
Hywel Dda Community Health Council

Every mind matters.

September 2021



Accessible formats

This report is also available in Welsh.

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About the Community Health Councils (CHCs)

CHCs are independent bodies that reflect the views and represent the interests of people living in Wales in their National Health Service (NHS). CHCs encourage and support people to have a voice in the design, planning and delivery of NHS services.

CHCs are often thought of as the independent watchdog of the NHS within Wales. There are 7 CHCs in Wales. Each one represents the “patient and public” voice in a different part of Wales.

Each CHC:



Carries out regular visits to health services to hear from people using the service (and the people providing care) to influence the changes that can make a big difference



Reaches out to people within local communities to provide information, and gather views and experiences of NHS services. CHCs use this information to check how services are performing and to ensure the NHS takes action to make things better where needed



Gets involved with health service managers when they are thinking about making changes to the way services are delivered so that people and communities have their say from the start



Provides a complaints advocacy service that is free, independent and confidential to help people to raise their concerns about NHS care and treatment.

CHCs hear from the public in many different ways. Before the coronavirus pandemic, CHCs regularly visited different NHS services to hear from people while they were receiving care and treatment. CHCs also heard from people at local community events, and through community representatives and groups as well as at CHC meetings and in our offices.

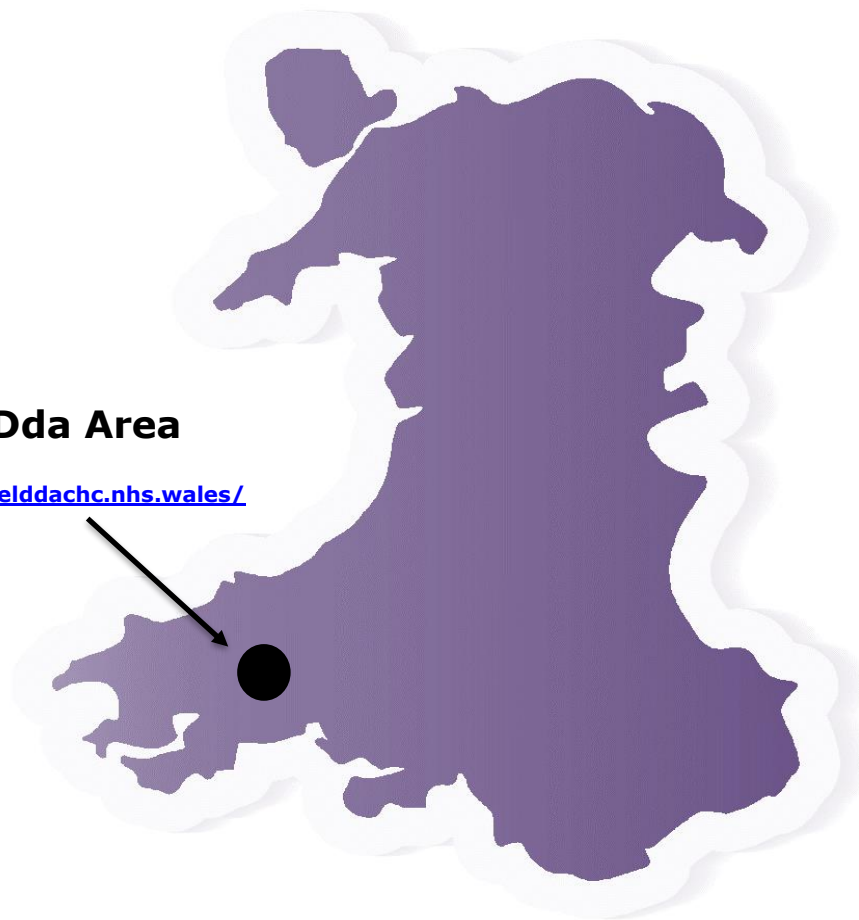
Since the coronavirus pandemic, these ways of listening to people have not always been available, so CHCs have focused on hearing from people in different ways. Whilst we cannot meet people on a face-to-face basis because of the restrictions in place, we have found that many people have learned new ways of doing things differently using technology. This includes surveys, apps, videoconferencing and social media, which we have used to hear from people directly about their views and experiences of NHS care.

We also know that not everyone has been able to do this and there may be people finding it harder to be heard under these very unusual pandemic times.

