North Wales Community Health Council

Mental Health & Learning Disability Services

Safe Space Engagement Events

Final Report

March 2021

Office contact details

Post: Unedau 1B & 1D, Parc Busnes Wilkinson, Ffordd De Clywedog, Ystad Ddiwydiannol Wrecsam, Wrecsam. LL13 9AE

Units 1B & 1D, Wilkinson Business Park, Clywedog Road South, Wrexham Industrial Estate, Wrexham. LL13 9AE

11 Llys Castan, Ffordd y Parc, Bangor, Gwynedd. LL57 4FH

11, Chestnut Court, Parc Menai, Bangor, Gwynedd. LL57 4FH

Telephone: 01248 679 284 or 01978 356178

E-mail: Admin2@wales.nhs.uk
Website: https://gogleddcymrucic.gig.cymru/

Social Media:

Contents

Background Information	**Page 4**
Methodology	**Page 5**
Structure of the Events	**Page 6**
Summary Report – *Crisis, Kindness & Promises*	**Page 7**
One Simple Thing	**Page 18**
What people told us – transcripts of comments	**Page 23**
Acknowledgements	**Page 49**
Powerpoint presentation explaining “Safe Space” approach	**Page 50**

Introduction

This report has been produced by North Wales Community Health Council (North Wales CHC)

North Wales CHC is the independent watchdog for NHS services in North Wales and we seek to encourage and enable members of the public to be actively involved in decisions affecting the design, development and delivery of healthcare for their families and local communities.

North Wales CHC works with the local NHS, as well as inspection and regulatory bodies, to provide the crucial link between those who plan and deliver the National Health Service in North Wales, those who inspect and regulate it, and those who use it.

North Wales CHC maintains a continuous dialogue with the public through a wide range of community networks, direct contact with patients, families and carers through our enquiries service, complaints advocacy service, visiting and wider engagement activities and through public and patient surveys.

North Wales CHC represents the "*patient and public voice*" within the geographical area covered by Betsi Cadwaladr University Health Board (BCUHB).

Background Information

North Wales CHC has well publicised and longstanding concerns about mental health care in North Wales. The quality of mental health care in North Wales became an issue of national concern with the revelations about Tawel Fan and the subsequent Ockenden and HASCAS reports highlighted serious and fundamental failings. More recently, the inappropriate discharge of all patients receiving community based mental health care at the start of the Coronavirus pandemic highlighted the necessity for a better understanding of the needs of patients.

Betsi Cadwaladr UHB have been developing a delivery plan for the latest stage of "Together for Mental Health" (*a Welsh Government strategy*), the plan will cover the following key areas identified by Welsh Government;

- improving access to mental health support for children and young people
- further improvements to crisis and out-of-hours provision
- improving the access and range of psychological therapies
- supporting vulnerable groups

There has been a great deal of effort and attention focussed on the events at Tawel Fan. Rightly so, there are lessons to be learned and not forgotten.

Moving forward, North Wales CHC believes it is now time that the opinions of ***current*** service users, patients, carers and the public are sought in order for the BCUHB to prepare a delivery plan for the modernisation of mental health and learning disability services. Our Safe Space events are intended as a scoping exercise to make wider engagement by Betsi Cadwaladr UHB as effective and inclusive as possible.

Methodology

NWCHC has extensive experience of undertaking public engagement and formal consultation exercises across North Wales. Our experience has enabled us to develop wide-ranging networks across the region and to build upon our resources and tools for undertaking public engagement.

Since March 2020 and in light of COVID-19 restrictions, the NWCHC has acquired the technology and skills to undertake virtual meetings.

Initially the CHC held a minimum of six virtual events with each event focusing on broad themes of mental health services in North Wales:

- Community Mental Health
- Older Persons Mental Health
- Substance Misuse Services
- Learning Disabilities
- Adults with Functional Mental Health Problems & Adult Psychiatric Services
- CAMHS & the transition to Adult Mental Health Services

More events were added to the list, including;

- LGBTQ+ Service User experience
- Covid and Mental Health Care
- Mental Health Services in Agriculture/Rural Communities

At the start of each session we asked people about their experiences during the pandemic. It is clear that Covid has had a huge impact on service delivery and on patients themselves.

This report contains all recorded comments so far and attempts to identify themes, trends and learning issues.

Structure of the Events

Introduction from NWCHC, outlining the nature and purpose of the events – this includes details of the ways in which information shared would be used; the importance of confidentiality within the events; that information would need to be shared in the event that evidence of serious harm or potential criminal wrong doing came to light.

Discussions are based around the '7 C's';

***C**ompliments, **C**omments, **C**oncerns and **C**omplaints; **C**are planning and **C**are delivery; **C**ommunication and engagement.*

It was envisaged that some people might not want to be part of any group discussion and might wish to talk on a one-to-one basis. All participants were informed that this could be arranged.

Participants were also asked, at the start of the session, to imagine they have a magic wand that would allow them to change "One Simple Thing" about mental health services in North Wales.

Although each session was themed, discussion often covered every aspect of mental health services because people usually perceive their care journey as a continuum rather than in "boxes".

Timetable of Events

Topic	**Date**	**№ of Participants**	**№ of Sessions**
Community Mental Health Care	10/12/2020	18	2
Adults Psychiatric Inpatient Services	14/01/2021	16	2
Older Persons Mental Health Services	01/02/2021	16	2
Child & Adolescent Mental Health Service	04/02/2021	18	2
Learning Disabilities	08/02/2021	12	2
Substance misuse	11/02/2021	7	2
LGBTQ$^+$	22/02/2021	7	2
COVID-19 and Mental Health	22/02/2021	11	1
Agriculture & Rural Communities & Mental Health	24/02/2021	8	1

Summary Report
Crisis, Kindness & Promises

"*I used mental health services a lot during the pandemic, it's been a nightmare. I haven't had the best experience, and having to do everything over the phone when in a crisis. I asked for a call-back when in crisis, and received a call-back two weeks later. There was no point calling me back two weeks later, by then I had sorted myself out with support from friends*".

"Was treated at the Ablett Unit a few years ago. Did not have a good experience at all. The environment was cold and hostile and there was no privacy, it felt brutal".

Crisis Care

In all of the sessions, access to crisis services was regarded as problematical, the discharge of large numbers of patients early in the pandemic was referenced many times;

- *Everything stopped when Covid started, CAMHS just shut down. Everyone received a letter saying 'your therapy has ceased'. The amount of referrals we received at the College for counselling were high, which was a heavy weight on us.*

People spoke of the difficulty of accessing crisis services and the feeling of being "fobbed off".

"When people have had a bad experience on top of another bad experience, they get fed-up. I spent four hours in A&E with my husband in crisis and then I got sent home. You get to the point of exhaustion".

Amongst those we spoke to there was a perception that barriers had been set up to restrict access to crisis care;

- *Where do people in crisis go to access help? Pre-pandemic people used to go through A&E. How do they now access services? There should be a telephone number in everyone's care plan (if they have one)*
- *A few months ago I went to the ED at Ysbyty Gwynedd and was sent home. When I went to ED I was relatively in control, but I was told I was wasting their time and then 24 hours later I had to go back to ED as an emergency. I wasn't offered to speak to anyone at the hospital.*

Use of telephony and accessing staff by telephone was raised as a problem across all aspects of the service;

- *When the pandemic started, all contact went to telephone contact only. I received help once a week. I felt isolated at home.*
- *I received a daily phone call. My Care-Coordinator was amazing. If I was struggling, the contact was increased.*
- *Communication is poor. Not able to contact your caseworker or social worker. Nant y Glyn unit – could never get through to anyone on the telephone.*

"Some of the Mental Health Teams won't even give us a direct number or mobile number to call if needed. We have suggested they do text reminders, but they are unable to do that apparently"

We spoke to many service users who would greatly prefer video calling. They told us this was now standard for GP consultations and they did not understand why it couldn't be done for MH&LD patients. Patients with autism felt that it was extremely difficult to do anything other than video calls as they needed to see the facial expressions of the caller.

- *On the phone, you miss a lot when you can't see someone's face, especially when you are struggling. It would be a fantastic idea to have Zoom contact.*
- *Some Support Workers do deliver sessions over Zoom.*
- *Communication is so poor. No "one for all" solution is good for everyone, maybe a mix of phone calls and Zoom.*
- *I was seeing a psychiatrist every 6 months but was discharged just as my depression changed. I receive telephone communication with the Community Psychiatric Team, but I struggle to deal with telephone calls. During a suicidal phase, I cut myself off social media and from phone calls, so a telephone helpline is of no use. Zoom would be good, seeing the person is important.*

Many reported being told that they would receive a call from their NHS professional by a certain date, only to never be called at all. Universally people understood the pressure in the service and would rather have realistic date for a call back than an over-optimistic promise that couldn't be delivered. ***It was felt that failure to call back when promised undermined trust.***

LGBTQ+

We spoke to young people and third sector colleagues dealing with young people. Many felt that NHS mental health services were out of touch and displayed some out-dated views;

- *Being LGBTQ+ is an issue with a particular age range in staff, some think it's your problem or an illness. I was told they couldn't assess me (because of sexuality) and I felt irrelevant, and it made the situation worse. I ended up back at hospital in a worse state. I felt discriminated and offended.*
- *Discrimination needs to be eradicated across the board, and all staff should undertake at least some basic training.*
- *All staff working in MH should be aware of the different types of LGBTQ+, there needs to be a bit more understanding.*
- *BCUHB - great that they've got the Stonewall award, but that's more for Staff.*
- *There is very little promotion to encourage LGTBQ+ to talk. There is very little acknowledgement of LGBTQ+ community even in the sexual health clinic.*

In our (LGBTQ+) support group, Mental Health is the biggest issue we speak about. Health Workers need to understand individual needs.

