly patients will be able to get hold of their key worker or care coordinator
- > how assessments will take place
- > how long it will take to be referred from primary to secondary services
- > how crisis services will deliver care
- > how hospitals will ensure that inpatient beds are available, that patients are not discharged too early, or that they are not transported out of their local area for treatment.

In addition:

- Multiple options provided for people to access their care (e.g. telephone, video call, but also alternatives if these are not preferred).
- Clear communications strategy for patients and carers provided.
- Plan takes into account and caters for families'/carers' needs.
- Plan mitigates the danger from certain medications for mental illness, e.g. those which require regular testing (clozapine clinics).
- Clear points of contacts provided.

3. Remote working

- 3.1 We are concerned that there may be an assumption that remote services can be provided to people with a serious mental illness on an ongoing basis beyond lockdown.
- 3.2 Virtual services have limited value for those in highest need; personal contact is a key therapeutic element of services provided to those who are very ill.
- 3.3 In future increasing virtual meetings *between professionals* could surely make travel time and resources available for more not less face-to-face meetings with vulnerable patients.

4. Prudent mental health care

4.1 We are concerned that, while the support of people with serious mental health problems has been compromised by a lack of national guidance, there has been widespread misrepresentation of the mental health impact of the pandemic which may have unhelpful short and long-term consequences.

- 4.2 Specifically it should be recognised that proportionate worry or concern about the pandemic is not a mental health problem; the great majority of people will not have any significant mental health problem as a result of the pandemic.
- 4.3 Further, for the great majority of those who do experience a mental health problem as a result of the pandemic the appropriate providers of support will be families, schools, employers and others who have routine contact.
- 4.4 Mental health services need to focus their support on those in the greatest need, especially those with a serious mental illness who depend on services to keep safe.
- 4.5 One of the worst potential consequences of the pandemic would be to increase the longstanding problem of inappropriate treatment (not least treatment with medication) of people with lesser mental health problems or without any mental health problems.

5. Further evidence

5.1 Please find enclosed:

- A press release about the Hafal survey of mental health patients during lockdown plus an overview of its findings
- Correspondence between Hafal's Chair Mair Elliott and Minister for Health and Social Services Vaughan Gething regarding mental health service provision during the pandemic
- A press statement on the discharge of mental health patients in North Wales during the pandemic
- Hafal's latest journal (with enclosed Senedd Election 2021 manifesto) which includes a series
 of interviews with service users, carers and mental health professionals about how services
 should develop in the wake of the pandemic.

6. Contact

Head of Communications

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PRESS STATEMENT

30/04/20

Survey raises concerns about the provision of mental health services in Wales during the Covid-19 outbreak

A national survey by Welsh charity Hafal has revealed the problems experienced by patients across Wales in accessing support during the Covid-19 outbreak.

The survey, which was completed by over 300 participants from across the country, reveals that while the mental health of 74% of respondents has been negatively affected by the coronavirus outbreak, nearly two thirds (63%) had been unable to access their GP in the previous two weeks.

Almost half of respondents (46%) had not been informed about what is happening with mental health services in their area, and 37% had services cancelled within the previous fortnight. 14% had experienced difficulties in getting hold of their Community Mental Health Team, and 44% had not been informed about what they should do or who to contact if their mental health deteriorates or they experience a crisis.

Participants reported a number of issues with mental health services during the lockdown including the following:

"I booked an 'emergency appointment' (in January) for the middle of March, this was cancelled by telephone, until further notice, three hours before I was due to be there."

"My review was cancelled. I had a lot I wanted to discuss and don't know when it will be rescheduled."

"My partner's ECT has been cancelled because of this Covid-19. He has become very low and is depressed and suicidal. Spoken to the CMHT but they said it can't be helped it's the virus?"

"My CPN has left. I don't know who my new one is and not heard from anyone."

Hafal's Chief Executive Alun Thomas said: "The survey results are extremely concerning and they confirm what we are hearing on the ground: that people are often so concerned that services are under pressure from Covid-19 that they are not calling for help when they first need it, but that when they do ultimately call for help they are struggling to access mental health services during the lockdown.

"For people with a serious mental illness, this poses a real threat to health and wellbeing."

In an open letter to the Minister earlier this month Hafal Chair Mair Elliott raised her concerns about the current state of mental health provision, stating: "As Chair of mental health charity Hafal I am writing to you urgently to express my grave concerns about the safety of the most vulnerable mental health patients and their carers and families in Wales during the coronavirus outbreak and to seek your assurance that their safety will not be compromised.

"We are witnessing the almost complete disappearance of CMHT support, access to clozapine clinics for our clients significantly impacted, early discharge from inpatient units, and closure of inpatient units with major reconfiguration of services seemingly focused on dementia beds."

Hafal is continuing to support people with a mental illness across Wales via its 22 county networks and through it's "Promise" which pledges ongoing support to anyone in its client group.

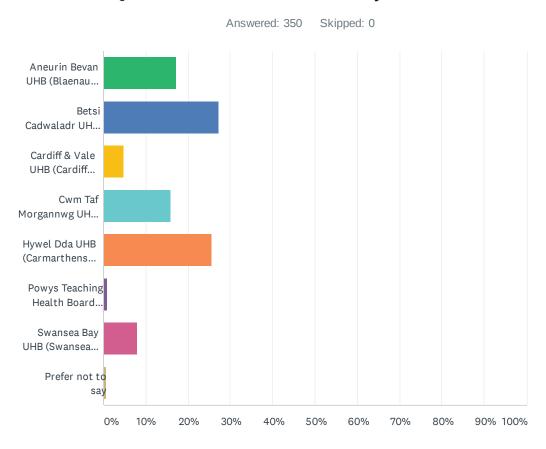
For more information please contact Head of Communications

ENDS

Notes to Editors

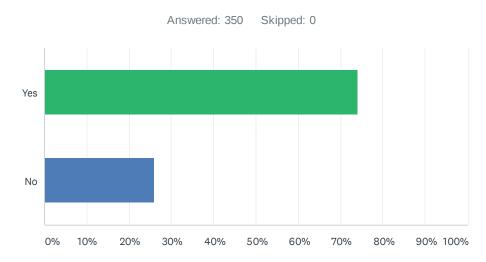
1. Hafal is a leading Welsh charity supporting people of any age with a mental illness, physical illness or disability, and their families and carers. Covering all areas of Wales, Hafal is an organisation managed by the people it supports. For more information go to: www.hafal.org

Q1 Which area of Wales do you live in?



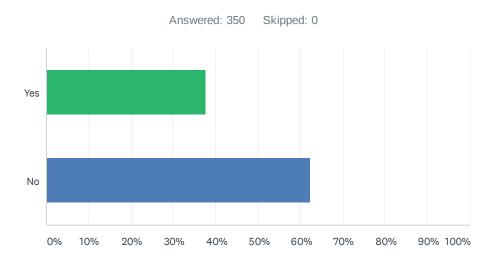
ANSWER CHOICES	RESPONSES	;
Aneurin Bevan UHB (Blaenau Gwent, Caerphilly, Monmouthshire, Newport, and Torfaen)	17.14%	60
Betsi Cadwaladr UHB (Anglesey, Conwy, Denbighshire, Flintshire, Gwynedd, and Wrexham)	27.14%	95
Cardiff & Vale UHB (Cardiff, and Vale of Glamorgan)	4.86%	17
Cwm Taf Morgannwg UHB (Bridgend, Merthyr Tydfil, and Rhondda Cynon Taf)	16.00%	56
Hywel Dda UHB (Carmarthenshire, Ceredigion and Pembrokeshire)	25.43%	89
Powys Teaching Health Board (Powys)	0.86%	3
Swansea Bay UHB (Swansea, and Neath Port Talbot)	8.00%	28
Prefer not to say	0.57%	2
Total Respondents: 350		

Q2 Has your mental health been negatively effected by the recent coronavirus outbreak?