Hywel Dda CHC represents the interests of people living within the three counties of Carmarthenshire, Ceredigion and Pembrokeshire.

Hywel Dda Area

<https://hywelddachc.nhs.wales/>



About West Wales Action for Mental Health (WWAMH)



West Wales Action for Mental Health (WWAMH) has worked closely with Hywel Dda CHC since both organisations formed and we have worked jointly with the CHC on this report.

WWAMH has been working across West Wales to improve mental health care and support for over 30 years. It is a mental health development charity registered with the Charity Commission.

Our Main areas of work are:

1. Project Development and support
2. Facilitating joint working
3. Information
4. Training Services
5. Health Promotion
6. Service User and Carer Involvement.

WWAMH facilitates a number of mental health forums and networks across West Wales. These help bring people with lived experience, carers, voluntary organisations and statutory organisations together to share experiences and to work together.

Throughout the last 15 months, WWAMH has had on-going conversations with individuals with lived experience of mental health difficulties, their friends/families and carers and also a wide range of voluntary organisation across West Wales to talk about their experiences of mental health support. WWAMH has had a mixture of responses that reflect the differences in these experiences.

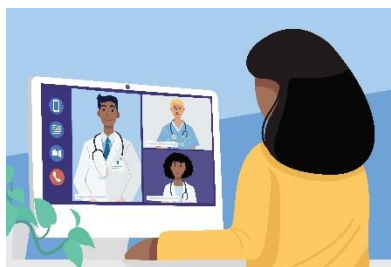
Background

We often hear from people about the care they receive when they are experiencing poor mental health. We hear some positive experiences but often we hear about people struggling to get the care that they need. People often turn to the CHC for advocacy support or to WWAMH for help when they find themselves in challenging situations.

We have been keeping an eye on mental health services over recent years to understand what people's experiences are like. A few years ago, Hywel Dda University Health Board consulted people about ways in which it could 'transform' mental health care. We know that there were planned changes taking place in mental health services aiming to improve services for people.

However, in March 2020, life as we know it in Wales changed significantly because of the coronavirus pandemic. Along with this, people's access to all sorts of health care changed rapidly. We have heard from people about the impact this had on them.

During the pandemic, many services which aim to support people when their mental health is poor, had to change. These changes were intended to keep service users, staff and supporting families safe from Covid-19. It meant that people could no longer go to the hospital or clinic appointments that they had planned. This meant that their care was different.



The CHC wanted to find out more about how these changes were making a difference to service users. Whilst we had intended to ask people about their views on mental health services, the pandemic meant that we had to consider more than just the planned changes that we already knew about. We also had to find out what people's mental health care was like during a worldwide time of upheaval.



What we did

CHCs can usually plan visits to NHS premises to talk to people as they are getting care. This can be in a clinic, a GP Surgery, an out-patient department or in a hospital ward. This allows us to hear people's first-hand experiences.

In 2020 we couldn't do this. Many NHS premises were less accessible. We couldn't visit NHS sites to ask patients and service users what their care was like.

To help overcome this, CHCs were able to find out about people's views and experiences in other ways:

- through enquiries that continued to come into CHC offices by phone, email and post
- by individual stories being shared with the complaints advocacy service
- through contacts with local community networks who could tell us what they were hearing in their local areas
- information coming in to us from community representatives and groups
- social media discussions on Facebook and Twitter
- by monitoring health board activities and performance reports during the pandemic

However, we still wanted to make sure that people could tell us their views easily. So, from April 2020, all CHCs across Wales used a simple national on-line survey so that people could tell us whatever they wanted about their pandemic health care. We didn't specifically ask about primary care, mental health, dentistry or delayed operations. Instead, we asked people:

- Where they lived
- What NHS service they wanted to tell us about
- What their experience was
- What suggestions they could make

We know that on-line methods can be helpful because many people have learned new ways of communicating and doing things differently with technology during the pandemic. Email, social media comments and online surveys are now more frequently used by people to share their experiences.

We also know that not everyone can use these different ways of communicating for a number of reasons.

Some people may have found it harder to have their say or to be heard during lockdown because they have been less able to speak to others in a way that suits them

The results of our national survey as well as our usual ways of hearing from people meant that we were told about experiences from people living in Carmarthenshire, Ceredigion and Pembrokeshire about their mental health care.