Consistency of Care

People found it difficult to deal with constant changes in the staff they deal with. Lockdown has exacerbated this problem. There was frustration with repeating their story again and again and many felt it added to their distress to constantly repeat distressing experiences.

Re-telling your story isn't great, you don't want to be telling your story again over and over.

- *I was discharged at the beginning of first lockdown – received a phone call from CPN saying was discharged and was given a leaflet. Since the services resumed, have received 10 minutes telephone calls by unknown members of staff. I have been given a new CPN, and have had to re-tell my story. Been discharged again last week as I have been offered counselling from my employer.*
- *We have now been bounced back from CAMHS to a Neuro-developmental Team. I'm never clear who I'm speaking to and I have to answer the same questions again and again.*

Transition from Child & Adolescent Mental Health Services (CAMHS) to Adult Psychiatric Services

The CAHMS service ends at 18 and many patients will go on to access Adult Psychiatric Services at some level. We were informed that, long before a patient's 18th birthday, CAHMS starts to withdraw, usually at 17years old. The transition is by no means seamless and the difference in culture between the two services is distressing to many.

We heard that young people who were long-term patients of CAMHS had a very patient-centred service that some described as "handholding". At 18 they would be expected to manage appointments, phone calls and every other aspect of their care.

Our son had been under CAMHS for a number of years and discharged at 18 years of age. He deteriorated and, as a family, we had nowhere to turn to. GP would not discuss his problem as he was 18 years old and would need to visit the GP himself. He slipped between the net. Sadly he committed suicide. The only place as a parent I could turn to was the GP and they were unable to help.

- *There's a huge gap between the services and there's no transition*
- *Patients are falling between CAMHS and adult services, there is no smooth transition.*
- *Those who have had CAMHS support through their lives, still need the support even after they have turned 18yrs old.*
- *There needs to be a young persons/ CAMHS/ adult mental health service (from 18yrs – 25yrs old).*

Participants reported poor administrative links between CAHMS and Adult Psychiatric services;

- *19 year old discharged from CAMHS at 17 years old, assumed his records would automatically go over to the Adult Mental Health Service and they would contact us. He hit crisis during Covid and had to go through referral system from the beginning. They had no record of his notes, it was as if he had never been in the system.*

Parents told us that there is a lack of consistency in relation to assessments between divisions with completely different services in, say, Wrexham and Flintshire.

- *Trying to arrange a neuro developmental assessment for a10 year old who is currently under the CAMHS system for the past 7 years.*
- *Parents are paying privately for a diagnosis as they cannot wait for CAMHS any longer.*
- *CAMHS in Wrexham do not acknowledge all conditions (they do in Flintshire), it's a postcode lottery*
- *I'm a mother of a child in the mental health system. The child has been assessed by a Paediatrician twice, and we took the diagnosis of Oppositional Defiance Disorder to*

CAMHS (Wrexham). We were told that this is not done on CAMHS. It took nearly a year to get a foot in the door, with people asking us lots of questions but not giving us any answers.

Parents felt that there was tendency to attribute lack of progress in treatment to poor parenting skills and that they were disbelieved when reporting behavioural issues;

- *A large number of children with neuro developmental problems often have parents who have mental health diagnosis as well. It is really difficult for these parents to make contact to get help for their children. Knowing where to go and knowing there is help available would be a lot of help.*
- *If parents disclose they have a mental health diagnosis when trying to access help for their children, they are often discriminated against*
- *CAMHS will often refer parents to parenting courses (when there is no progress). If I don't go on the parenting course, I am seen as not engaging.*
- *Parents have been accused of fabricating illnesses.*
- *My 10 year old been saying he does not want to be alive since the age of 5, CAMHS suggest he cannot be serious. I cannot and will not take the risk with my child's life, I will always take it seriously.*
- *Wrexham area there is a lot of discontent re CAMHS and a number of parents ready to come forward with complaints. The relationship between the service and parents has broken down.*

Adult Psychiatric in-Patient Services

Women who had been in-patients expressed concerns about safety;

- *When I used to work for another organisation, I visited mental health units regularly. During one visit to the Ablett unit, there was a woman who was sleeping on a couch, she had a history of abuse and trauma, and had asked to be around females only, had men wandering in and out of her room. This was raised with the staff, and was told that it was fine.*
- *If people ask to be admitted to a same sex ward, it doesn't always happen as there are some areas that are open to all.*
- *Some patients prefer having an integrated mix of male and female patients on the ward.*
- *Mixing genders is normal but there needs to be a safe-space for single sex.*

Staffing levels and continuity of staff was a seen as a key issue;

- *There is a lack of continuity of staffing especially whilst being rehabilitated in the community. Patients are not seeing the same staff, and they cannot therefore build a rapport with staff – there's no sense of continuity.*
- *There is a lack of staff, beds and provision.*

Planned changes to psychiatric intensive care units (PICU) had some people worried;

- *Psychiatric Intensive Care services – people need to be as close to their home as possible.*
- *If there is only one PICU in North Wales, it would mean that people need to travel to the unit. If an inpatient needs to access the PICU, it would mean taking two members of staff from the ward to take the patient to the unit. Staffing levels are already poor, and this would cause staffing issues, especially if it was during the night-time shifts.*
- *It would also be onerous for police if someone needs to access the unit from North West Wales, and having to be taken to the unit at Wrexham*

Those who had been in-patients felt that exercise should be an important part of their care;

- *For some reason they've stopped letting patients use the garden area at the Ablett. When I was in there, going to the garden areas was a huge help.*
- *Activity – there's no budget for activity, and providing activity could occupy patients, which would free-up the staff to catch-up on their other work. Some units raise money themselves for the activity budget.*
- *The value of exercise for people with mental health issues is hugely important.*
- *Why don't BCUHB use university students who are studying sport science to give them experience? This is the approach used in the third sector.*
- *The new build needs to be mindful of the need to exercise and rehabilitate. There needs to be plenty of outside space. There is no air-conditioning in the Heddfan unit, in the summer it is boiling hot, and in the winter it's cold.*

There was disappointment that the Ablett Unit replacement would be delayed due to planning issues;

- *Lessons should be learnt from the older units, when planning for the rebuild of the Ablett unit. BCUHB need to involve service users in the rebuild of Ablett.*
- *It's disappointing that the planning application for the Ablett was turned down, and it is extremely disappointing that the project has been delayed.*

Older Persons Mental Health Services

Loneliness and isolation was a key theme. Many people were worried about lack of IT skills and equipment as video conferencing becomes the norm.

People were worried about vulnerable older patients being cared for in inappropriate environments;

- *A number of older patients with severe episodes of dementia/ delirium are admitted to psychiatric units – are these appropriate places for them to be?*
- *I attended the Ablett unit once as a CHC member and reported my concerns to the CHC (how patients were sleeping in recreation rooms). Within two days, the CHC visited the site and the issue was sorted out.*
- *MH is a vast area and Covid had forced the BCUHB to shift Dementia and Alzheimer's patients to Wrexham, but that was a mistake as staff there were not trained to deal with those patients.*
- *A friend in her 80s had a severe MH episode a few years ago, and was admitted to Hergest. It was an inappropriate place for her to go to. She recently had another episode and again admitted to Hergest. She was then transferred to the Ablett. Her husband is also in his 80s and relies heavily on relatives and neighbours to help with meals, which has been difficult during the pandemic. The family have not been able to visit her or speak to her in Ablett. Not sure whether it's a MH issue or whether she has Dementia, however, Hergest and Ablett are inappropriate settings for patients like her.*

It is important to distinguish the difference between MH and dementia. Both need different care and shouldn't be classed together.

Learning Disabilities

Overall, feedback on Learning Disabilities Services was positive and some contrasted this with other services in the mental health directorate.

- *The Learning Disabilities nursing team in Conwy have stepped up during the Covid pandemic to support people, even face to face.*
- *As far as I know, patients with Learning Disabilities (LD) didn't get discharged like the MH patients early on during the pandemic.*
- *Clients with LD were risk assessed, so that support was focussed where it was needed.*
- *In North Wales, the relationship between the Health Board and the Local Authority is the best in Wales, it's very strong. It is the most developed partnership arrangement, and the partnership boards function well. There seems to be a commitment on both sides, which isn't the case in the rest of Wales.*
- *When Health Boards try to deliver LD as same model as MH provision, it doesn't work.*
- *Partnership with the Local Authority is important, but you don't see it with adults MH. In LD it's seen as shared partnerships, which is a testament of the confidence of LD health staff and the partnership board to continue with it.*

There were some notes of caution;

- *Finding placements for individuals with complex needs is a challenge, and these usually need to be new builds, so finding land is also a challenge.*
- *When you have clients who rely on you and need your support, but then the short term funding comes to an end, it's so difficult for us and our clients. There are cuts to budgets at local authorities, but we can't stop what we're already doing.*

There were also concerns about the experiences of people with Learning Disabilities in District General Hospital care and training was seen as the answer to this issue – in the same way it has been for dementia patients;

- *I have had staff saying to my daughter "how do you expect us to treat you, if you don't co-operate" or "if you don't co-operate, we'll call security". The attitudes of general hospital staff towards patients with LD needs to change.*
- *How do we help non-LD practitioners know how to deal with patients with medical and LD needs? Training and education for non-LD general staff at hospitals should be mandatory.*
- *Good practice at Ysbyty Maelor – a communication book is used, which is brilliant. It indicated people's preferences. There is also a 'passport' used there. Some staff however don't focus in on preferences, so it needs to continually be highlighted. The framework is there, it just needs staff to be reminded of how important it is to support patients with LD in hospitals.*

Substance Misuse

This session was not well attended and we intend to revisit the subject. We did, however, have some important contributions on alcohol misuse. The link between alcohol and domestic abuse was highlighted;