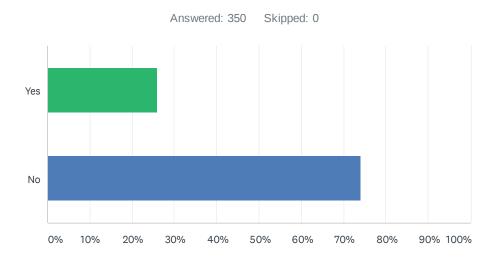
ANSWER CHOICES	RESPONSES	
Yes	74.00%	259
No	26.00%	91
TOTAL		350

Q3 Have you been able to access support from your GP in the last 2 weeks?



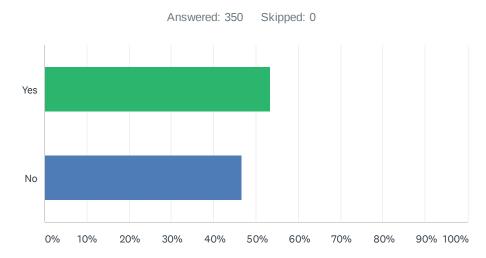
ANSWER CHOICES	RESPONSES	
Yes	37.71%	132
No	62.29%	218
TOTAL		350

Q4 Have you tried to seek support from mental health services in the last 2 weeks?



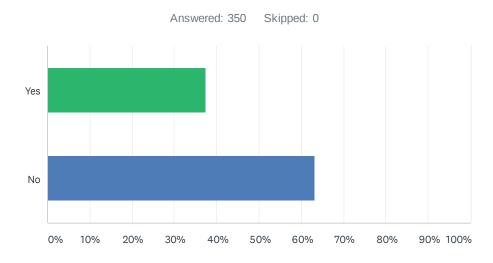
ANSWER CHOICES	RESPONSES	
Yes	26.00%	91
No	74.00%	259
TOTAL		350

Q6 Have you been told what is happening with services in your area?



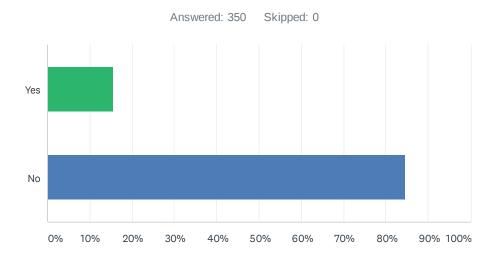
ANSWER CHOICES	RESPONSES	
Yes	53.43%	187
No	46.57%	163
TOTAL		350

Q7 Have you had any services / visits / clinics cancelled in the last 2 weeks?



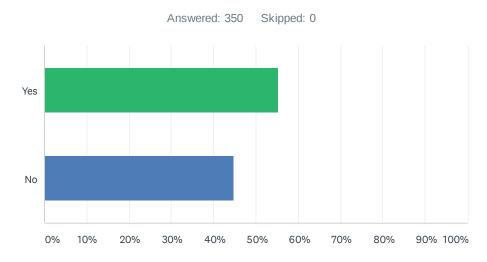
ANSWER CHOICES	RESPONSES	
Yes	37.43%	131
No	63.14%	221
Total Respondents: 350		

Q8 Have you or anyone you know experienced difficulty in contacting the Community Mental Health Team over the last 2 weeks?



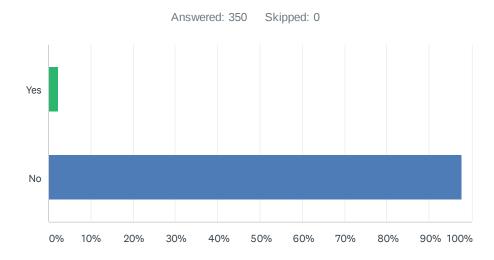
ANSWER CHOICES	RESPONSES	
Yes	15.43%	54
No	84.57%	296
TOTAL		350

Q9 Have you been told what you should do/who to contact to get support if you feel your mental health is getting worse or you experience a crisis?



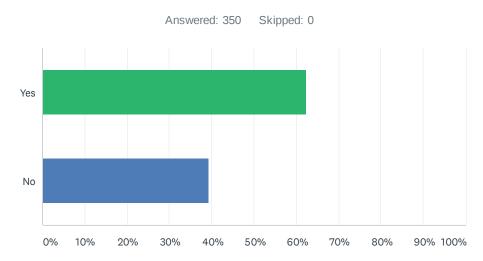
ANSWER CHOICES	RESPONSES	
Yes	55.14%	193
No	44.86%	157
TOTAL		350

Q10 Have you or anyone you know been an inpatient in a mental health ward in the last 2 weeks?



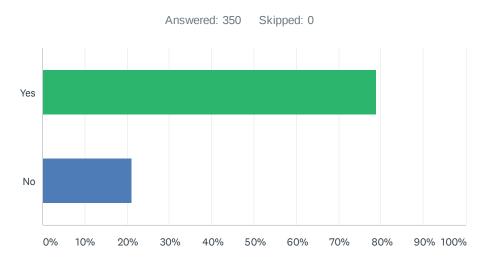
ANSWER CHOICES	RESPONSES	
Yes	2.29%	8
No	97.71%	342
TOTAL		350

Q11 Are you self-isolating?



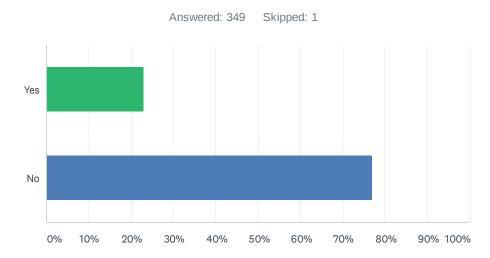
ANSWER CHOICES	RESPONSES	
Yes	62.29%	218
No	39.43%	138
Total Respondents: 350		

Q12 Have you been able to access shops?



ANSWER CHOICES	RESPONSES	
Yes	78.86%	276
No	21.14%	74
TOTAL		350

Q13 Have you had any financial issues over the last 2 weeks?



ANSWER CHOICES	RESPONSES	
Yes	22.92%	80
No	77.08%	269
TOTAL		349

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An open letter to Vaughan Gething, Minister for Health and Social Services

Thursday 2nd April 2020

Dear Minister

Requesting your undertaking to protect people with a serious mental illness during the present crisis

As Chair of mental health charity Hafal I am writing to you urgently to express my grave concerns about the safety of the most vulnerable mental health patients and their carers and families in Wales during the coronavirus outbreak and to seek your assurance that their safety will not be compromised.

My concern is specifically for inpatients, including both voluntary inpatients and those held under the Mental Health Act, those in care homes and supported housing, and patients supported in the community by CMHTs, CAMHS, or other specialist services.

An article published earlier this week on the University College of London Institute of Mental Health website captures the current challenge: "In this national emergency, it seems clear that those with the most severe and complex mental health needs are going to be at significantly higher risk of negative outcomes... We need to act now to prevent a catastrophic failure in care for those in our society with the highest vulnerability."

First, let me assure you that we are fully aware of the challenges posed by the coronavirus pandemic. We are making every possible effort to reconfigure services in response to the crisis, taking on all advice from the Welsh Government. We continue to provide vital support to our clients and stand ready to look at how we might be able to adapt capacity and expertise as part of the health and social care workforce.

What I am asking from statutory services is that they also meet this huge challenge for this vulnerable group of patients. We need a guarantee that services will keep these patients and their families and carers safe in these difficult times.

I am not, of course, talking about sustaining services as they are normally delivered. These are not normal times. We have a narrower ambition: simply to keep people safe from harm.

This means:













- 1. Keeping our client group who can sometimes live chaotic lives or have functional impairments safe from coronavirus
- 2. Keeping them safe from neglect, self-harm, and suicide
- 3. Keeping their carers and families safe
- 4. Mitigating the real danger from certain medications for mental illness, especially those which require regular testing.

We are not confident that these essential goals will be met. We are witnessing the almost complete disappearance of CMHT support and access to clozapine clinics for our clients, early discharge from inpatient units, and closure of inpatient units with major reconfiguration of services seemingly focused on dementia beds.

I do not need to tell you that it is essential that in-patients, including voluntary patients, are not discharged too early: it puts them at extreme risk. And how could it be justified? In-patient facilities are literally there to ensure the safety of people with a serious mental illness – and this almost the full extent of their remit. A service that is there essentially to keep patients safe is a service that cannot be significantly reduced.