Hywel Dda Community Health Council also launched a separate on-line mental health survey in October 2020, to coincide with World Mental Health day. This meant that people who wanted to tell us specifically about mental health services had a way of doing this. We also made sure that people could have had paper copies of this survey and left copies of the survey in venues where people could access face-to-face mental health support.

Overall, during 2020, using the things we were hearing, we also asked Hywel Dda University Health Board to tell us specifically about some aspects of care for people with mental health issues or learning difficulties. For example, we asked:

- How people with severe or enduring mental health problems or learning difficulties would be cared for appropriately if they needed to go into a general hospital with coronavirus
- How adult acute inpatient units were managing to keep people safe from the spread of coronavirus and implementing social distancing and measures to keep people safe
- Whether coronavirus restrictions and staffing issues because of shielding etc were negatively impacting on in-patient capacity
- How mental health services were being delivered if face to face contact was not possible but people still needed some kind of input

- How people were being communicated with about their care and planned therapies, when services had to change very quickly.
- Whether more, or less people were being admitted to hospital under section or detained under the Mental Health Act
- How carers' needs were being considered when people were being required to stay at home. We know that for some people being inside for long periods can be challenging. Others might not find their homes to be places where they could feel safe or secure.
- Whether there were issues in accessing Personal Protective Equipment (PPE) to keep people safe in mental health settings
- About the impact that restrictions on visiting were having on people with dementia
- How people from the three counties, who were receiving in-patient long-term care outside the Hywel Dda area, were being supported at a time when family visits were not always possible
- About the support available for new mums who could not access family or community support easily after having their baby and who might be struggling alone with a new baby
- We asked about psychological support for people affected by coronavirus and who may have been in Intensive care. We also asked how people who might be suffering from 'long covid' (where someone has on-going symptoms after having coronavirus) were going to be supported

- Whether patients detained under the Mental Health Act were still able to have 'leave' from hospital premises
- Availability of bereavement support, recognising that many families were grieving for the loss of a loved one

What we heard

We want to share some of the stories that people told us about their recent experiences of accessing mental health support. This has been at a time when services had to be delivered differently. These different ways of working were sometimes felt to be helpful but some found the new ways of getting support, were not what they expected or needed.

Some people have reported receiving good mental health care and support throughout the last 15 months with little or no disruption to the help they receive (and an actual increase in care for some people). This has been very positive.

Other people have reported that even though they have been discharged from Secondary Care Mental Health services in the last 3 years, they have been contacted by staff from the Community Mental Health Team and asked if they were ok and needed anything. This again is really heartening to hear.

The comments we received also indicated that people were often struggling to access the care they needed. Sometimes the lack of face-to-face services was a problem. Others felt that telephone communication was too difficult. People often felt they there was no one who understood their situation.

... no support
and left feeling
abandoned

I can't just pop to the
surgery any more to
have a private chat.

...mental health
support for carers who
have been thrust into
intensive one to one
relationships for many
weeks...who else will
see that as a priority,
only others in the same
boat.

Some people have reported receiving daily and regular phone calls from Community Mental Health Team (CMHT) staff but no face-to-face contact, others have had regular face to face contact. Some have received text support only and some people have had no texts or phone calls and have made complaints to the CMHT about this and are working with an Advocate on this issue.

Often people put this down to the challenges of living in a locked down world which limited their usual ways of accessing support:

"I know my mental health is being affected but I care for my niece with severe autism so she is with me all the time. This means I can't go to see anyone until lockdown is over and explaining it over the phone is hard."

"... I cannot see a GP face to face to discuss the memory issues. This is all increasing my anxiety, which is not helping at all. Phone consultations have been given and have been handled well, but I need tests."

"...it's lockdown restrictions that are hindering them, especially being able to access the drop in centre in Haverfordwest"

Others have reported significant difficulty in accessing any support from Secondary Care Mental Health services. A number of people told us that they were abruptly discharged at the start of the pandemic by mental health services with no aftercare in place (apart from GPs, which have been very hard to access for some people).

People told us about challenges in accessing primary care and GP support. Sometimes they were being told to ring but then finding long delays waiting on the phone, others had no phone or not enough phone credit to stay on the line for the duration of the call.

Some people felt that the pandemic hadn't really made anything worse and that even before Covid, there had been some issues:

“Didn't get care before Covid, not sure anything will change. I've heard absolutely nothing about my care.”