- *Drinking is so easy at the moment, I need encouragement, more help and support and we need more counsellors.*
- *A lot of people are on their own, and we have noticed an increase in self-referrals. Males and females are having issues with alcohol. Being at home with their children all day, parents start drinking more.*
- *Some people have no access to services due to language barriers if Polish or Portuguese for example.*
- *Shoppers are buying a lot more alcohol than they used to, it's a coping strategy.*
- *Obesity, substance misuse and mental health will be a huge problem for society post-Covid.*
- *Drinking is a coping strategy for victims of domestic abuse, if they can't cope with the abuse.*
- *Bereavement, grief, home-schooling, furlough – people can't cope and turn to drink or drugs.*
- *Some GPs, due to either lack of training or lack of tolerance may feel that their time is being wasted by some people with substance misuse issues.*
- *Long term support is needed and a response to a crisis. Early intervention is needed across the board.*

Covid-19 and Mental Health

The consistent theme was that 3rd Sector organisations were picking up much of the load because people had been told to minimise contact with ED and GPs;

- Pe*ople were discharged from the MH team without having been assessed, which has caused major distress. The third sector organisations have been left to pick up the pieces.*
- *Third sector are seeing a lot more people over the past year that have complex needs as there is no one else available to help them.*
- *Third sector orgs transferred their services to online/ telephone when the lockdown started, they are the ones who actually care for the people through all of this.*
- *Mind Conwy had a number of people who were discharged from the MH service contact them for help. Communication is poor – appointments not being kept and patients not informed, when patients telephone the service there have been instances where the receptionists are rude, been put on hold for a long time, not being taken seriously. It has made people feel they would rather struggle on their own than having to find support.*
- *There is a lack of humanity in the service. Services are only interested in gatekeeping.*
- *Mind Conwy are receiving constant inappropriate referrals from CMHT. The referrals are so vague. It is really disheartening. Have tried to engage with the CMHT regarding the inappropriate referrals or about a concern regarding a patient, they don't want to engage, and will not put anything down in writing.*

- *There have been occasions that when contacting the Duty Officer you are told to call the police, who tells you to call 999 for an ambulance. But there is no medical need. People need help early to prevent them from becoming worse and needing secondary care.*
- *I have taken adults over to the CMHT twice and been told no one could see them. Taken them to A+E and they enter psychosis on a trolley, staff could not handle them. Very distressing for patients. The CMHT are hoping the police will attend to these people and 136 them, it's lazy.*
- *There is a lack of humanity in the service. Services are only interested in gatekeeping.*

This session also elicited concerns about abuse related to lockdown, family stress and alcohol abuse.

Agriculture, Rural Communities and Mental Health

The CHC ran this additional session because we heard from people in the agricultural industry who felt that they were even more isolated than usual.

- *It's been a difficult time for the farming community – stressful and lonely.*
- *80% of calls to FCN (Farming Community Network) helpline are because of stress. There is a need for 'out of office hours' support for the agriculture community i.e. evening and weekends.*
- *Access to services is wrong. People are told to go to their GP – but those agriculture workers won't go to their GP with anything. Outreach work has now stopped because of Covid, but it's the only way to reach the farming community.*
- *Farmers work all hours, so there needs to be a service available 24 hours a day.*
- *Those working in Farming need help 24 hours – crisis can be middle of the night for some.*
- *NHS professionals need to learn about how different the farming community is*
- *It is not a big ask to ask health professionals to have more awareness of how different the agriculture sector is. There needs to be training.*
- *The cancellation of agriculture shows will have a huge impact, farmers have lost the social interaction.*
- *For 3rd sector organisations agriculture shows were vital. People would call by the stand for a chat, and would feel easier about asking for help informally face to face.*
- *Financial stress on farmers, but it is not the biggest cause of mental health. One of the biggest is the lack of control over much of the work (being reliant on market prices, Brexit, weather)*

Sensory Issues & Communication

Representatives of the deaf community felt strongly that the needs deaf people were not considered in almost every aspect of mental health care. There was a call for Health Boards to accept that there is a need for a specialist deaf mental health care service, which will need specialist trained staff to work with deaf people.

- *People who are deaf with MH issues – they face many barriers*

- *Are there any specialist trained staff within CAMHS to treat deaf children. When you learn BSL, you learn about the culture and the barriers.*

The Third Sector

People valued the services they received from the Third Sector. However, the Third Sector professionals who attended the sessions where concerned about people being referred inappropriately.

"The Third Sector should be the icing on the cake, not the cake itself."

- *Acknowledge what the Third Sector do*
- *People were discharged from the MH team without having been assessed, which has caused major distress. The Third Sector organisations have been left to pick up the pieces.*
- *Third sector are seeing a lot more people over the past year that have complex needs as there is no one else available to help them.*
- *Mental Health services need to have better alliances with Third Sector organisations.*
- *Mental Health services should be provided, without having to lean on charities to fill in gaps.*
- *There is a huge over-reliance on the Third Sector to cover the gaps.*
- *The Voluntary sector has a really important role and the health service needs to work with them.*

It was suggested that the NHS should have longer term service level agreements or contracts with appropriate Third Sector organisations in order to develop robust and consistent services;

- *Third sector organisations are used for referral. There is a need for them to be contracted with officially.*
- *There are a few projects going on, but they are short term due to funding issues. It's a challenge. It took three years to get supported living set-up for a group of individuals. Finding placements for individual with complex needs is a challenge.*
- *When you have clients who rely on you and need your support, but then the short term funding comes to an end, it's so difficult for us and our clients. There are cuts to budgets at local authorities, but we can't stop what we're already doing.*

One Simple Thing

At the start of each session participants were asked, to imagine they had a magic wand that would allow them to change "***One Simple Thing***" about mental health services in North Wales. At the end we asked them to tell us what it was. Many of the answers were about kindness, respect and empathy. Many, also, wanted better co-ordination between NHS & Social Services professionals.

Community Mental Health Care

- Have extra professional staff working there.
- Consistency.
- Stable services at community level that are not subject to annual funding review.
- Would like to see better education i.e. an holistic family therapy approach to understand what's happening and why. This should be done in an appropriate child level, kids are worried about their mother or father when they go through something like this. Is there anyone that can explain what's happening – the whole family is affected.
- Advocacy activity is needed desperately, so that people have someone behind them to help them.
- A shift to and a focus on outcomes would be good, with regular checks to see if anything is making a difference.
- More co-working and communication between voluntary organisations and the NHS.
- Waiting times – they are too long. Someone in crisis can wait for up to a year before seeing someone, this is too long.
- Trauma – they need to ask why a person is in crisis instead of ignoring the background. People are complex and have many different needs, do not turn people away from the service. Treat the person not the diagnosis.
- Teach people coping strategies, listening is important.
- Need to break the stigma around mental health diagnosis. Need to get more information out across North Wales.
- NHS need to be providing the clinical care and then support needs to come from peers and other service users

Adult Psychiatric In-Patent Services

- For staff to treat each patient individually and not all the same.
- Treat the illness. No consistency.
- Improve access to mental health care. Where do people go when at crisis? There is no crisis intervention.
- Culture change is needed i.e. attitudes of staff
- Treat individuals with compassion.
- Individualised person centred support.
- Person centred support at acute wards.
- A total revamp and modernisation of the mental health services with fresh ideas and input.
- Day release / day care services integrated with the GPs.
- People need to learn lessons from the past.
- More support in the community. There is a huge gap between community and inpatient care.

Older Persons Mental Health Services

- Have a clear and simple process of how to access MH services;
- Make it about choice not about symptoms. Give people the choice and the help needed from professionals to reach where they want to be.
- The element of control and choice, with the individual at the centre of everything.
- Make accessing services easier. Phones are an issue for some people.
- It's about control and what the client wants. Help them to manage those choices to give them purpose.
- Invest into research of the brain. Organs in the body can repair or adapt. Dementia kills cells, how is research in this field progressing? We will then hopefully find a cure.
- Attitudes need to change. There is a lack of understanding, empathy and compassion.
- There needs to be a grief service after a trauma and this will also be needed after Covid.

Child & Adolescent Mental Health Services

- Mental health services for deaf children
- Smoother transition between CAMHS and Adult MH services (*hand holding service*)
- Advocacy for young people – have a service for those using Mental Health services, especially during the transition stage
- Remove the stigma around CAMHS
- Need more public involvement (friends group)
- Not having a closed door when looking for help
- To be taken seriously
- Support

Learning Disabilities

- General nursing staff need training re LD.
- Work with families and carers, and listen to the families.
- Communication is an absolute, and that it is tailored to the individual's needs.
- To ensure that the person with LD is at the centre of what's going on.
- Support people to access mainstream services.
- Flag or put a note on caller's address that they have LD for staff to know.
- Covid-19 has had an impact on those living in supported-living accommodation. They have been deprived of liberty.
- There is a need to keep the family connected. Making sure everyone knows what is happening.
- Families are feeling powerless to support their child / dependant
- Messages that are reported in the media / on social media can have an impact on the learning disabilities community, adding to their anxiety.
- Most interaction with staff have been over video calls. This can be difficult for someone with learning disabilities, families need to be involved.
- There should be a more person led approach. People need to be given a choice what method of communication they would prefer.
- Vaccine - dependant on what list parents / carers are, it could be months before it is safe to see those living in supported accommodation.
- Access to general hospital services – because of the current climate if a learning disabilities person would need to be admitted to hospital on their own, not sure, how they would cope with that. Very concerning.
- Volunteering – offered to volunteer over Christmas and go round to talk to patients at hospital and keep them company. Was told that the volunteers stopped over Christmas, which seemed unwise.
- Hospital wards are very busy places, volunteers are important to support patients.
- Staff in general hospital settings have very little understanding of learning disabilities needs. More training for staff is needed.
- Important as well to be prepared, have something written down to give to staff.
- Transition from Children services to Adult services is of concern. Instances of poor record keeping, information not transferred at the right time. No one wants to take responsibility.
- Continuing Health Care Funding is also a problem when transferring from Children to Adult services.
- Communication training for staff is needed – families and patients need to be listened to.
- Third sector organisations are used as referral. There is a need for them to be contracted with officially.
- Having a point of contact on wards that families can contact would be good.
- Llandudno Hospital dementia friendly work – could the health board look at this from a learning disabilities perspective. There are charities linked to BCUHB that have money.
- Is there a Learning Disabilities champion in the health board?
- Do not have an issue with the quality of care given, and the consistency of staff have been great.