This extends to patients in care and to those living in the community who often have very high needs: it is vital that they receive continuing care and support from staff that meets clear criteria for maintaining safety, with routines of contact sustained. We note that specialist community services seldom do more than respond to concerns about safety: so there is little room for reduction in these services.

It is important to note that providing services by phone or video conference will discriminate against individuals who do not have such technology - or are unable to use it. There should be multiple options for people to access their care; only providing telephone support does not allow for reasonable adjustments if a person does not want to or feel comfortable speaking over the phone.

There are also specific issues relating to medication: people on clozapine need continued access to safe blood tests. Consultant psychiatrist James P Pandarakalam explains: "Hospital admissions due to pneumonia are higher among clozapine treated patients. So, even if clozapine does not add to the vulnerability, once patients on clozapine catch COVID-19, they may carry a higher risk of pneumonia and its complications."

We are concerned that there is no recognition of the increased risk faced by patients who take clozapine. This medication has such an impact on the immune system that monthly blood tests are required before a new prescription is made available. Many or all of these patients should surely be part of the shielding group identified and receive the appropriate level of support, food parcels, and monitoring. People on other medications such as lithium also need close monitoring.

Finally, we are concerned about the variation between health boards in their approach to adapting for coronavirus, resulting in a 'post code lottery'. Some national strategy or plan would help to reduce this variation between areas in Wales.

Prif Swyddfa Hafal Uned B3 Parc Technoleg Lakeside Ffordd y Ffenics Llansamlet Abertawe SA7 9FE Hafal Head Office Unit B3 Lakeside Technology Park Phoenix Way Landaulet Swansea SA7 9FE











Let us be candid. These moments of stress on health and social services could bring out the old prejudices and place mental health at the bottom of the pile. But all lives are of equal value: protecting people with a serious mental illness from harm is on a par with protecting people from coronavirus. Having a mental illness should not mean someone waives the right to healthcare and the right to life.

I would welcome a speedy response setting out how services will protect people with a serious mental illness as set out in this letter. Meanwhile Hafal is taking advice on the legal duties of mental health services and will take all action necessary to ensure these are not breached.

I would also make an offer. If requested and provided with the necessary resources Hafal is prepared at very short notice to provide a basic level of support for community-based patients with a serious mental illness across Wales: our door is open.

I look forward to hearing from you.

MVZUMitt

Yours sincerely,

Mair Elliott

Chair

Hafal











Vaughan Gething AC/AM Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services



Ein cyf/Our ref VG/01912/20

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SA7 9FE

21 April 2020

Dear Mair,

Thank you for your letter of 2 April outlining your concerns about the impact of Covid-19 on mental health services and service users with more serious mental illness.

As you will understand, these are unprecedented circumstances and we have taken a number of steps to support health boards to free up capacity and resources to respond to the immediate pressures of the Covid-19 pandemic. However, I can assure you that the Welsh Government is clear that a level of mental health support must be maintained and I can confirm that the Chief Executive of NHS Wales, Dr Andrew Goodall, wrote to all health boards on 14 April to set out our expectations for the continued delivery of mental health services during the period of the pandemic. Whilst there will be an impact on mental health services, as there will be with all critical services, I do expect continuity plans to ensure safe and sustainable mental health support which recognises the relevant legal safeguards and requirements.

To support this, and to ensure that we maintain oversight of mental health services capacity and capability during this period, we have established a Welsh Government/NHS Mental Health Incident Group which is currently meeting on a twice weekly basis and includes Social Care Wales, Health Inspectorate Wales and Care Inspectorate Wales. Under the aegis of this national group officials are working closely with health boards to enable them to highlight issues and concerns in a systematic way. Health boards have also established Covid-19 mental health leads who meet with my officials on a weekly basis to provide assurance on service continuity and to escalate issues of concern so that these can be dealt with at pace. Added to these arrangements for mental health statutory services my officials have also put in place weekly meetings with the Wales Alliance for Mental Health so that any concerns or queries can be escalated and dealt with quickly throughout this period.

Canolfan Cyswllt Cyntaf / First Point of Contact Centre: 0300 0604400

Gohebiaeth.Vaughan.Gething@llyw.cymru Correspondence.Vaughan.Gething@gov.wales

Bae Caerdydd • Cardiff Bay Caerdydd • Cardiff CF99 1NA

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

In relation to the specific concerns you have raised regarding early discharge and closure of in-patients units, I can confirm that in-patient units remain open. Where appropriate and safe, patients have been supported to be cared for in the community in line with normal practice. We are not aware of any unsafe discharges and continue to receive assurance from health boards that this remains the case.

You also raised concerns regarding Community Mental Health Teams and whilst I am aware that as part of the response to Covid-19 some community services have been consolidated, my expectation is that this is to ensure services can be sustained even with a potential reduction in staffing, and not to diminish or reduce the local support.

On the issues that you have raised regarding the immune-suppression effects of Clozapine and potential Covid-19 risk for patients, I understand that my officials wrote to Hafal's Chief Executive on 31 March to respond to these concerns. In terms of access to Clozapine clinics, health boards have provided assurance that all patients who require access to clozapine are receiving it.

Whilst I recognise that all critical services will be impacted in some way by the pandemic, I hope I have provided you with reassurance that mental health services have been positioned as key services to be maintained during this time. However, if you are aware of any specific circumstances where you have concerns about the safety of care being provided, I would encourage you to raise that concern with the appropriate health board as a matter of urgency. I would expect the health board to provide a thorough and satisfactory response to your concerns.

I welcome Hafal's support and the continued engagement with the weekly meetings that officials have established with the Wales Alliance for Mental Health to co-ordinate our efforts to support services users during this challenging period. These weekly meetings also the most appropriate mechanism for Hafal to raise, and to receive timely responses, to any future concerns during this period.

Yours sincerely,

Vaughan Gething AC/AM

Y Gweinidog lechyd a Gwasanaethau Cymdeithasol

Minister for Health and Social Services

Prif Swyddfa Hafal Uned B3 Parc Technoleg Lakeside Ffordd y Ffenics Llansamlet Abertawe SA7 9FE Hafal Head Office Unit B3 Lakeside Technology Park Phoenix Way Landaulet Swansea SA7 9FE











An open letter to Vaughan Gething, Minister for Health and Social Services

Thursday 23rd April 2020

Dear Minister

Thank you for your letter of 21st April 2020. However, I do not feel that your response has provided me with what I asked for – both as Chair of Hafal and as a service user. Put simply, I am still unclear about what I and other people who depend on specialist support can expect from mental health services during this difficult time.

Dr Goodall's letter on the 14 April to NHS Trusts refers to local business continuity plans as the place where temporary service arrangements will be spelled out: but without national guidance does this not create a post code lottery? Surely we need leadership from the top which sets minimum standards on key aspects of service delivery (and not just compliance with the Mental Health Measure which should go without saying) such as: how quickly we will be able to get hold of our key worker or care coordinator; how long it will take to be referred from primary to secondary services, how crisis services will deliver care; and how hospitals will ensure that inpatient beds are available, that patients are not discharged too early, or that they are not transported out of their local area for treatment.

We urge you to set out national minimum standards urgently but meanwhile we request sight of the local business continuity plans (also as a matter of urgency) so that we can advise people with a mental illness on what to expect. I do not share Dr Goodall's apparent optimism that these plans actually do set out details of what level of mental health service will be sustained during the crisis - I, of course, hope I am wrong.

Like other patients I speak to, I am very keen to play my part during the Covid-19 crisis, mainly by having realistic expectations of services and being as accommodating as I can of any changes to delivery which inevitably have to be made. But to do this I need to know what the revised service is actually offering me. As a leader, I have a duty to Hafal's members and client group: you will recall that Hafal's client group are all those people in Wales who are affected by serious mental illness including family and carers. Part of this duty is to ensure that our members and client group have clear information – whilst I can guarantee that Hafal will continue to provide high-quality services (many third sector peers can confidently do the same for their respective organizations), I cannot currently give clear information about statutory mental health services to our members. I understand the pressures that we all face at this time, however we are still in a democratic state and the public will hold those in power accountable when this crisis eventually subsides.