Some felt that the pandemic had clearly made a difference to their care, whether this was for their physical health, mental health or both. They felt that they were worse off and told us that small things could have been really helpful:

“Monthly or weekly (depending on severity of mental health) telephone calls to make sure that people were keeping their heads above water and if meds needed to be prescribed. People felt that they needed to manage on their own and not bother the nhs.”

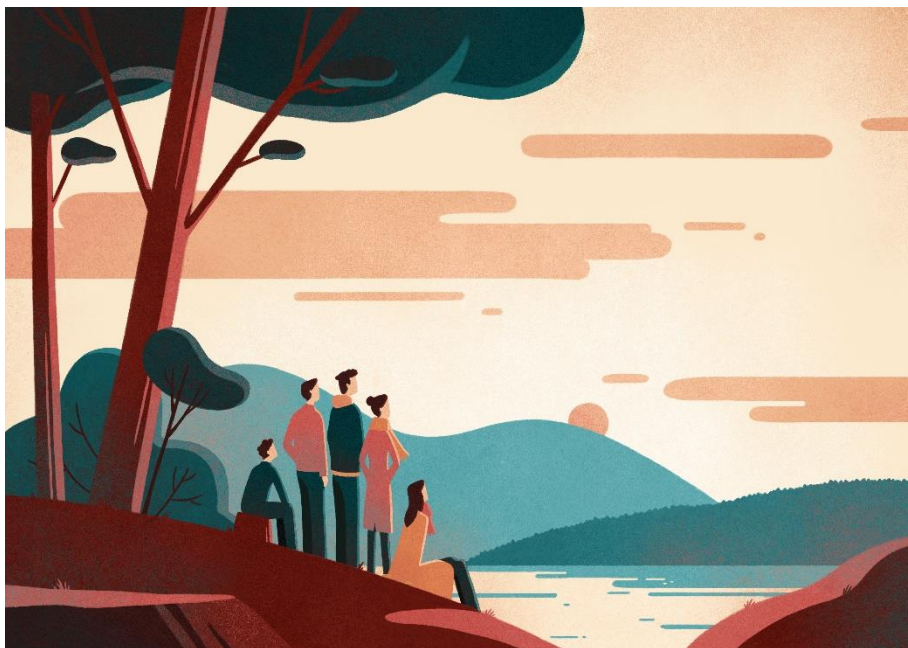
“They need to talk to us and make sure that we are not forgotten, get the treatment we need now.”

“I'm under cmht in neighbouring local health board, even worse- keep saying they'll offer me a phone appt in place of a much-needed consultation, no follow through... The cmht have no excuse really, all I need to do is speak to someone, the delay is bordering on cruel.”

Some people have reported having increased support from voluntary mental health services throughout the pandemic. This has sometimes included help with practical issues such as shopping, accessing medical appointments and regular phone calls and texts.

Some people have reported that they have had access to therapies in different, innovative ways. For example, a walk and talk approach was used by Veterans NHS. This means they have been able to continue their therapy safely, in the outdoors, with their therapist.

This has also had some additional benefits for example, being outdoors has enhanced the therapy, as opposed to the traditional building-based therapy. Some people have reported the benefits of the nature-based outdoor activities offered by voluntary organisations and how this helped them through lockdown and also access to the creative arts activities on line (and in nature sometimes also).



Some people have reported the use of video support via the NHS has been helpful also and helped being able to access such therapy from home, rather than having the anxiety of public transport or travelling to different locations.