- There needs to be better integration of services. Integrated care team have not delivered on what they promised to do.
- Concern that children with hearing difficulties are being diagnosed as having learning disabilities. There needs to be specialist training of mental health staff to recognise the signs of hearing difficulties.
- Need for schools to work closer within multi-disciplinary teams
- Parents need to have the support right at the beginning.
- Deaf organisations would welcome the chance to volunteer on wards.
- Look at the decision making tool
- Better transition between Children and Adult services
- Joint working with schools
- BSL to be rolled out to staff as soon as possible.

Substance Misuse

- The harm reduction team are trying to ensure safe use of injections, and have rearranged their outreach by visiting addressed rather than using a bus for people to attend. By visiting addresses they've been able to liaise better with the housing department and other public services, which is now a more wrap around service.
- Drinking is so easy at the moment, I need encouragement, more help and support and we need more counsellors.
- What could we do together to support clients, and help signpost to different services to improve their lives?
- Long term support is needed and a response to a crisis. Early intervention is needed across the board.
- BCUHB has an obligation to provide interpreters for any medical appointment. They need to reach out to those communities (such as Polish and Portuguese), they are vulnerable.
- Outreach is vital and Welsh speaking staff particularly in the field of Mental Health, for people to communicate when distressed or unwell. It's difficult for people to express themselves in a second language. BCUHB needs to make the effort.

LGBTQ^{+}

- Education – staff need to have basic training to give everyone a fair and equal chance and support.
- Accessibility – for people to know where they can go when they need support. Clear pathways.
- A bridging system between CAMHS and CMHT, and keep a good momentum going from CAMHS.
- GP surgery having something/ somewhere where (trans) people can go and say what they need without worrying about feeling uncomfortable.
- Keep in regular contact with young people, even if it's just a phone call.
- Flexibility and understanding, regardless of personal views.

Covid-19 & Mental Health

- Kindness and empathy
- To remember carers matter as well, not just the patient.
- Look at it as a family, take a holistic approach.
- Video conferencing appointments.
- Wellness sessions at Ty Derbyn were fantastic, need to have something similar again.
- Need to recognise they have to co-work and collaborate with social care.
- Respect and taking responsibility.
- Acknowledge what the third sector do
- To take ownership and to have continuity.
- Accessibility – to ensure that communication is in the appropriate format.

Agriculture, Rural Communities & Mental Health

- Normalise Mental Health in the agriculture sector.
- More weekend availability
- Go back to focussing on prevention
- Recognise Mental Health as an illness, don't brush it off with '*you'll get over it'* or '*you'll be fine'* and not be embarrassed about it. They just need help.

What people told us – transcripts of comments

"We want a total revamp and modernisation of the mental health services with fresh ideas and input"

Community Mental Health Services – 10th December 2020

- When the pandemic started, all contact went to telephone contact only. I received help once a week. I felt isolated at home.
- I received a daily phone call. My Care-Coordinator was amazing. If I was struggling, the contact was increased.
- One thing that went awry was my medication review. It took a long time to get anywhere with it, and there was a lot of communication between the Community Mental Health Teams and my GP. I was given an endless supply of *Diazepam*, which is addictive. It took a few weeks to get my medication sorted; there was a communication issue between my GP and the Community Mental Health Team.
- When people were discharged from the BCUHB services at the beginning of the pandemic, they did not receive any phone calls or contact from anyone.
- The support organisation CALL, is available 24/7, but information about it needs to be shared and better promoted. There is always someone at the end of the phone at CALL.
- I-CAN have done a huge amount of work with contact, similar to befriending. The GP can refer you to I-CAN, and service users can choose how often they would like to receive communication.
- During self-isolation, people receive less contact.
- There are so many organisations, people don't understand what they all do, and who they need to contact for help or if in a crisis.
- A list of numbers of different organisations by itself is no help.
- I was seeing a psychiatrist every 6 months but was discharged just as my depression changed. I receive telephone communication with the Community Psychiatric Team, but I struggle to deal with telephone calls. During a suicidal phase, I cut myself off social media and from phone calls, so a telephone helpline is of no use. Zoom would be good, seeing the person is important.
- Plas Brith, Dolgellau doesn't currently have a Psychiatrist.
- I was disappointed when I was discharged earlier in the year, the service disintegrated. *"I feel the service has disintegrated"*
- Video-calls with service users would be helpful i.e. Zoom. I could cope with it better than a phone call.
- On the phone, you miss a lot when you can't see someone's face, especially when you are struggling. It would be a fantastic idea to have Zoom contact.

- Some Support Workers do deliver sessions over Zoom.
- Communication is so poor. No "one for all" solution is good for everyone, maybe a mix of phone calls and Zoom.
- There's not enough checking on things such as medication reviews at GP level or with other professionals.
- You constantly have to ask for everything.
- There is no clear pathway or care plans. A lot of emphasis is put on carers and relatives to keep pushing for things.
- The system is failing people not the people within the system.
- It's very frustrating.
- Nobody will give you a direct telephone number or email address for you to contact.
- I had a brilliant GP who had fantastic communication with Pwll Glas, Mold. By them having such good communication, it helped me receive good mental health services.
- Areas of Community Mental Health services that need improvement is the front line. People on the phone or at the door need training in dealing with people in a crisis who need support. It is crucial.
- My husband had a good Care Co-ordinator, she saw us once in the summer and again recently. Our Care Co-ordinator is now retiring and we were given the option of my husband being discharged from the service, but we declined. There is a wait of 3-months for a new Care Co-ordinator.
- There should be a consistent service approach. We've had four different Care Co-ordinators in the past six years.
- The Mental Health Teams don't understand Asperger's. Once diagnosed, it felt as if the teams wanted to get rid of us.
- My husband enjoys talking, so when all contact was moved to telephone contact during the lock-down, that was fine and my husband was happy talking through his problems.
- Our Care Co-ordinator spent a long time getting my husband transferred to a different Psychiatrist. He needed his medication reviewed but nobody was getting anywhere.
- We were told recently that our Psychiatrist has now left, they are on rotation. We see someone different every time.
- There is a shortage of Psychiatrists generally.
- With Asperger's, Mental Health professionals say it's an educational issue, but education professionals say it's a Mental Health issue. Better communication is needed; no one will take responsibility for you.
- My husband is intelligent and amenable, the doctors don't understand that he can be a wreck one minute and then ok. It's an art of mimicking as needed.
- Care Co-ordinator said we should have received a letter from the Psychiatrist when he requested tests, we should have received a copy of the letter. We didn't. It's a communication issue, we just want to be kept in the loop about what's going on.
- Some of the Mental Health Teams won't even give us a direct number or mobile number to call if needed. We have suggested they do text reminders, but they are unable to do that apparently.
- Mental Health services need to have better alliances with third sector organisations.

- A friend of mine has no confidence in Plas Brith, so I help to support him. It would be good if another organisation could come in as a 'caring friend' as not everyone has the support from friends.
- People are lonely and their usual coping mechanisms have been lost this year due to Covid.
- I've been helping my friend, but I'm not a trained professional and I worry that I might not be doing the right thing or offering the right advice. Having a semi-professional Advocacy service would help.
- If you phone CALL, it's a Freephone number and they have a database of all the support organisations. You can ask them to look for the right support organisations to help you.
- Diagnosis is seen as negative labels, they should be seen as positive sign-posts.
- If the individuals could have the right support, they could flourish.
- Once the care and treatment plan has been done, there's no follow-ups, and it's not discussed regularly – although it should be.
- Some of the Mental Health Team are limited in how they think. There doesn't seem to be an ambition to see the person flourish. If the person is articulate and tries options to manage their condition this seems to be seen in a negative light. They don't like people trying to help themselves.
- My husband received exceptional mental health support from Bangor University whilst he was studying part time. He had great support during his course, but he needs support from Care Co-ordinators. Once they were told of the university help they suggested he could be discharged from their service. There needs to be a link between both.
- When people have had a bad experience on top of another bad experience, they get fed-up. I spent four hours in A&E with my husband in crisis and then I got sent home. You get to the point of exhaustion.
- There's no end goal or outcomes. Professionals need to listen to service users as well as their family and carers. It's all about communication.
- There are some good people working in Mental Health, but there are some that are not so good and it seems they have lost the connection with service users.
- Some service users and their carers find that accessing any of the services in the community is impossible, and that's what needs to be fixed.
- If there was more provision and more continuity, more people would be helped.
- People in different tiers need to go back to their GP for re-referrals.
- Some GP Clusters fund various services, but it varies across North Wales. Seems to be a postcode lottery.
- What do MIND and CRISIS and other organisations do? People don't know who to contact and what they do. It's even more difficult now, as many places won't let people put up posters on their walls.
- A single point of access would be good.
- I-CAN used to be based at the A&E department at Ysbyty Maelor, Ysbyty Gwynedd and Ysbyty Glan Clwyd. When people came in the A&E would call I-CAN and someone would go to the A&E and sit with the individual. Hubs are now starting to re-open and it is hoped that they will also go back to A&E after the Covid vaccines have taken place.