I attach a copy of our bulletin "Coronavirus – Protecting People with a Serious Mental Illness" which we hope will inspire action by the Welsh NHS and others.

Yours sincerely,

MavZhitt

Mair Elliott Chair

Hafal

















PRESS STATEMENT 03/04/20

Statement on the discharge of mental health patients in North Wales during the pandemic

Responding to the <u>BBC report</u> revealing that almost 1,700 mental health patients in North Wales have been wrongly discharged from support services during the pandemic, Hafal Chair Mair Elliott stated:

"We are appalled but sadly not surprised to find that huge numbers of vulnerable mental health patients have been discharged by Betsi Cadwaladr Local Health Board in what they state is an 'error': the Board should of course have had a coherent plan to deliver a slimmed-down but sufficient mental health service which would keep patients safe but instead they have deserted their vulnerable patients and put them at risk. We are also gravely concerned that the number announced by the Health Board appears to be only a fraction of those who were affected by this approach.

"We warned at the beginning of April that there was insufficient national guidance on how a safe level of mental health service would be maintained across Wales, and we have not seen credible information from Local Health Boards about what minimum service remained available to patients and how they can access it. I wrote to the Minister of Health on April 2nd warning that patients were being discharged from services and that support for those with the greatest needs was being severely reduced but did not get anything beyond vague assurances that Local Health Boards would cover these matters in their local plans - and yet in spite of repeated requests we have still not seen Local Health Boards' contingency plans for maintaining essential services.

"A question that must be answered by the Minister is who has misled him? In his two responses to my letters he repeatedly confirmed that he had been assured that such matters were in hand and that we could be reassured that services were in place. Who gave these assurances to the Mr Gething, and why were they not followed up and fact checked? In the case of Betsi Cadwaladr, given that the Board is still in special measures, why weren't their actions monitored or scrutinised?

"So this is not a surprise at all - and we fear that because of the lack of national leadership and guidance patients may well have been let down in other parts of Wales as well.

"Though it will be important to learn lessons, right now the priority is to fix the problem and ensure the safety of mental health patients: a good start would be for the Minister to issue guidance on the minimum service available throughout Wales; and this would need to revised, not less than every month, to indicate the increased level of service as the pressures from the pandemic diminish."

ENDS

For more information please contact Matt Pearce, Head of Communications, by email at matthew.pearce@hafal.org or by phone on 07812 107904.

Notes to Editors

- 1. To download Mair Elliott's correspondence with the Health Minister visit: https://www.hafal.org/2020/04/hafal-coronavirus-briefing/
- 2. Hafal is a leading Welsh charity supporting people of any age with a mental illness, physical illness or disability, and their families and carers. Covering all areas of Wales, Hafal is an organisation managed by the people it supports. For more information go to: www.hafal.org



"I want the 'new normal' to be that people are treated with respect"



Children's Commissioner for Wales: 'Major change needed' in

mental health and wellbeing care for vulnerable children

Some of Wales' most vulnerable children are being bounced between services who cannot agree who is responsible for their care, according to a new in-depth report published by the Children's Commissioner for Wales, Professor Sally Holland (pictured).

According to the Commissioner, in most areas of Wales children experiencing distress with mental health, emotional wellbeing and behavioural issues are not getting the help they need. She said that

as the nation slowly and carefully begins to plan its recovery from the pandemic it is more important than ever to ensure services come together to provide tailored help that meets their individual needs, and avoids them having to navigate complicated systems and multiple sources of help.

The Commissioner said getting support should be a simple and smooth process and that no child should be told that they are at the 'wrong door' when they ask for help. The Commissioner wants every part of Wales to take action towards a 'no wrong door' approach, learning from the practical examples from across Wales which are highlighted in her report and from the positive changes that have emerged in services as a result of the pandemic.

The report sets out a series of recommendations for all Regional Partnership Boards around their duties, and for the Welsh Government, including the need for robust accountability mechanisms and to ensure funding, support and monitoring of work towards long-term strategies. The Commissioner has committed to meeting with every Regional Partnership Board again in 2021-22 in order to check up on and evaluate their progress against her recommendations. Young people will be invited to accompany the Commissioner at these meetings.

Professor Holland said: "We can and must completely change how some of our most



vulnerable children's needs are responded to. Too often, I hear of situations where health, social care and other professionals are, sometimes literally, arguing over the heads of children with complex needs; when they cannot agree who is responsible for their care. As one young person told me during this work: We need to unite to uncomplicate."



NEWS

Traumatic experiences leave mark on pupils, new study by Cardiff and Swansea Universities finds

The pupils of people with post-traumatic stress disorder respond differently to those without the condition when they look at emotional images, a new study has found.

The study looked for traces of traumatic events in the eyes of patients with PTSD, which can occur following a distressing event and causes greater sensitivity, or hyperarousal, to everyday events and an inability to switch off and relax.

Researchers measured pupil size while participants were shown threatening images, such as vicious animals or weapons, as well as other images that showed neutral events, or even pleasant images.

They found the response of people with PTSD was markedly different, including to people who had been traumatised but did not have PTSD.

Depression 'doubles' during coronavirus pandemic

In August the Office for National Statistics reported that twice as many adults in the United Kingdom were reporting symptoms of depression compared with the same time last year.

Almost one in five adults (19.2%) were likely to be experiencing some form of depression, indicated by moderate to severe depressive symptoms during the coronavirus pandemic (June 2020). This had almost doubled from around 1 in 10 (9.7%) before the pandemic (July 2019 to March 2020).

The ONS research examined data from the same 3,500 British adults both before and during the pandemic. Statisticians found those most likely to say they had been affected by depression in June were younger adults (aged 16 to 39), women, those "unable to afford an unexpected expense", and disabled people.

Read more @ ons.gov.uk





At first, the pupil failed to show the normal sharp constriction that is caused by any new visual stimulus, but then their pupils grew even larger to the emotional stimuli than for the other participants.

Professor Robert Snowden from Cardiff University's School of Psychology said: "The research suggests that these people are in a constant state of vigilance and react strongly to arousing images."

Another unexpected result was also found. The pupils of the patients with PTSD not only showed the exaggerated response to threatening stimuli, but also to stimuli that depicted "positive" images, such as exciting sports scenes.

Read more @ cardiff.ac.uk

Mental Health Wales is published by **Hafal**. If you have any comments, please contact us at:

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We hope you found the latest issue of our journal useful! To support our work in providing the latest mental health news and information you can make a donation to Hafal at our JustGiving page.





WHAT SHOULD THE NEW NORMAL FOR MENTAL HEALTH SERVICES LOOK LIKE? Here's what you told us...

MAIR ELLIOTT, PATIENT ACTIVIST, CHAIR OF HAFAL

Do you think mental health is sufficiently resourced, and how would you like to see the situation change?

No, I do not. There has always been a lack of resource in mental health services. In fact, I do not remember a time in which there was sufficient resource to meet demand. The pandemic has highlighted this profound lack of resource. From a lack of era-appropriate technology to a lack in staff numbers, we've seen this resource deficiency impact those who need specialist care.

I have seen across the whole of the health service that this pandemic and subsequent decision making has had a negative impact on patients with all different diseases, conditions, disorders and illnesses. However, despite 'reassurances' from government and local health boards, mental health services have been hit badly. It appears to me that the progress made over the last couple of years to achieve parity between physical health and mental health was just an illusion. This pandemic has put specialist mental health services back at the bottom of the pile.

I would like to see further protection for mental health services, with higher level ring fencing of mental

> we need to restructure how we see 'value for money' by giving emphasis to patients' wants, needs and ambitions

health monies. This means the money dedicated for mental health services will be better protected. There needs to be a minimum percentage of health and social care budgets dedicated to mental health with flexibility to expand to meet demand, particularly as we recover from the recent pandemic.

We need to restructure how we see 'value for money' by giving emphasis to patients' wants, needs and ambitions. Patients should have a much higher degree of choice in how resources are used to support them.

Where specifically do you think resources need to be focused?