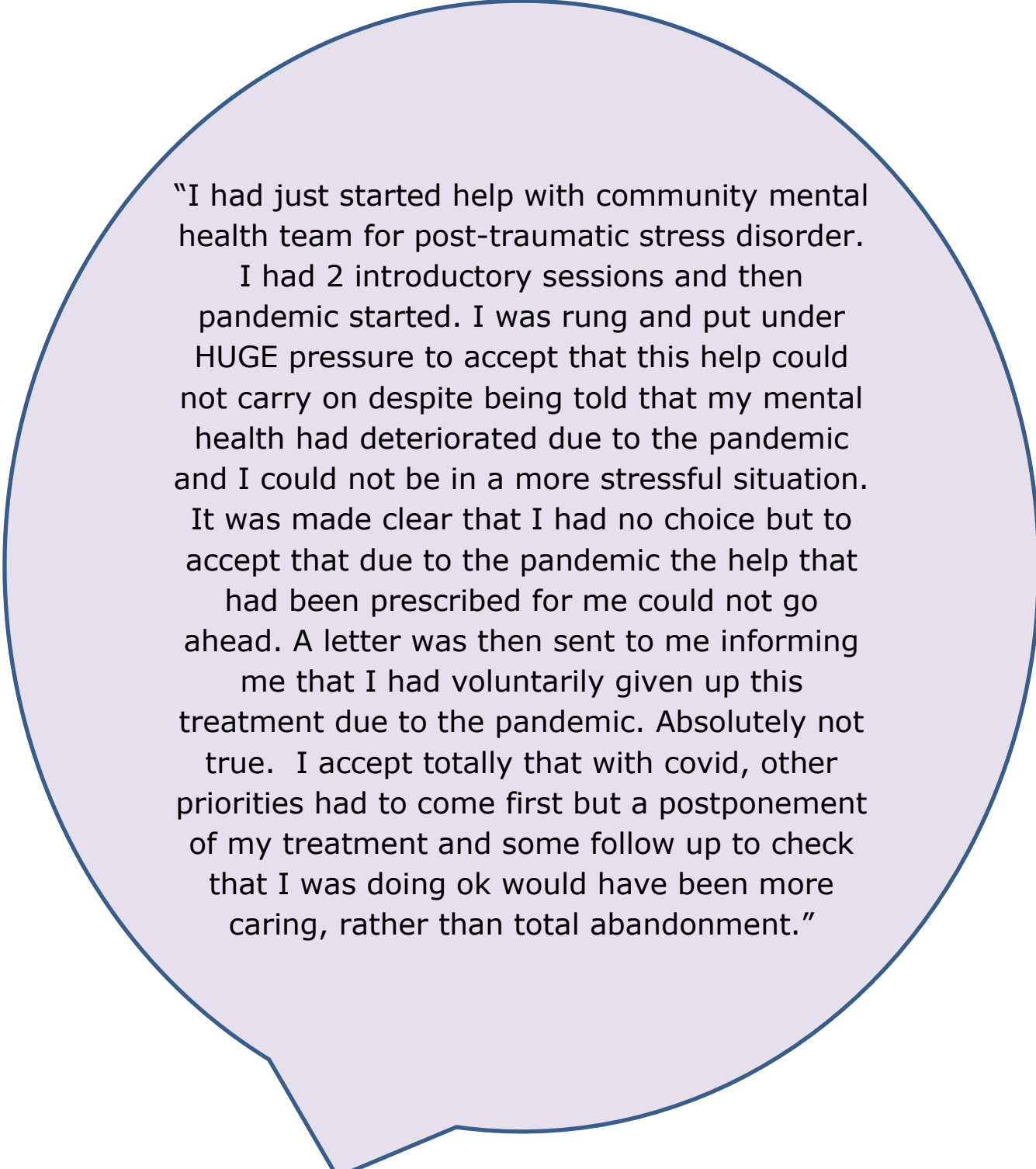
The use of Zoom and video activities were offered very quickly in the voluntary sector and many people have taken part in these. Some people have reported that they appreciated the availability of video approaches and on-line activities. They also noticed an increase in these new ways of working and told us that this has helped them to access support that they previously would not have been able to get.

There are also times when people cannot easily access support delivered in more traditional ways such as face-to-face appointments. This can be because of mental health issues such as social anxiety, or childcare issues or transport problems or the need to fit sessions around work/commitments etc. This means that the changes that have arisen from the pandemic have made it easier and more convenient for some people. These need to be considered as ways of working in the future.

Others have struggled to engage with these new ways because of various digital exclusions such as lack of internet connection, lack of finances for data/Wi-Fi, no equipment, no confidence or knowledge on how to use devices.

Many of the voluntary organisations and Local Authorities have put in place support to help overcome these barriers but for some people it is still hard to engage this way. Some aspects of mental health can make this very hard, such as hearing voices, struggling with concentration and focus or feelings of paranoia and high anxiety levels.