- There are gaps however; I-CAN is not always there – only limited hours.
- There is a concern that the Community Mental Health will be overwhelmed following the Covid pandemic.
- Mental Health services should be provided, without having to lean on Charities to fill in gaps. There is a huge over-reliance on the third sector to cover the gaps. *“The third sector should be the icing on the cake, not the cake itself.”*
- The Voluntary sector has a really important role and the health service needs to work with them.
- Service users helping other service users is brilliant when properly managed.
- A drop-in in Porthmadog kept shortening their hours. It was badly run, but they had good staff who were trying to do their best.
- There needs to be better communication between the inpatient ward and the community mental health team. Ward don’t inform the individual’s Care Co-ordinator that they have been on the ward. This would be good as continuity of care / point of contact, to make sure that you’re ok.
- There is a strange system in relation to discharge from hospital.
- Hear a lot from people who had been discharged at the beginning of the Pandemic. At a time when support was needed the most, services were not available to those who needed them.
- Access to services can be difficult for a lot of people
- Communication is poor; some were only told they had been discharged when they turned up to their appointments.
- Video conferencing – need to make more use of this, a lot of service users prefer face-to-face conversations. Some people find telephone calls quite stressful, especially when dealing with Anxiety.
- Crisis support – needs investing in, this is poor nationally. There is a lack of trained staff able to deal with people in crisis.
- Autism services was shut down completely, the communication was so poor.
- Lack of continuity – this causes more stress and anxiety to service users. Have to repeat their story several times to different workers.
- Service Providers need to listen to the voices of service users.
- Trauma – from my previous two ‘sections, I have not been asked about trauma, they don’t want to listen to the reason behind what is causing patients to suffer.
- Caniad – they are the voice of the service users on mental health services. One attendee had volunteered with Caniad and had been reprimanded for raising too many issues with the services. Also was told off for helping another service user.
- Caniad had refused to take on one NW resident as a volunteer as they had received services outside of North Wales, even though this person had previously received treatment at North Wales.
- Need to listen to those who cannot access services, the seldom heard.
- There is an 8-week waiting list for CADMHAS.
- Service users are finding it hard to access Community Mental Health Services. Assistance is too limited; all it does is push the problem further down the line.

- Hear many problems from Flintshire residents having problems accessing services.
- One attendee said that Nant y Glyn, Denbighshire is terrible.
- One attendee had gone private because the waiting time on the NHS was too long. Had received excellent service from 'Able Futures' a free government funded programme in Wales. Had a call back within 24 hours of initial contact and had been assigned a support worker within 2 weeks, and counselling sessions. No limit on number of counselling sessions allowed. 9-month programme and the support worker will be with the person throughout the journey.
- Support needed for farmers, their families and those who work within the agricultural sector. Needs to be more co-working between the NHS and voluntary sector. The clinical care must be given by the professionally trained staff, but further support can be given by volunteers, but both sides need to speak to each other, such as when a patient is discharged, need to include the volunteers supporting these service users in a 'case conference' when deciding on the future care plan.
- It was felt that GPs are using the voluntary organisations more and more rather than referring to NHS, this could be a very dangerous step. It is important to understand that the voluntary organisations are there to support and refer, and not to provide clinical treatment.
- One attendee had been referred by GP and had been assessed by the hospital. Was not put on a waiting list because employer could offer 4 counselling sessions at the work place.

Adult Psychiatric Inpatient Services – 14th January 2021

- Clients' mental health issues have increased since the beginning of the first lockdown in March 2020, and many of them had been discharged from the mental health services at BCUHB, therefore pressure on charity organisations increased.
- The lockdown increased anxiety and mental health issues.
- It takes a lot of time for organisations to help with safeguarding people suffering from depression or self-harming.
- Some charity organisations have received 50% more people seeking help, which is putting strain on the organisation and their staff, who are working hard to support people on the phone or in online groups. It's a whole system issue.
- People were saying that they didn't have any support and organisations were encouraging them to get additional support for the mental health through their GP.
- When I used to work for another organisation, I visited mental health units regularly. During one visit to the Ablett unit, there was a woman who was sleeping on a couch, she had a history of abuse and trauma, and had asked to be around females only, had men wandering in and out of her room. This was raised with the staff, and was told that it was fine.
- Bed occupancy rates are unacceptably high.
- Some patients who leave the hospital and return to the community for rehabilitation, are having to go back to the hospital and end up sleeping on chairs due to lack of beds available.

- There is a lack of continuity of staffing especially whilst being rehabilitated in the community. Patients are not seeing the same staff, and they cannot therefore build a rapport with staff – there's no sense of continuity.
- There is a lack of staff, beds and provision.
- Psychiatric Intensive Care services – people need to be as close to their home as possible.
- If there is only one PICU in North Wales, it would mean that people need to travel to the unit. If an inpatient needs to access the PICU, it would mean taking two members of staff from the ward to take the patient to the unit. Staffing levels are already poor, and this would cause staffing issues, especially if it was during the night-time shifts.
- It would also be onerous for police if someone needs to access the unit from North West Wales, and having to be taken to the unit at Wrexham.
- Mental health services vary from location to location.
- If people ask to be admitted to a same sex ward, it doesn't always happen as there are some areas that are open to all.
- Some patients prefer having an integrated mix of male and female patients on the ward.
- Mixing genders is normal but there needs to be a safe-space for single sex.
- For some reason they've stopped letting patients use the garden area at the Ablett. When I was in there, going to the garden areas was a huge help.
- If the issue was due to not having enough staff to accompany patients to the garden areas, then the people who don't need accompanying need to be able to go there.
- People need a transition before going back to the community.
- Activity – there's no budget for activity, and providing activity could occupy patients, which would free-up the staff to catch-up on their other work. Some units raise money themselves for the activity budget.
- The value of exercise for people with mental health issues is hugely important.
- Why don't BCUHB use university students who are studying sport science to give them experience? This is the approach used in the third sector.
- Lessons should be learnt from the older units, when planning for the rebuild of the Ablett unit. BCUHB need to involve service users in the rebuild of Ablett.
- The new build needs to be mindful of the need to exercise and rehabilitate. There needs to be plenty of outside space. There is no air-conditioning in the Heddfan unit, in the summer it is boiling hot, and in the winter it's cold.
- Heddfan isn't covered by CCTV in all areas. Rooms are good and there is one double room for husband/wife to stay together.
- Heddfan is fabulous, although it is a sterile and clinical environment.
- There is a lot of emphasis on exercise for older patients, and younger patients are given play co-ordinators, but the people in the middle are left to fend for themselves.
- A number of older patients with severe episodes of dementia/ delirium are admitted to psychiatric units – are these appropriate places for them to be?
- It is difficult for people to get into any mental health services, whether this be primary, CAMHS or acute support. The whole system is struggling.
- Some GPs aren't putting people forward for mental health support because they know they won't get any.
- In Flintshire, people are put forward by their GP or Social Services. 50% of people put

forward for help are not getting help.

- Readmission figures are interesting, these are available with a freedom of information request. In one unit, five patients were readmitted twenty times, and some were readmitted five times in a short period of time.
- Readmissions is a real problem.
- Some people seem to do so well in mental health units, and when they go out to the community it all goes wrong, and they end up having to go back to hospital straight away.
- There are some excellent staff.
- Patients are desperate for face to face support and not just on Zoom. Some people who don't have IT skills feel they are digitally excluded.
- Concerned that BCUHB is released from mental health special measures.
- Thanks to the CHC for listening.
- Was treated at the Ablett Unit a few years ago. Did not have a good experience at all. The environment was cold and hostile and there was no privacy, it felt brutal. Did not like the way staff treated patients. Witnessed staff being very rough with one young man and antagonised him to make him worse. The staff had no empathy. All they wanted to do was dope the patients. Mealtimes were horrible. The unit is not at all fit for purpose.
- Lack of staff puts pressure on the staff. Rehabilitation ward no longer available for female patients.
- Visited A+E at Ysbyty Gwynedd in crisis, pleaded with staff to be admitted as an inpatient at the Hergest Unit. Was told by two members of staff from the unit that she did not want to be admitted as an inpatient and that she was a "fully functioning" person as she was working.
- Community Mental Health Services in North Wales is very poor. For 18 months, no one has been in touch from the CMH team.
- Been told by the GP 'unless you are suicidal you will not be seen'
- Another participant had a friend who had been struggling with his mental health and had been in and out of the Hergest Unit on a regular basis. The family had tried to engage with people in the Hergest unit when they were concerned that he was struggling. Unfortunately, it ended badly in suicide. There was very little engagement with the staff, and the CMHT was not there to help.
- Out in the community there is very little help for people. Too much of a gap between inpatient care and community care.
- BCUHB has a legal obligation to provide patients with Care and Treatment Plans. Not all mental health patients have one. Without a treatment plan, you are not able to access the care and treatment you need. When a GP was asked what a patient should do if feeling suicidal, they did not know because there was no care and treatment plan.
- Communication is poor. Not able to contact your caseworker or social worker. Nant y Glyn unit – could never get through to anyone on the telephone.
- People do not know what help is available through third sector organisations. Walton Centre has a helpline for patients, they self-fund it through fundraising.
- Families do not know whom to contact when someone is in crisis. There is a breakdown in the pathway between inpatient and community services.
- Where do people in crisis go to access help? Pre-pandemic people used to go through

A&E. How do they now access services? There should be a telephone number in everyone's care plan (if they have one)

- There is no support for those working in the agriculture sector. It is an isolated way of living, working around the clock – no support.
- How are services going to be monitored in future if the CHC is to be abolished? The work by the CHC around Vascular Services was fantastic.
- They have been allowed to come out of special measures without sorting out the problems that put them into special measures in the first instance.
- Would not feel safe in any of BCUHB hospitals.