I think there is a good case to define the role and the boundaries of what mental health services can and should do. I see a movement towards medicalising normal or reasonable distress in the general public, which I find really uncomfortable. It is okay to grieve for the loss of a loved one, or to feel low when life is throwing its curve balls at you, but to medicalise these normal experiences is to take a person's agency away. I believe we need to re-instate the boundaries of mental heath services as specialist health services for those who are experiencing difficulties above and beyond the normal or reasonable distress. It should not be the role of mental health services to be a wellbeing service for the whole of the general public. Therefore, funding for mental health services should not be diverted towards the mental wellbeing movement. The mental wellbeing of the wider population depends on individual responsibility, strong families, responsible employers, and good public services - not on mental health services.

Going forward I would also like to see resources within mental health services focused on true and meaningful co-production at the individual level through to the governance of services. I feel a system with meaningful coproduction would reduce or even

I think there is a good case to define the role and the boundaries of what mental health services can and should do

stop coercion, gas lighting and medical trauma of patients. Meaningful coproduction would look like the surrendering of power from medical staff, such as psychiatrists, to bring patients up to a level playing field. What 'co-production' I see at the moment is still very tokenistic.

Moving forward, how should we be supporting the mental health and wellbeing of children and young people?

The mental wellbeing of children and young people depends on supportive families, schools and colleges, and well-supported training and work opportunities.

Child and Adolescent Mental Health Services (CAMHS) should be there specifically for young people who have serious mental health challenges; they should act quickly to resolve problems or sustain support for as long as needed. This will only be possible if there is a clear threshold of need for their services.

But no child or young person should fall between different levels of support: multi-agency consideration of all children in difficulty should always result in a positive referral, whether to pastoral care within a school, advice services, primary care, or CAMHS as appropriate.

Too many children are 'treated' with drugs for problems which arise from unstable family environments or insufficient educational support: this is a serious abuse, and it needs to change.

We hear a lot these days about the 'new normal'. What would you like the 'new normal' to be for people receiving mental health care?

I would like to see a much higher degree of choice from the moment someone enters services to the day they are discharged from services. Care and treatment should not be something done to you, but a process of



shared decision making, responsibility, mutuality and respect. I would like care and treatment to be focused around the needs and ambitions of the patients, not the predetermined goals from a medical model of care. I would like the quality of Care and Treatment Plans (as required under the Mental Health Wales Measure 2010) to drastically improve for all people accessing mental health services. I would also like to see the access to and availability of psychological therapies widened, with much more variety in what psychological therapies are available. CBT should not be the only option for everybody.

To put it simply, I want the new normal to be that people accessing services are treated with respect, are given choice and have appropriate treatments to meet their ambitions in life.

I would like to see a much higher degree of choice from the moment someone enters services to the day they are discharged from services

BETH REES, TIME TO CHANGE WALES CHAMPION

Do you think mental health is sufficiently resourced, and how would you like to see the situation change?

Before the pandemic, mental health services were stretched and were not servicing all those that needed help and intervention. During the pandemic, there has been an increase in those being diagnosed with mental health problems and therefore increased pressure on services. This will require more funding to address the pressure. Funding for mental health services should be ring-fenced at a higher level to deal with the increase and ensure all those who need support get it.

Where do you think more resources need to be focused?

I think more resources need to be available for those in mental health crisis. For example, giving more funding to frontline Community Mental Health Teams who deal with people in crisis on a regular basis and to hospital wards that currently aren't running a 24-hour service would be very beneficial. When I was in a mental health crisis, the mental health ward at my local hospital wasn't open when I needed support and I was sent home on the understanding I wouldn't hurt myself. How many more people are being turned away in their time of need? Too many.

The visibility of mental health problems has increased during the pandemic. Going forward, how do we build on this awareness and combat the stigma surrounding mental illness?

I think we build on this awareness by showing how we're helping those affected, how we're providing the support that's needed and how many lives will be changed through the government making the necessary changes. To combat the stigma, share more stories of people who have lived experience and how they're affected daily. Show that the government are taking mental health seriously and the positive impact their decisions will have on everyday people.

I've found that sharing my story has not only been therapeutic for me but has made people more aware of stigmatised conditions such as Borderline Personality Disorder. Sharing stories and creating positive conversations will help to combat the stigma surrounding mental health.

What services and support would have been helpful for you?



Talking therapy from the NHS would have really helped me years ago when I was struggling with my mental health. I was put on a waiting list and years later, am still waiting. As mentioned, having the local hospital mental health ward open 24 hours would have meant I got the help I needed in crisis instead of sending me home with my fiancé and Mum and putting an emphasis on them to look after me to ensure I didn't do any more harm to myself.

Do you feel there is enough emphasis on early intervention, and how can services be improved to be more responsive?

Early intervention is so important. I think we're not helping people soon enough. Services only seem to be available to those who are at a critical stage and have almost passed the point of intervention. I think more education needs to be done with GPs so that they can recognise when someone would benefit from counselling or medication or group support. It would also be good to let GPs know at what level intervention is needed and what help someone can access at what level. Mental health teams need to be given clearer guidelines on what intervention they can provide and if they can't help, when to refer to other agencies for support.

Looking ahead, what changes would you like to see in primary care mental health support? And what would you like mental health care to look like in the future?

I absolutely think that primary care could be more effective in referring people to appropriate support. The average person wanting help won't know where to turn or how to get help so these teams need to keep that in mind, even if it's directing people to guided self-help routes, for example. From personal experience, I think mental health care has gotten more patient focussed. Whenever I'm in crisis and have seen my GP, they have always asked me what I think about their suggestions, do I have any comments about it and is there anything they can do that hasn't been suggested. I know this isn't the same for everyone. Before I moved, the health board I was with previously didn't seem to take my mental health or my concerns seriously. After I moved and changed health boards, I've had a much more positive experience.

In the future, this care should be accessible to all who need it. It should be fit for purpose and make people

I absolutely think that primary care could be more effective in referring people to appropriate support

with mental health conditions feel empowered and part of the process of managing their minds. With more funding, better education and sharing more experiences, I would hope that mental health care in future would be a positive experience for more people.

SHARON JONES, CARER, HAFAL DEPUTY CHIEF EXECUTIVE

Do you think mental health is sufficiently resourced, and how would you like to see the situation change?

No, I don't think it is sufficiently resourced. Mental health has always been known as the 'Cinderella' of services because it is so under-funded. This has been exposed during the Covid-19 pandemic which has posed huge challenges for mental health services and revealed the vulnerability of those services when the wider NHS comes under pressure. During the pandemic we witnessed the disappearance of CMHT support and early discharge from services. Mental health went back to the bottom of the pile, as it were.

Mental health services need a larger percentage of the health budget – not least to recognise the increased and lasting pressure on mental health services arising from the pandemic. It's not about giving mental health

mental health services need a larger percentage of the health budget



a special priority, it's simply about making the allocation of resources reflect the needs of patients in Wales.

Where do you think more resources need to be focused?

Mental health services are losing their way: there is an urgent need for them to define their role clearly, refocus their work, and avoid medicalising normal life events.

continued...

specialist mental health services should give priority to those in greatest need

Funding for mental health should not be diverted to support the responsibilities of public-facing general services to protect the mental wellbeing of their clients. It should focus on those with problems above a clear threshold of need.

Mental health services at primary care level should support those who require health care and redirect those whose problems are not ones of health. Specialist mental health services should give priority to those in greatest need, aiming to assist those patients receiving higher-end services to achieve recovery and move down into lower-level support services, as this will have the greatest impact in terms of improving people's lives - and additionally in reducing the cost of their care and treatment.

The current Together for Mental Health strategy, now approaching its end, needs to be replaced with a more focused plan aiming as a priority to achieve specific outcomes for those who need to use mental health services.

What improvements are needed in the way carers are supported in their role?

Carers and families should be treated with more respect and have a clearer role in the recovery of the people they care for — and this role should be formally agreed. After all, they are the ones who are likely to provide the most care for the person concerned, and who know them best. Too often, families and carers are not listened to or engaged with by services, which means they are missing out on vital information.

Mental health services should "contract" with carers as a third party so that each partner – patient, service, and carer – agrees their contribution to the patient's care and recovery.