For others who had only just started getting help for their mental health before the pandemic they didn't know what they could now get because they were not used to the system:

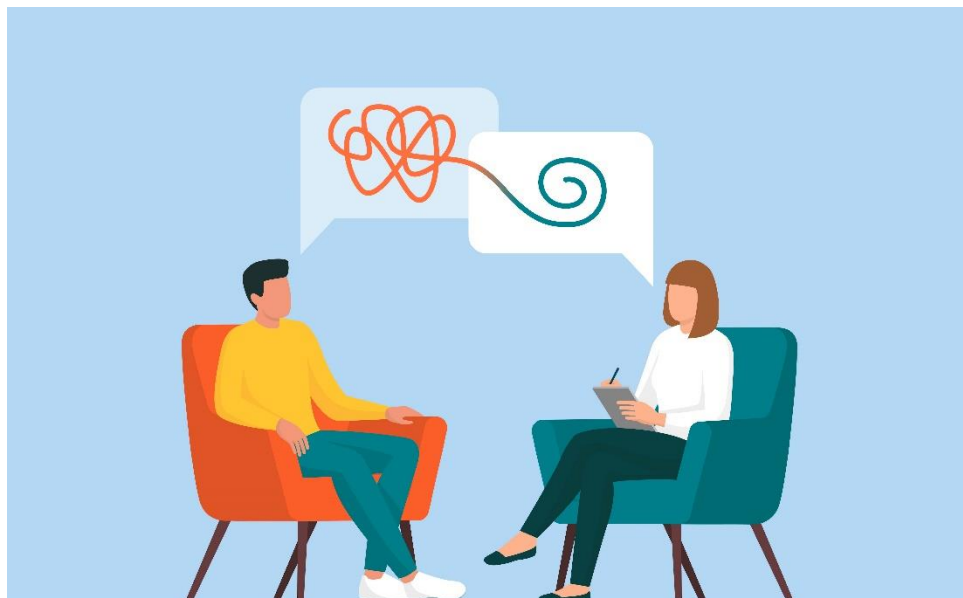


"I had just started help with community mental health team for post-traumatic stress disorder. I had 2 introductory sessions and then pandemic started. I was rung and put under HUGE pressure to accept that this help could not carry on despite being told that my mental health had deteriorated due to the pandemic and I could not be in a more stressful situation. It was made clear that I had no choice but to accept that due to the pandemic the help that had been prescribed for me could not go ahead. A letter was then sent to me informing me that I had voluntarily given up this treatment due to the pandemic. Absolutely not true. I accept totally that with covid, other priorities had to come first but a postponement of my treatment and some follow up to check that I was doing ok would have been more caring, rather than total abandonment."

We heard that people were also worried that the pandemic would create long waits for treatment:

“...There was a six month waiting list for any NHS counselling, three and a half months for a referral to the Community Mental Health Team... still waiting more than 6 months for Eye Movement Desensitisation Reprocessing (EMDR)... she has recently been informed it may be another year before EMDR treatment will be available.”

“No appropriate resources available in a timely manner.”



“Have been waiting 18 months for EMDR from the Hywel Dda Community Mental Health Team. The pandemic has not helped with the waiting time.”

“Extremely long waiting time when I have been very very low.”

Others were worried about the impact of their mental health on their day-to-day work, recognising that the employment situation was possibly more precarious because of the pandemic:

“I have developed some severe mental health problems and issues with my memory, I need to know if there is a reason for this as it is affecting my job...”



People told us they knew what helped them, they had ideas about the services that could have helped them and the things that didn't:

“When I went for help, they suggested I used the box breathing method to help me. Covid is everywhere and this [is] all they could offer me.”

“...directory of available self-referral services”

“More resources and a clear pathway...”

“GPs need to keep their end of the bargain by phoning back when promising”

“It was good seeing someone weekly, and when lockdown restrictions were lifted and was able to leave the house, to have support.”

We heard about frustration that people felt when they were having to make numerous phone calls to chase things up for themselves. Long waiting times for call-backs were unhelpful. It meant that people sometimes ended up going to A&E departments in desperation or trying to seek help privately.

People did not feel that communication was as good as it should have been and this needed to improve so people could be clearer about what was happening and when things were going to happen for them

Others told us that they sometimes heard that they had been discharged from mental health care without any prior discussions. In particular, when the first lockdown happened, families felt that they had to cope without having any real support available to them.

Carers and family members in particular have found the lockdown, closure of many face-to-face services and isolation very difficult. Due to their caring role it has been very hard for them to access support services. They have often reported trying to cope on their own without any mental health services support, and that their own mental health has suffered as a result.