Older Persons Mental Health Services – 1st February 2021

- Could the CHC do a session in relation to Autism and MH. I work for an autism service, perhaps we could work together in relation to the engagement. I'm happy to help publicise it with my networks.
- Perhaps also a female specific session – pre and peri natal teams could get involved.
- If you're autistic and need to go to hospital, you tend to get sent to units miles away, outside of Wales.
- The way autism is classified in MH is that it's a neurodevelopmental condition.
- Some older people aren't diagnosed and it is seen late in life. Services are still set up for children and there's no understanding in the adults/ older people services.
- The isolation is always there, there's no family support once the parents die.
- The mix in the Ablett makes it a toxic environment. Someone I know spent time there and it made her worse. There was either noise and screaming or completely isolated in a room. There was no in-between.
- It's a hard job as a nurse in MH, you need the correct training and resources. Health Board rely heavily on agency staff.
- People are struggling to make any connection during a difficult time.
- People are feeling isolated, emotional and lonely.
- Befriending Services should be co-ordinated.
- There needs to be more community support / involvement.
- There need to be more of a strategy/ policy for those that need community support including carers.
- Many people are reluctant to say they are struggling and the situation can become quite desperate.
- I care for my kids and my mother who lives nearby. Covid has been difficult for them as well. We try to do video-calls to my mother to ensure she's ok. My mother doesn't receive any services from NHS except her medication. This is coming through, but it's taking a little longer for it to arrive.
- Covid has had a negative impact on the clients I work with. They feel isolated, especially those who have no access to IT. Relatives aren't able to visit them either.
- People who have hearing difficulties struggle with phone calls, they feel isolated and lonely, and some have been very upset.
- On a positive note, when I have contacted the Mental Health services, I have received a prompt response, sometimes in the same day.

- A lot of my clients are in the 50s-60s age group, who haven't yet received the Covid vaccine.
- I will let you know Age Concern's experience of Covid vaccinations.
- Some people prefer video consultations with Mental Health services rather than over the phone.
- Age Concern's caseload and workload has increased during the past 12 months. Since March 2020 we have been working from home, doing regular calls with clients. People say they're fine but they really aren't, and we only find out that they're not ok when they've gone into a crisis.
- We have transferred to a new organisation, but we are still addressing clients' needs. We have sometimes needed to ask the police to check on people if we haven't heard from them. We can pick up on the signs and act on them quickly.
- BCUHB introduced clear PPE masks to help those people who are hard of hearing. Video consultation is preferred, and BSL interpreters should be booked for these consultations. Some people have no access to i-pads and technology and struggle to use the phone.
- Health Boards struggle to accept that there is a need for a specialist deaf mental health care service, which will need specialist trained staff to work with deaf people.
- Staff aren't learning BSL or assessing people in a sign-language friendly form.
- The need for a specialist deaf mental health service needs to be pushed.
- You can't help people unless you understand what they want and how they want to achieve it. It demands time – people need time to get across their feelings and anxieties.
- GPs do not have enough time to listen to people and there is little continuity of care.
- People need continuity of care and the ability to build up relationships.
- I attended the Ablett unit once as a CHC member and reported my concerns to the CHC (how patients were sleeping in recreation rooms). Within two days, the CHC visited the site and the issue was sorted out.
- MH is a vast area and Covid had forced the BCUHB to shift Dementia and Alzheimer's patients to Wrexham, but that was a mistake as staff there were not trained to deal with those patients.
- It's disappointing that the planning application for the Ablett was turned down, and it is extremely disappointing that the project has been delayed.
- A friend in her 80s had a severe MH episode a few years ago, and was admitted to Hergest. It was an inappropriate place for her to go to. She recently had another episode and again admitted to Hergest. She was then transferred to the Ablett. Her husband is also in his 80s and relies heavily on relatives and neighbours to help with meals, which has been difficult during the pandemic. The family have not been able to visit her or speak to her in Ablett. Not sure whether it's a MH issue or whether she has Dementia, however, Hergest and Ablett are inappropriate settings for patients like her.
- It is important to distinguish the difference between MH and dementia. Both need different care and shouldn't be classed together.
- Contact with family is so important.
- *This is me* initiative – is it being used in North Wales? Where is BCUHB with it? It is being used in some general wards at hospitals in N Wales.
- People with Dementia can't speak for themselves, and during the pandemic, relatives who would usually help them are not allowed to see them to check they are ok. Those

people are vulnerable.
- People need continuity of care, to gain trust and confidence. This approach can help them manage their own issues.
- After I lost my son, I struggled with my MH. You have to take back control.
- A portion of your life is removed after you've suffered a trauma, my doctor helped me gain back control of my life and control my medication. I no longer need to take medication, and I manage my MH.
- It's sometimes the parents who suffer the most, they need support.
- Getting into the service is difficult. Can only make appointments via a telephone to see a GP. Deaf people could be suffering in silence as they struggle with making telephone calls.
- People who are deaf with MH issues – they face many barriers.
- Depending on what has happened, you can't always repair the issue but you can be supported to move on.

Child & Adolescent Mental Health Services – 4th February 2021

- Concern with lack of referral and support available for young people. How far down the chain will they get before they get a referral.
- What support is out there for the teaching community. The mental health of teachers has a knock on effect on school pupils.
- Since Covid-19 do the schools receive support from organisations re. mental health and how is this support delivered now schools are closed.
- Referrals to the CAMHS service were taking a long time pre-Covid-19, but have since become worse.
- In2Change have had strong links with the CAMHS service (for clients already in the system) but have recently been having difficulties due to staff leaving the service.
- Only one CAMHS unit in North Wales, is this enough? Care should be closer to home.
- Patients are falling between CAMHS and adult services, there is no smooth transition.
- 'Once for North Wales' shouldn't apply to services for people who are vulnerable or young adults with mental health / learning disabilities.
- There should be more partnership working between CAMHS and third sector organisations as is happening in some other areas of Wales.
- There's a fantastic network in the third sector with support for young people and children.
- In South Wales there are MH partnership boards with third sector. Unfortunately they are very reliant on grants and cannot plan long-term due to funding issues.
- Is there anyone overseeing who gets involved in the third sector – they should be monitored, and the people involved should have training.
- Are there any specialist trained staff within CAMHS to treat deaf children. When you learn BSL, you learn about the culture and the barriers.
- There is disjointed transition between CAMHS and adults services. With some 17 year olds losing out on treatment for months or weeks before their 18th birthday.
- A smooth transition service is needed for those moving from CAMHS to adult mental health services.

- Those who have had CAMHS support through their lives, still need the support even after they have turned 18yrs old.
- There needs to be a young persons/ CAMHS/ adult mental health service (from 18yrs – 25yrs old).
- Trying to arrange a neuro developmental assessment for 10 year old who is currently under the CAMHS system for the past 7 years.
- 19 year old discharged from CAMHS at 17 years old, assumed his records would automatically go over to the Adult Mental Health Service and they would contact us. He hit crisis during Covid and had to go through referral system from the beginning. They had no record of his notes, it was as if he had never been in the system.
- Son had been under CAMHS for a number of years and discharged at 18 years of age. He deteriorated and as a family we had nowhere to turn to. GP would not discuss his problem as he was 18 years old and would need to visit the GP himself. He slipped between the net. Sadly he committed suicide. The only place as a parent I could turn to was the GP and they were unable to help.
- Autistic children need a note on their GP file 'must listen to parent' and this needs to remain on file throughout their life
- 19 year old autistic son would not be able to ring or speak to a doctor without his parent.
- There is a big medical anxiety in the autistic community.
- Small things can cause anxiety in an autistic child / person, even though they are intelligent and articulate.
- Friend's son fell between CAMHS and Adult Mental Health Service when 18. GP wouldn't speak to the parents. Lack of continuity between services.
- Parents don't feel they are being listened to.
- There is not enough training and awareness within the medical profession of autism. Services do not fit autistic needs.
- GP's need better understanding of what autism is and what it means for the family.
- If an autistic person is in employment, they are tagged that they don't need help, but they can quickly go into crisis.
- A large number of children with neuro developmental problems often have parents who have mental health diagnosis as well. It is really difficult for these parents to make contact to get help for their children. Knowing where to go and knowing there is help available would be a lot of help.
- If patents disclose they have a mental health diagnosis when trying to access help for their children, they are often discriminated against
- CAMHS will often refer parents to parenting courses
- Parents have been accused of fabricating illnesses.
- BCUHB will need to listen to parents
- Teachers don't have the resources to give autistic children what they need. Autistic children often get expelled.
- Had to fight tooth and nail for extra help at school. Had to pay privately for extra help. Never felt supported, always felt a nuisance.
- Schools and GP's need to understand that these children have their own ways of being.
- Not a single service walk the walk, they only talk the talk. They don't know how it is at home.