How can the quality and roll out of carers' assessments be improved?

Recent evidence shows that the Social Services and Wellbeing Act is not being fully implemented across Wales: this is something the Welsh Government needs to address urgently, as this gives carers the same rights as those they care for.

Because the Act isn't being fully implemented across Wales, not enough mental health carers are receiving the needs assessments which they are entitled to, and even those who do receive assessments are not necessarily receiving comprehensive assessments of their needs. The focus doesn't just need to be on ensuring all carers in Wales have an assessment: there needs to be a focus on quality as well. Assessments need to address not only what carers need to fulfil their role as a carer, but also their personal support needs. For example, are they getting help to maintain their employment? Are their physical health needs being met? Are they having opportunities to have a social life?

carers and families should be treated with more respect and have a clearer role in the recovery of the people they care for



SUZANNE DUVAL BEM, BME MENTAL HEALTH MANAGER, DIVERSE CYMRU

Suzanne Duval is BME Mental Health Manager for Diverse Cymru and was awarded the British Empire Medal (BEM) in the 2018 Queen's Birthday Honours List for dedicating 18 years of work and activism within the BME (Black and Minority Ethnic) Mental Health sector in Wales. Suzanne told us about how she would like equality to be at the heart of services in the future...

"Mental health is the fastest growing pandemic in the world. But it doesn't seem that services have anywhere near enough money.

"The saying goes that 'prevention is better than cure', so I would say let's focus on prevention to stop escalation, but that has to be a focused action as 'one size does not fit all'. And of course, in an ideal world all services should have a recovery remit.

"We should always try and prevent the medicalisation of life problems. Not all appearances of illness need medication. Sometimes, people 'feel' they need something and a lot of GPs will oblige. We can't have it all ways, asking for something and getting it and then it turns out we shouldn't have had it in the first place, but we think/feel much better for having it or being denied it (like they do now with antibiotics) and then getting it from the internet/pushers, etc.

"In the Mental Health Act Review of 2018 it states quite clearly in there that there are 'profound inequalities' for people from ethnic minority communities accessing mental health treatment and it calls for cultural competency in services.

"We once did a roadshow around Wales and we went to six of the seven health board areas to talk to BME people about their good and bad experiences with the mental health system, and some of the stories they told us were terrible. I can't believe that in the Twenty-First Century we are dealing with Seventeenth-Century attitudes.

> I can't believe that in the Twenty-First Century we are dealing with Seventeenth-Century attitudes



I think what's sometimes missing in practice is humanity

"Black men are still far more likely to be in the mental health system. Their route into the mental health system is rarely through the doctors or the community mental health team. It's usually through the judicial system.

"Equality needs to be at the heart of services. This can be achieved through taking up the Diverse Cymru Certification Scheme which is endorsed by the Royal College of Psychiatrists in Wales and equips services with skills and tools to enable them to think and act in a culturally competent way: not only to their patients/clientele, but to each other and the wider community. It becomes 'second nature'.

"I think what's sometimes missing in practice is humanity. It's not about people not being politically correct. They've lost their humanity. They need to see someone as a person and treat them appropriately."



During the summer Hafal asked a hundred people from across Wales about what needs to change in mental health services in the medium-to-long term. Participants strongly agreed with all of the following statements. They were also asked to suggests how the points could be turned into action. Here's some of the feedback...

1. Resources for Mental Health and Social Care – mental health should be given the same priority as physical health care when it comes to funding

How we can turn this into action?

- "More money into mental health services, more staff, a faster referral system"
- "It has to be enthroned in law that mental health services receive equal priority for funding in order that waiting times and the range of services are improved"
- "The whole of health needs to be looked at afresh so that resources are put where they are needed most"
- 2. Prudent Mental Health Care mental health services need to focus on those most in need while other agencies such as schools and employers should take more responsibility for people's general wellbeing

How we can turn this into action?

- "People who are very ill need quick access to services so they should be a priority for referrals"
- "Employers need support to train staff to support others"
- "Better education and support for employers so a pathway to support is available as required"
- "Regular sessions in schools to encourage children to take care of their mental health'
- 3. Young People those seeking help with a mental health problem should always get a positive response from their school, college, employer or mental health services

How we can turn this into action?

- "Clear pathways for support CPNs attached to schools"
- "Access to advice and support for schools so they know how to respond to someone experiencing mental health issues"
- "Young ambassadors who have experienced and who are trained to signpost"

4. Empowerment and Choice – users should be supported to make their own plan for recovery and to choose between care and treatment options

How we can turn this into action?

- "Involve people in decisions that affect them"
- "Involve the service user in the care plan, ask questions give clear simple info so they can make a choice"
- "Having control over your own life surely helps recovery, and someone is more likely to stick to recovery if they have had a say on it"

5. Carers and Families – should be respected as key partners by services and supported both in their caring role and personally

How we can turn this into action?

- "Include them in every plan, allow for them to be part of the decision making processes"
- "Carers and families need to be more involved and included in decisions"
- "Keep the line of communication open to carers"

6. Diversity and Fairness – mental health services should ensure that all groups are supported

How we can turn this into action?

- "Far more to be done for vulnerable groups, particularly LGBTQI+, BAME and homeless people across Wales"
- "Diversity training as part of qualification/employment training"
- "Access, inform and maintain contacts within all communities"

Finally Hafal asked: are we missing anything important? Let us know your ideas about what needs to change in mental health services.

This is a sample of the comments they received:

- "More out of hours services and a mental health A & E"
- "Far more counseling services should be attached to every GP / Health Centre and funded accordingly"
- "More Occupational Therapists to drive through the philosophy of empowering individuals to take an active role in their care"
- "Far more needs to be done to assist those people with mental health issues who are detained by the police"
- "Too much pressure is placed on our local police services to deal with individuals with mental ill health"
- "First and foremost, if you say 'I'll talk to you soon', do it. I've been struggling. My doctor called me once in 12 weeks"
- "Staff need to actually care for the people they support and have the users best interests at heart"
- "More multiagency working"
- "The earlier the intervention the better the outcome"
- "Early engagement is paramount in the success of treatment"
- "What is required is a cultural shift in our view of mental health and a greater commitment to recovery"
- "More communication with the patient in hospital and in the community"
- "It seems a shame that people seeking help are often forced to escalate presentation to achieve help, e.g. an increase in self harm or attempts at taking their life before services see them as severe enough to require help'
- "GP Cluster commissioning is ad hoc and has created postcode lottery access to services, even within the same UHBs"
- "Access to psychological therapies in particular is especially dire"

JO ROBERTS, PATIENT ACTIVIST

Jo Roberts is a mental health campaigner who was on the receiving end of the Mental Health Act for over 30 years. In the past she has received compulsory treatment; some of that treatment was deeply unpleasant and even terrifying. Jo is campaigning for a progressive Mental Health Act fit for the 21st Century – an Act that gives patients and carers in Wales and beyond a fairer deal. We spoke to Jo about what she wants future mental health care to look like...

Do you think mental health is properly resourced? Where do you think more resources should be focused?

From my experience, I think a lot more resources need to go into treating a mental illness as quickly as possible and improving in-patient care.

Over the years I've spoken to so many people who have been seriously ill and too many of them had to reach a crisis point before anything was done. Of course, by this time they were so ill that it was a mountain to climb to get better. The point is that mental illness is really treatable, even serious conditions like schizophrenia and bipolar. And like any illness, if it's caught early then the impact on the patient's life is far less. Just think of cancer treatment.

In-patient care also needs to be overhauled. I know this would cost a lot of money, but the savings in the longer term would be huge. The problem I've found is that while hospital care is very, very expensive the accommodation is often grim and there is no real recovery focus, which means patients don't recover quickly and are locked away for years and years at great personal cost to them, and at great cost to tax payers as well. If the investment was made and they were turned into therapeutic places with a clear recovery path, it would have a big impact on people's recovery – and for many, this would avoid very long and costly stays in hospital.

a lot more resources need to go into treating a mental illness as quickly as possible and improving in-patient care



in future, compulsion should be balanced with rights for patients

What should this kind of in-patient care look like?