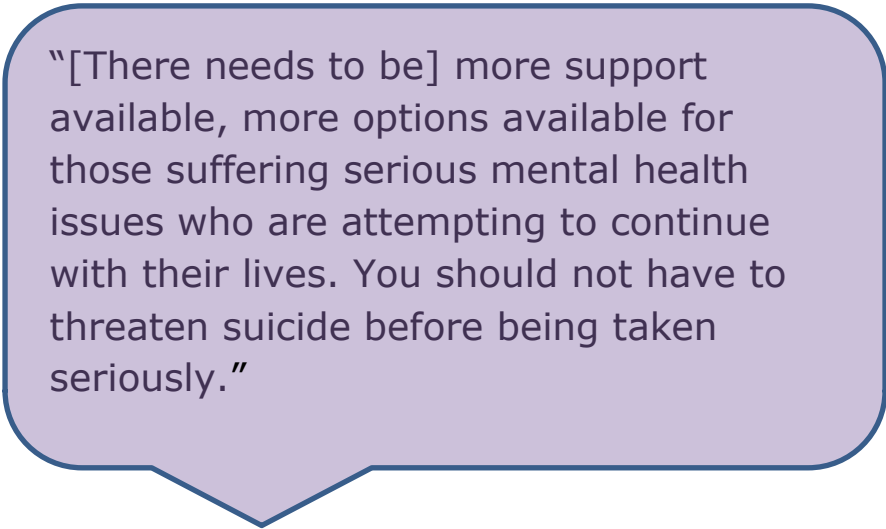
Some family members have reported high levels of distress and anxiety because they have not been able to visit their loved ones on the wards. In some cases, there has been little help to support communication and contact with in-patients.



Although our survey was not specifically aimed at children and young people, we heard from parents who were not sure what would happen in terms of support when their children had to move into adult services during the pandemic. This meant that they were not prepared for what might happen next.

In the WWAMH networks and forums, concerns have been expressed regarding the increase in mental health difficulties in children and young people. Additionally, for many there has been and a struggle to access specialist help for young people. We have heard more about an increase in eating problems and difficulties as well as self-harm. We have heard that people find that there is limited local support available for these (even prior to Covid 19).

We also heard that people often felt that they had to become seriously unwell before they could get help:



"[There needs to be] more support available, more options available for those suffering serious mental health issues who are attempting to continue with their lives. You should not have to threaten suicide before being taken seriously."

Learning from what we heard

Hywel Dda CHC and West Wales Action for Mental Health found that they heard very similar experiences across the 3 counties during the pandemic. We recommend that Hywel Dda Health Board considers the following key areas for action:

1. The Health Board needs to find effective ways of keeping people updated about mental health services and use a range of communication methods to do this.

Prolonged gaps in communication soon become weeks of silence. This is really unhelpful when people are struggling with their mental health. Just keeping in contact with people even just to confirm they are still on the waiting list and to check how they are is crucial and respectful.

2. The Health Board should regularly review waiting lists to identify whether options can be given to people when they need input and support.

This may be by offering befriending/mentoring support while people on the waiting list, sending them info on other activities and support that may be helpful. Keeping up to date waiting lists and current information.

3. Whilst people may not be able to have face-to-face support or therapy, some people may feel that phone calls are helpful in the interim and these may need to be part of an active offer by the Health Board

Some people may now prefer phone or video appointments and therapy. This might not be suitable for everyone but could make a big difference to others.

4. The Health Board needs to have clear ways of discussing discharge arrangements with people so that they do not feel decisions have been made without them having their views heard.

This may also mean finding ways to ensure that carers/families are included in this process where appropriate.

It means making sure that any discharge is planned, with aftercare arrangements in place. We all need to recognise that families may need support in helping keep their loved ones well at home. Support should be responsive and easily available. Families/carers need access to information and to be included in care and support planning.

5. Many people have expressed a need for easy and quick to access direct mental health support for all ages.

The Health Board needs to consider ways of providing responsive mental health triage/assessment, direct information and support, talking therapies and therapeutic social, arts/creative and skills based activities. There is also a need to have easy access to financial and welfare rights help and support. Some people have reported it has been very hard to access this and get hold of services on the telephone. There is also a demand for family support.

Conclusion

Our mental health services had to change suddenly to keep people safe during the pandemic. People's mental health did not stay still during this time. The need for care and input, often urgent care was still needed but less readily available.

We also know that the pandemic and lockdown have also affected people's mental health and there will be more people needing support in the future. Hywel Dda CHC and WWAMH will continue to monitor these services and always want to hear from people using these services.