- Been told that I had ‘scaffolded’ my child, but if I as a parent didn't- who would. I am trying to support the most precious thing in my life, my child.
- I am made to feel an inconvenience. If I don't go on the parenting course, I am seen as not engaging.
- No support for parents.
- The buzz word for governments at the moment is Mental Health and the effect of Covid. They haven't looked at the children already in the CAMHS system. Services are not there.
- People do not see what goes on behind closed doors. Parents are under a lot of stress. There needs to be a better understanding between CAMHS, adults services, schools and GP's.
- Parents are the experts - they need to be listened to.
- 10 year old been saying he does not want to be alive since the age of 5, CAMHS suggest he cannot be serious. I cannot and will not take the risk with my child's life, I will always take it seriously.
- Complaint has been made about CAMHS and an apology given, but no lessons were learnt. There needs to be changes.
- Wrexham area there is a lot of discontent re CAMHS and a number of parents ready to come forward with complaints. The relationship between the service and parents has broken down. Parents are paying privately for a diagnosis as they cannot wait for CAMHS any longer.
- CAMHS in Wrexham do not acknowledge all conditions (they do in Flintshire), it's a postcode lottery
- I knew my son was different, but didn't know why. I was made to feel as though it was my parenting. Although I am a very strict parent. I feel as I was blamed for his behaviour rather than being listened to. I was sent on a parenting course, it didn't help it was designed for parents who didn't know how to parent. It's very lonely.
- I feel all parenting courses are a stalling tactic because CAMHS don't have a real clue on mental health requirements because not much lived experience in their training, some things have to be experienced.
- I’m a mother of a child in the mental health system. The child has been assessed by a Paediatrician twice, and we took the diagnosis of Oppositional Defiance Disorder to CAMHS. We were told that this is not done on CAMHS. It took nearly a year to get a foot in the door, with people asking us lots of questions but not giving us any answers.
- All roads lead to CAMHS but there’s no help from CAMHS *“They are an empty vessel”*. We have now been bounced back from CAMHS to a Neuro-developmental Team. I’m never clear who I’m speaking to and I have answer the same questions again and again.
- A child with mental health issues doesn’t present their behavioural issues at sessions.
- I was so desperate to be seen and heard by someone, that I staged a ‘sit-in’ until I eventually was seen by someone. That person has now taken ownership and is co-ordinating things for us and I’m waiting to see what happens.
- Usually co-ordination is poor to non-existent. There is really no continuity. Why is there no holistic approach that includes the whole family?
- Nobody takes responsibility for you while you progress through CAMHS.
- My child was given four weekly therapy sessions, which was colouring in and playing

with slime. It was irrelevant to a 10 year old child.

- My child has never been able to sleep, and we were eventually given melatonin and my child now sleeps.
- CAMHS gave us nothing in terms of treatment. We ended up calling 'Action for Children' for support.
- From my experience, it is impossibly hard and the parents' views mean nothing and are always top-trumped by teachers or anyone in authority.
- There is no early intervention.
- It is exceptionally hard to get anywhere.
- Many patients are falling between both CAMHS and Adult Mental Health Services. There is a huge gap between both services and service users are being lost between them.
- There was a lack of empathy towards me and my child on how it impacts on us as a family.
- I think CAMHS as a title scares parents and children.
- It's like an institution of its own in some people's minds.
- Our services young people could give feedback as most of them are involved with CAMHS, get in touch and we'll sort something out. (Ruby In2Change).
- Thank you again for hosting this. It's great for people to have their views headed. I hold out hope that BCUHB will listen, and work with all sectors.
- I feel there is little support for parents.
- I was sent on a parenting course when my son was very young. I know my son was different but didn't know why. I was made to feel as though it was my parenting. Although I am a very strict parent. I feel as I was blamed for his behaviour rather than being listened to. It didn't help going on the course, it was designed for parents who didn't know how to parent.
- I feel all parenting courses are a stalling tactic because CAMHS don't have a real clue on MH requirements because not much lived experience in their training, some things have to be experienced, but without violence which many parents experience.

Learning Disabilities – 8th February 2021

- The Learning Disabilities nursing team in Conwy have stepped up during the Covid pandemic to support people, even face to face.
- As far as I know, patients with LD didn't get discharged like the MH patients early on during the pandemic.
- Clients with LD were risk assessed, so that support was focussed where it was needed.
- Some individuals with LD have managed well during the pandemic, but others who are more isolated have struggled with the mental health as well as their LD to manage the communication and what they are/ aren't supposed to do during the pandemic.
- Social visits should allowed – they are vital to the individual.
- Day services were opened in Conwy in September 2020, but the numbers that attended were low. People are still scared of Covid. People are choosing to isolate due to the fear of Covid.
- The employability and skills programme work with people from the age of 16 and help those individuals who have become redundant. They have issues but they need to get

back to employment. The programme helps the individuals with their barriers, mental health issues and helps them with their CVs. There's a caseload of 400 in Conwy.

- People with LD don't know where to go during the pandemic. They tend to be more wary and back off. They are isolated at home with low morale.
- When people lose their jobs, they suddenly lose the link to their friends and the routine. They don't want counselling, but they need some sort of interaction and sense of purpose. This can sometimes lead to depression, and we need to look at that as well as those with MH problems.
- Loneliness is an issue.
- LD nurses in LDMH services work with people who are referred to their service, and are very focussed on crisis management and the prevention pathway.
- Covid has brought an opportunity for nurses to re-focus their work on prevention.
- People are unsure of the information about the lockdown. It's important to get the correct information and guidance out to everyone.
- People are worried about when they'll get their vaccination. People with LD have not yet been vaccinated, it is hoped that they'll be moved up the priority list to either group 4 or 6.
- Younger people with LD living in care homes are not on the priority list, but it would be a huge issue if they caught Covid and had to be admitted to hospital.
- People in supported living or in care homes had restrictions initially, but that has now changed.
- I'm concerned about the impact the pandemic is having on people with LD accessing their annual health checks. The uptake has gone down since Covid.
- The health outcomes for people with LD is poor, and I'm concerned how the Covid period is going to have an impact on that.
- People haven't been going to see their GP, and people with LD can't communicate well enough to tell us if they aren't feeling right. More work needs to be done around this with the GPs and Community LD nurses.
- Mortality rate for people with LD is low.
- Early intervention continues to be an issue. If someone can't communicate, how do we know if they're ok?
- With regard in-patient care, it's difficult with bed availability at Bryn y Neuadd (ByN). Covid has had an impact on beds at ByN.
- The quality of the accommodation at ByN is better, they have recently been refurbished.
- There are issues, and a lot of them are to do with the face that people are ready to move on from ByN, but there's nowhere for them to go to in the community or locally.
- Language is also an issue with placements, it's important for people to be able to speak in their preferred language.
- The Learning Disabilities Transformation Programme is doing a piece of work around supported living/ accommodation for people with LD. The report will be shared with the CHC.
- There are a few projects going on, but they are short term due to funding issues. It's a challenge. It took three years to get supported living set-up for a group of individuals.
- Finding placements for individual with complex needs is a challenge, and these usually need to be new builds, so finding land is also a challenge.

- When you have clients who rely on you and need your support, but then the short term funding comes to an end, it's so difficult for us and our clients. There are cuts to budgets at local authorities, but we can't stop what we're already doing.
- Advocacy service – we have people who ask for advocacy. There are advocacy services available, but people don't know about them or how to access them. People don't know they are there. It's a nightmare navigating people to the right services.
- It's difficult for parents at the moment. Some children are challenging to support at home, which is also difficult for the families.
- What's available differs across North Wales, it's different in every county.
- In Conwy, we have weekly meetings with the educational lead for Additional Learning Needs and schools, where we discuss any issues. The Social Services and the Education department is one department, which makes it easier for us to work together better and more effectively.
- We work with the Community Resource Teams and Localities Teams to discuss children's cases.
- Transition still remains patchy and is still a challenge in North Wales.
- Access to support is limited. There are 60,000 people with LD and only 15,000 of them access services, which shows that accessing services is a problem.
- Early intervention is a big challenge in relation to Children and Young people.
- There are health inequalities, we still can't get people with LD their health checks. A substantial number of people with LD have died due to Covid.
- Access to information that people can understand and in the correct format is an issue.
- WAST have found that people are wary of phoning 999. People are scared of catching Covid, and they are also scared of people in PPE and masks. This has had an impact on communities accessing our services.
- Lifespan service provide expert early intervention for families, however, accessing the service is an issue.
- The individual's level of challenging behaviour can affect how they can access / are eligible to receive services.
- Intervention is based on presenting needs.
- LD nurses are working with children who are waiting for a diagnosis. Nurses are trying to take back the role of early intervention and crisis prevention.
- Conwy council offer on-line health & well-being courses, and fruit & veg boxes are delivered to individuals, trying to prevent crisis.
- In North Wales, the relationship between the Health Board and the Local Authority is the best in Wales, it's very strong. It is the most developed partnership arrangement, and the partnership boards function well. There seems to be a commitment on both sides, which isn't the case in the rest of Wales.
- Improving Care, Improving Lives review shows that people are spending too long in hospital, which also highlighted a range of challenges. Individuals are subject to far less therapy than if they were at home.
- It's often very rarely a crisis of the individual, it's the inability of the system that fails, not the individual.
- Nationally there is a lack of people with the skills to support individuals with challenging behaviours.

- Unless we start developing and training staff, there will be an ongoing cycle where individuals with behavioural issues are moved to hospitals.
- Consortium in North Wales is very good and helpful.
- There needs to be an investment in skilling up people with LD and their families.
- When Health Boards try to deliver LD as same model as MH provision, it doesn't work.
- Partnership with the Local Authority is important, but you don't see it with adults MH. In LD it's seen as shared partnerships, which is a testament of the confidence of LD health staff and the partnership board to continue with it.
- Recruitment – if you work in LD services, it's a passion. BCUHB isn't doing enough to promote the service and the good things being done.
- Good practice at Ysbyty Maelor – a communication book is used, which is brilliant. It indicated people's preferences. There is also a passport used there. Some staff however don't focus in on preferences, so it needs to continually be highlighted. The framework is there, it just needs staff to be reminded of how important it is to support patients with LD in hospitals.
- I have never seen a communication book, so it doesn't get used everywhere.
- I have had staff saying to my daughter "how do you expect us to treat you, if you don't co-operate" or "if you don't co-operate, we'll call security". The attitudes of general hospital staff towards patients with LD needs to change.
- How do we help non-LD practitioners know how to deal with patients with medical and LD needs? Training and education for non-LD general staff at hospitals should be mandatory.
- There is now an NHS health profile instead of a passport, which was brought in to try to improve experiences.
- The mobile network coverage at Ysbyty Maelor needs to be improved. There is a very small team working there and when you try to contact them on their mobile numbers, there's never any network for them to answer. The staff have asked for a pager so that they can be contacted, but this was refused.
- The LD community teams aren't always accessible, they aren't well promoted or signposted, they are not on the BCUHB website links. It's poor communication.
- Most people with LD want a door they can knock on or a phone number to call. The services are poorly advertised on the Health Board website and also publically.
- In Wrexham it's like banging your head against a brick wall.
- There is very little support out there.
- What's the minimum provision that BCUHB have to give? There's nobody responsible for a lot of stuff, you keep getting passed to someone else.