There is a need to have minimum standards for hospitals. Some are simply not good places to be. These standards should include private rooms, gender segregation if chosen, access to phone and email, and education and recreational opportunities every day. And hospitals need to provide a decent, therapeutic environment – not something that looks like a prison.

When I was in hospital up in Northampton, it was run on points: I had to earn these points to be able to phone my family once a week. We had to claim points every hour. If you swore or raised your voice you lost a point. If you lost three points in a day you were put into a 'blank' room – all walls, no windows. You'd stay there for 24 hours. No compassion was showed by staff because everything was points-orientated – they were not allowed to show emotion.

It's really important that a choice of location is offered as well – for example whether to go to a local hospital or travel further to a specialist unit. When I became ill I was sent far away so that my family couldn't visit, and this had a really negative impact on both me and my family.

In patients need choice in other areas, too. Anyone detained under the Mental Health Act should have the option to access a personal health budget based on the cost of in-patient care so they can design and purchase their own treatment and care package at an independent hospital or in the community. And if they lack capacity then they should be supported by a team of guardians as chosen by them. There should also be a minimum, guaranteed choice of treatments available to all patients subject to compulsion – including psychological therapies.

What do we need from a new Mental Health Act, and how can it deliver patient rights and choice?

Fixing the law on mental health is a wider issue than just reforming the rules on who can be detained. It is about a fundamental shift away from coercion and towards respect and dignity.

The Mental Health Act has tied everybody in knots over the justification for using compulsion. In reality the only justification for detaining someone is to ensure people's safety.

In future, compulsion should be balanced with rights for patients – and not just when compulsion becomes necessary but well before that. Legal rights to care and treatment would prevent the need for compulsion in many cases. When safety is at stake then the law should be able to intervene – but it should be available to the patient to satisfy the need for safety by means of their choice so long as safety is achieved.

I understand that compulsion is sometimes necessary but it is always frightening, expensive, and counterproductive in terms of mental health. The most valuable change for all concerned would be to reduce the use of compulsion safely. Also, the law may be required to ensure safety but it should never be used to compel people to accept a particular course of care and treatment at a particular place — or to accept a substandard environment.

I think it's barbaric that in this day and age, people who are very seriously ill are treated as criminals. Other civilised countries understand that we should distinguish clearly between crimes committed purposefully and harm caused unwittingly by people whose illness has overwhelmed their judgement. We have an awful lot of catching up to do, and a new Act gives us that opportunity.

we need a new, specialised pathway for people with a serious mental illness who enter the criminal justice system

Many people in mental health crisis find themselves inappropriately embroiled in the Criminal Justice System. How can this be changed?

Basically we need a new, specialised pathway for people with a serious mental illness who enter the criminal justice system. This pathway needs to protect them from the damaging and traumatic environments of detention, courts, and imprisonment. Wherever possible it should divert them to the most appropriate service at each opportunity along the pathway.

Nobody with a serious mental illness should be in a police cell or prison. Back when I first reached crisis no beds were available so I was sent to prison for a fortnight, which is ridiculous. In all circumstances, hospital and other specialised provision should be available – with appropriate levels of security, of course – whether or not any offence was directly connected to a mental illness.

While prison is still used the needs of women and young people need to be addressed. We need to ensure appropriate provision is available close to home, in Wales.

At every stage, recovery and resettlement should be the foremost priority. Care and Treatment Plans required under the Mental Health Measure provide a practical model for this.

Read Jo's Blog on the reform of the Mental Health Act at: hafal.org/josblog



DR CLARE CRIBB & DR IAN COLLINGS, CONSULTANT PSYCHIATRISTS, GELLINUDD RECOVERY CENTRE

Gellinudd Recovery Centre is an international award-winning in-patient facility near Swansea which places peer support and patient empowerment at the heart of its service delivery. We spoke to the ground-breaking Centre's Consultant Psychiatrists Dr Clare Cribb and Dr Ian Collings about what they would like the 'new normal' for mental health services to look like...

Do you think mental health is sufficiently resourced, and how would you like to see the situation change?

CLARE: There is a growing recognition of the need for integrated healthcare, i.e. recognition of the fact that physical and mental health problems co-exist in up to 40% of all healthcare presentations. Historically we have separated physical and mental healthcare out when planning services with significantly less resource allocated to mental healthcare. I would certainly like to see greater focus on reducing social inequality, which plays a big part in the genesis of what we call mental illness.

IAN: It is critical that funding for mental health services is ring fenced and increased in real terms. Resources in my view need to be targeted toward prevention and education, particularly in younger adults and children. It is entirely understandable that we are all focused on the Covid pandemic and the risk of further waves in the winter but we need to be prepared for a tsunami of mental health problems in every age group as a direct consequence of the pandemic. The causes of this are complex but related to direct impact and indirectly through lockdown and increased social isolation. We have seen a report recently that the prevalence of people with depressive symptoms has doubled during the pandemic. These rates will no doubt be also seen in anxiety disorders, self-harm and suicide.

Where do you think more resources need to be focused?

we urgently need investment in care for those with serious mental illness, simply to provide adequate and humane care to those in acute need

clare cribb

CLARE: We urgently need investment in care for those with serious mental illness, simply to provide adequate and humane care to those in acute need. The closure of mental health beds over the last 10-15 years has created a culture in which only those whose behaviour is very risky are able to access services, and I worry that a great many people are not receiving the care they need.

IAN: All services need increased resources but we do need to move towards a society that promotes mental wellbeing and educates people about mental wellbeing from an early age: this is why schools are so critical. Generally I am a huge fan of early intervention services; it makes sense that if you can intervene earlier with a biopsychosocial approach to treatment you can improve outcomes immeasurably.

CLARE: I am a big fan of the approach used for mental health services in Finland (Open Dialogue) in which the entire family or network of the patient is called in to work with professionals and promote dialogue right from the first 'crisis'. I believe that all mental health practitioners should have a basic training in how to meet with families to facilitate communication and then have the capacity to offer this support in their work.

You provide care at an award-winning mental health hospital. Why is the service so innovative, and what would you like in-patient care to look like in the future?

CLARE: Gellinudd has compassion and respect for its patients at the heart of its approach. The aim there is to create a homely environment with a mixture of mental health professionals and peer mentors. These mentors have a specific expertise when supporting patients in their recovery, and are not something you would find in many NHS or private sector hospitals.

IAN: For me it is so innovative because of the level of service user involvement it has had in its development. All services should aspire to be developed in a truly coproductive way. For the future I would like to see mental health services developed around the community and the individual that lives in that community. They should not be on the periphery of the community. Mental health services should be much more embedded and seamless with primary care so people can access acute mental health services and even, if necessary, inpatient services in their own community. This does require investment. From my perspective as a rehab psychiatrist, rehab services in



the future should be a hub and spoke model with the hub being community support/placements and the spokes encompassing assertive outreach services and inpatient services. At present our rehab services seem to be the other way around.

How can we increase patient choice in future?

IAN: Patient choice is critical to all parts of the health system be that cancer treatment or mental health treatment. We should embrace a health service where we strive for excellence and service users have a say and can choose our services based on that. However as we move more to a internal market in terms of services this could mean some services get left behind and I am not sure that is the philosophy of the NHS because you may find that those without a voice might be also left behind. The approach needs to be thought through and not leave services behind.

CLARE: I would prefer the word 'agency' to 'choice'. In my experience, people in the middle of a mental health crisis just want to be offered good, local, reliable care rather than a range of choices. The mental work of decision making is beyond most people who are ill enough to need admission. The ongoing climate of austerity and consequent closure of beds means that in reality clinicians are lucky to find a bed anywhere, let alone be able to offer choices. I would worry therefore about a focus on providing choice when first we need to ensure that the service is available at all.

What would you like to see from the new Mental Health Act?

CLARE: Many of us working in mental health would like to see changes that bring the Act more in line with mental capacity legislation, i.e. we all have as much right to accept or refuse treatment for what is labelled mental illness as we do for physical health treatments. I

it makes sense that if you can intervene earlier with a biopsychosocial approach to treatment you can improve outcomes immeasurably

ian collings

welcome the proposed increased focus on family and carers rights. Having been a carer myself for a family member detained under the Act, I am well aware of the inconsistencies and confusion that can arise.