What next...?

We want our findings to be seen and we want them to act as a starting point for making improvements for people. Our report will be shared with Hywel Dda University Health Board so that they can understand the challenges that this situation has on members of the public.

Thanks

We thank everyone who has taken the time to share their views and experiences with us about their health and care services during the pandemic. Your views and stories have been invaluable in helping us explain to NHS organisations and Welsh Government, what it has felt like for people during the pandemic when they have a health issue.

Please continue to share with us your stories and experiences of NHS services. The link to our general survey is below. You can click this if you are reading our report on-line or you can copy the link and paste it into your browser

Link to survey: <http://ow.ly/ezsy50ER6ZG>

MANAGEMENT RESPONSE

Report Title: CHC We asked about mental health in Hywel Dda and you told us....

Completion date: 31st March 2022

Report Reference: N/A

Ref	Recommendation	Management Response	Completion Date	Responsible Officer	Progress
1.	The Health Board needs to find effective ways of keeping people updated about mental health services and use a range of communication methods to do this.	Keeping in contact with service users and carers throughout the pandemic has proved challenging for those currently under services and those on waiting lists. The Mental Health/Learning Disabilities (MH/LD) directorate had to adapt quickly to the lockdown conditions to provide other mechanisms to keep in contact with people and to let them know about any changes. Going forward the LMHPB will review its communication strategy and consider how to develop that to ensure wider public communication. This will be raised as an agenda item on our Local Mental Health Partnership Board (LMHPB) to ensure that the principles of co-production continue going forward.	31/03/2021	Warren Lloyd, LMHPB	LMHPB was given a pandemic response by operational services at the meeting on 4 th March 2021. It has been agreed with the chair of the LMHPB that communication and engagement with stakeholders, including service users and carers will become a standing agenda item.
2.	The Health Board should regularly review waiting lists to	In response to the pandemic, each service had a system in place to	31/08/2021	Liz Carroll,	Waiting lists are currently monitored and reviewed

	identify whether options can be given to people when they need input and support.	review waiting lists and keep in touch with people who were waiting for a service. The MH/LD has established a 'Keeping in touch' group to establish some consistency across service and ensure there is good practice around 'safety netting' those who currently sit on a waiting list.		Director of MH/LD	through the MH/LD Business Performance and Planning Group including a quarterly deep dive into each service.
3.	Whilst people may not be able to have face-to-face support or therapy, some people may feel that phone calls are helpful in the interim and these may need to be part of an active offer by the Health Board.	This will be addressed through the MH/LD 'keeping in touch group'.	31 st March 2022	Selina Marshall, Chair	'Keeping in touch' Task and Finish Group has been established, next meeting 27 th September 2021.
4.	The Health Board needs to have clear ways of discussing discharge arrangements with people so that they do not feel decisions have been made without them having their views heard.	A discharge audit will be developed by the Quality Assurance Practice Development (QAPD) team in collaboration with operational services. Complete the audit and develop improvement plan based on the results.	31st March 2022	Helen Thomas Bone, Senior Nurse QAPD	A discharge audit has been designed for inpatient units and is on the HB annual audit plan. The inpatient audit tool has been developed based on the AIMS accreditation standards, the QAPD team will work with the CTP lead and nominated operational staff to adapt for use in community MH/LD services. Results of the audit will inform the development of a service wide improvement plan

5.	Many people have expressed a need for easy and quick to access direct mental health support for all ages.	The MH/LD Directorate have been implementing a 111 Welsh Government pilot project. Trained Mental Health practitioners are embedded in the 111 service to guide and direct people to the appropriate service as required.	31 st March 2022	Kay Isaacs, Head of Service Adult Mental Health	<p>This single point of access will improve access to mental health services, this pilot will become a substantive 24hour, 7 day a week service, funded by WG. Substantive job descriptions are currently being developed to support the expansion of the service, which is currently being provided 7 days a week, Monday to Friday 6.30pm – 10.30pm, weekends 2pm until 10pm. It is expected that the 24/7 service will be implemented from December 2021 pending recruitment. There has been a rolling evaluation throughout the pilot. Ways of communicating the availability of the 111 service are currently being explored by the project team.</p> <p>The QR code for collating service user feedback is currently being developed and a question has been added asking about ease of access to service.</p>
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Contact details



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