IAN: From a service user perspective I would suggest more regular opportunities for review of care/detention by independent bodies such as the mental health tribunal with responsibilities to not only assess the lawfulness of detention but also give advice on treatment options. I would like the Mental Health Review Tribunal to be less adversarial too.

From my perspective I would be keen if there was less bureaucracy to give me more time to support service users. I suppose ultimately the question is should the Act be more capacity-based; I would be keen to see how the revised Act in Northern Ireland, which has become more capacity-based, is evaluated before I reach a conclusion on that.



Understanding the impact of the Covid-19 pandemic on people living with mental health problems

The pandemic and the restrictions it has caused has had an effect on everyone but it has been particularly difficult for people with mental health problems.

At the National Centre for Mental Health (NCMH), we have launched a new study into the impact the Covid-19 pandemic has had on those living with mental health conditions.

Professor Ian Jones, director of NCMH, said: "The Covid-19 crisis has already had an incredible impact. At NCMH we want to ensure that the particular experiences of people with mental health problems aren't forgotten.

"We would like to understand how the crisis has affected your day-to-day life and what it has meant for the treatment and support you are receiving."

Some findings so far

We had a great early response to the survey when we launched in June and really appreciate people taking the time to complete it. Our researchers have begun analysing the responses from more than 3,300 people.

1,318 people reported experiencing worse mental health symptoms during the pandemic and 463 people shared that they had struggled to access medication.

In the section regarding employment, 868 people stated they were keyworkers, while 679 worked from home. 487 people reported a loss of income due to the pandemic.

This data is vital in understanding the mental health consequences of this unprecedented time in human history.

Taking part

We want as many people as possible to complete the survey. It is open to everyone over the age of 18 who has experienced a mental health condition.

Both new participants who are not already a part of our NCMH cohort study and those who have already helped with NCMH research are invited to take part.

Professor Jones said: "It's vital we understand the impact of the Covid-19 crisis on those living with mental illness. We hope the findings of this study will help inform the NHS and policymakers to provide better services and support.

"I would like to say thank you in advance for helping us make a difference."

More information about the study and how you can take part can be found on the NCMH website ncmh.info/covid-19

Mair's Manifesto

SENEDD ELECTIONS: 6 May 2021



X VOTE FOR

MENTAL HEALTH!





MY NAME IS MAIR ELLIOTT AND I'M CHAIR OF WELSH CHARITY HAFAL. ON BEHALF OF HAFAL'S MEMBERS ACROSS WALES I AM ASKING SENEDD ELECTION 2021 CANDIDATES TO PLEDGE THEIR SUPPORT FOR:-



Increasing the spend on mental health and ensuring that resources for mental health are fully protected: both NHS funding and funding provided to local authorities for mental health social care



Developing and delivering a new mental health strategy which prioritises those with the greatest need and supports a serviceuser centred mental health system



Improving support for young people and ensuring that specialist CAMHS only deal with the much smaller numbers of young people with the highest needs



Increasing access to psychological therapies



Improving support for carers across Wales so that they can achieve a better quality of life

Inside: find out more about the key issues - and how you can raise them with candidates...

WHY DOES THIS ELECTION MATTER?

The Senedd Election 2021 is important to people with a mental illness and their carers: health matters are devolved to the Welsh Parliament and there are some other key areas which are addressed in the Senedd including Education, Housing and Social Care.

WHAT ARE THE ISSUES CONCERNING OUR MEMBERS?



As a Member-led organisation we know from experience what issues face people in Wales with a mental illness and their carers every day. During Summer 2020 we ran our "Talk to Hafal' campaign, speaking to people across the country about what they want from services in the future, and from the next Welsh Government. These are the priorities we identified:

1. MENTAL HEALTH AND SOCIAL CARE NEED GREATER RESOURCES

Funding for mental health services should be set at a higher level – not least to recognise the increased and lasting pressure on mental health services arising from the Covid-19 pandemic. This funding should be applied as minimum percentage of health and social care budgets, and the ring-fenced percentage should be expanded as necessary to achieve parity with other health and social care needs. Funding for mental health should not be diverted to support the responsibilities of public-facing general services to protect the mental wellbeing of their clients. Value for money should be ensured through commissioning services based squarely on patients' needs.

2. MENTAL HEALTH SERVICES NEED TO FOCUS ON THOSE WITH THE HIGHEST NEEDS

There is an urgent need for mental health services to define their role clearly, refocus their work, and avoid medicalising normal life events. There is also a need for mental health services to focus on achieving specific outcomes.

The welcome recognition in recent years that mental wellbeing is an issue for everybody does not mean that mental health services should expand their role. Specialist mental health services should give priority to those in greatest need, aiming to assist those patients receiving higher end (and more expensive) services to achieve recovery and move down into lower-level support services, as this will have the greatest impact in terms of improving people's lives - and additionally in reducing the cost of their care and treatment. These high-level interventions need to be provided quickly.

3. FOCUS YOUNG PEOPLE'S MENTAL HEALTH SERVICES ON THOSE WITH THE HIGHEST NEEDS AND SUPPORT SCHOOLS, COLLEGES, AND EMPLOYERS TO PROVIDE PASTORAL CARE TO YOUNG PEOPLE WITH LOWER LEVEL PROBLEMS

The mental wellbeing of children and young people depends on supportive families, schools and colleges which take their responsibility for pastoral care seriously, and well-supported training and work opportunities.

Child and Adolescent Mental Health Services (CAMHS) should be available immediately for young people who have <u>serious</u> mental health challenges; they should act quickly to resolve problems or sustain support for as long as needed. This will only be possible if there is a clear threshold of need for their services. But no child or young person should fall between different levels of support and they should always receive a positive referral to an appropriate source of help.

4. PATIENTS NEED MORE OF A SAY ON THE SERVICES THEY USE

Patients using mental health services at all levels should be empowered to exercise choice. For example, patients in secondary mental health services should all have a Care and Treatment Plan as required under the Mental Health (Wales) Measure 2010. Typically these Plans are constrained by the availability of services commissioned through traditional assessments of need. This position should be reversed: all secondary mental health services should be commissioned by reference to these Plans. Patients should be able to access funding for psychological treatments of their choice from any approved provider, and - if they need hospital care - where practicable have a choice of which hospital they go to.

5. CARERS AND FAMILIES NEED BETTER SUPPORT TOO

Carers and families need to be treated as key partners in the provision of mental health services. Carer assessments should address both what carers need to fulfil their role as a carer and their personal support needs. Support for carers should cover their need to sustain or gain employment and access to benefits as appropriate. Mental health services should "contract" with carers as a third party so that each partner – patient, service, and carer – agrees their contribution to the patient's care and recovery.

To address these 5 priorities we also need:

- > Action to address inequalities in mental health care, especially for black and minority ethnic communities
- > Appointment of a Minister for Mental Health to protect the interests of those who use mental health services and to lead the essential changes required to mental health care

WHAT SHOULD I BE ASKING MY LOCAL CANDIDATES?

Ask your local candidates about any local or national issues that are important to you. These are some suggested questions about the main issues:-

- > How will you ensure that mental health services are properly resourced and get a fair slice of the cake?
- > How will you ensure that specialist mental health services give priority to those in greatest need and are available as quickly as possible?
- > How will you ensure that Child and Adolescent Mental Health Services (CAMHS) are available immediately for young people who have serious mental health challenges?
- > How will you ensure that patients using mental health services are empowered to exercise choice?
- > How will you ensure that the needs of carers and families of people with a mental illness are met?

HOW SHOULD I APPROACH MY CANDIDATE?



- > Ring, email or videocall your candidate's office you could visit their office either on your own or in a group, or set up a conference call
- > If you meet in person or virtually with your candidate be specific with your questions and get them to guarantee what their party will do write down what they say, or get them to write it down
- > Follow up your visit or call with a letter to emphasise your points
- > You can also attend local hustings. Again, remember to make a note of candidates' answers to your questions!

Remember to have your say and use your vote!