Substance misuse – 11th February 2021

- There may be a significant sector of the population i.e. refugees, asylum seekers etc who don't have any official or medical records kept – how many of these people in North Wales who won't be picked up with regards to help with substance misuse or offered the Covid vaccine.
- There needs to be more GPs and nurses, and a better mix of skills.
- I have alcohol issues and I wasn't allowed to go to CAIS, they refused me. I was offered counselling service from Parabl.

- When I went out and asked for help, they weren't very forthcoming.
- The harm reduction team are trying to ensure safe use of injections, and have rearranged their outreach by visiting addressed rather than using a bus for people to attend. By visiting addresses they've been able to liaise better with the housing department and other public services, which is now a more wrap around service.
- I don't think people attended the bus due to the fear of catching covid. And there's also stigma.
- I haven't been offered any face to face appointments with a doctor.
- There is a long waiting time for an appointment with a counsellor in this area. There isn't enough provision.
- During lockdown, it affected my drinking. Driving a car stops me drinking, but being at home in lockdown, I drank more.
- Drinking is so easy at the moment, I need encouragement, more help and support and we need more counsellors.
- A lot of people are on their own, and we have noticed an increase in self-referrals. Males and females are having issues with alcohol. Being at home with their children all day, parents start drinking more.
- Vesta provides counselling.
- Some people have no access to services due to language barriers if Polish or Portuguese for example.
- Shoppers are buying a lot more alcohol than they used to, it's a coping strategy.
- Obesity, substance misuse and mental health will be a huge problem for society.
- What could we do together to support clients, and help signpost to different services to improve their lives?
- There is a cultural acceptance – we drink with families, and at family parties there is alcohol.
- It's a problem when people stop drinking, they are pushed out of the circle.
- Drinking is a coping strategy for victims of domestic abuse, if they can't cope with the abuse.
- Bereavement, grief, home-schooling, furlough – people can't cope and turn to drink or drugs.
- People aren't always aware of public services available to help them.
- Some GPs, due to either lack of training or lack of tolerance may feel that their time is being wasted by some people with substance misuse issues.
- Long term support is needed and a response to a crisis. Early intervention is needed across the board.
- It takes months to get a counsellor, trying to get hold of someone is difficult. I've been told that the counsellor can't see me again for another 6 months at Parabl. It's not enough and it's not good enough.
- We need hundreds more counsellors in North Wales.
- The one at Parabl was good, but you need long term.
- How are we reaching out to people who don't go to their GPs? It's difficult enough for me and I go to see the GP.
- It may be more difficult during lockdown to get drugs, but it's easy to get hold of alcohol.

- I drink due to physical pain – I have a medical issue and nothing beats the pain better than alcohol.
- BCUHB has an obligation to provide interpreters for any medical appointment. They need to reach out to those communities (such as Polish and Portuguese), they are vulnerable.
- Outreach is vital and Welsh speaking staff particularly in the field of Mental Health, for people to communicate when distressed or unwell. It's difficult for people to express themselves in a second language. BCUHB needs to make the effort.
- Penley hospital have less and less people there now, there are only a few people there.
- NWCHC is very good in dealing with complaints.

LGBTQ+ - 22nd February 2021

- I used the MH services a lot during the pandemic, it's been a nightmare. I haven't had the best experience, and having to do everything over the phone when in a crisis. I asked for a call-back when in crisis, and received a call-back two weeks later. There was no point calling me back two weeks later, by then I had sorted myself out with support from friends.
- I had to fight all last year for a MH support worker, I finally received one last week.
- Phoning and having to repeat myself over an over to different people is very frustrating.
- You expect them to do something rather than just say "let's see how you go".
- Young people with MH issues find it a real trauma having to reintroduce themselves and fight to access services and support.
- It's vital that people can access services in the way that works for the individual, whether that is a phone call or a virtual meeting. Waiting two weeks for access to Crisis isn't acceptable.
- Everything stopped when Covid started, CAMHS just shut down. Everyone received a letter saying 'your therapy has ceased'. The amount of referrals we received at the College for counselling were high, which was a heavy weight on us.
- It was stressful to see people's mental health deteriorating and there's no crisis support. It has been a strain on the college and the Samaritans.
- People tried to access CAMHS but the wait was so long. People are waiting two years for Autism assessments, and their education was suffering in the meantime.
- CAMHS told people to go to see their College counsellors. There's no pathway for those that are not in college.
- I'm not sure how some services are equipped to deal with Mental Health in LGBTQ+ community, when individuals access help, those individuals have to train the person, which is not acceptable.
- I used to work in early intervention in CAMHS, where people were going through the transition from CAMHS to Adult services. They were talking about trying to organise passports for people to carry over through to the adults services. In adults services, the onus is on the individuals to arrange and attend appointments and responsible for your own meds, whereas in CAMHS, the individual is wrapped in cotton wool. There should be some 'letting go' from CAMHS to help the individual be more

independent; and the Adults services need to be allowed to chase people if they miss appointments, even if it's only for a year at each side of the transition.

- Clients / involvers have gone from seeing their care-co-ordinators for an hour session at a time, to a 15 minute phone call during lockdown.
- Being LGBTQ+ is an issue with a particular age range in staff, some think *it's your problem or illness*. I was told they couldn't assess me and I felt irrelevant, and it made the situation worse. I ended up back at hospital in a worse state. I felt discriminated and offended.
- Discrimination needs to be eradicated across the board, and all staff should undertake at least some basic training.
- All staff working in MH should be aware of the different types of LGBTQ+, there needs to be a bit more understanding.
- I haven't received the appropriate level of help until now. I don't get daily intervention, and I'm fighting to keep my support worker – I've only had her for 4 weeks. I shouldn't have to have that stress. The support I'm getting now from MH services is rubbish.
- I have to beg for help. I need someone to be my backbone.
- I go to Gisda for support. I have to fight for any support and advocacy.
- A few months ago I went to the ED at Ysbyty Gwynedd and was sent home. When I went to ED I was relatively in control, but I was told I was wasting their time and then 24 hours later I had to go back to ED as an emergency. I wasn't offered to speak to anyone at the hospital.
- If I felt I could approach someone at Ysbyty Gwynedd I would feel more comfortable going there in a Crisis. Other than my GP or Ysbyty Gwynedd, there's not much more that I can do. I can't afford to see anyone privately. I did go to Wrexham one time and they were more helpful.
- There almost needs to be a young person's CAMHS/ adult mental health service (*separate service*) for those aged 18-24/25 years.
- I think a lot of young people who have used CAMHS would be interested in providing feedback, particularly around what they didn't like and did like.
- There seems to be a massive difference in the level of support given from the services, and that sounds like a good way to overcome the associated barriers with the transition.
- I think a co-ordinated and blended approach with statutory and voluntary sector including prevention and early intervention. Also any developments to all MH services, and transition should reflect and respond to service user feedback in a kind of continuous engagement model, to help shape and develop services.
- A lot of young people will tell us different things to what they've told their CAMHS worker in regards to the support they want / whether they want it continuing, which of course will then make it difficult for the CAMHS worker.
- I agree about the stigma with CAMHS. Possibly having CAMHS workers at our young people's groups to help bridge the gaps and eradicate the stigma of CAMHS.
- I don't have any CAMHS experience, but I have worked within a couple of CMHTS during my training, and personally I think we need to see more joint working between adult services and CAMHS during the transition period to make it an easier and less stressful process for the young person.

- Caniad can help escalate people's complaints to the relevant bodies. LITs are active in the East – in Flintshire and Wrexham.
- I was referred to CAMHS when I was 12 years old, and I was labelled. I was told I was capable and so I didn't need help. I was discharged at 14 yrs old, and was told it could take up to 10 years to take it up again. I was referred to the MH team when I was 18 yrs old. If I had had the early intervention, it would've helped with the transition. My key-worker doesn't seem supportive.
- There are waits for 2 years for an autism assessment.
- When CAMHS tell you that they've finished with you now, there's no bridge between CAMHS and the Adults MH team.
- CAMHS – Children and Adolescent MH service – they miss on the 'adolescent'. Students feel like they are being treated like children.
- They are labelled and then they are scared.
- There's a huge gap between the services and there's no transition. People are deteriorating and people are lonely during Covid.
- Lockdown with an unsupportive family if you identify as LGBTQ+ makes things worse.
- The College offers an hour session, either a telephone call or virtual session, just to connect with students. The College doesn't receive any support from BCUHB.
- There needs to be continuity and more collaborative working. The College supports them like a scaffolding.
- People are feeling excluded and lonely.
- Trans students – some of their services have stopped and some have been pushed back 2 years on waiting lists.
- Liaison with WG Gender Pathway has slowed down during the pandemic.
- Trans are scared to talk to the GP, they are made to feel violated. People feel disgusted after attending the GP.
- Anxiety is heightened by stress, and your issues can be worsened by trying to help and support friends.
- The MH impact it has on people is massive.
- A lot of trans-gender people live on their own, perhaps estranged from their families. They are dealing with Covid and loneliness all on their own – it's a worry.
- It's a nightmare living on your own, I'm lucky my parents are supportive, but people deal with a lot of hate crime.
- A lot of services shift the blame, telling you that "you're over thinking things, you'll be ok once the lockdown is over". But what about in the meantime?!
- You're given the impression that you don't know what you're talking about.
- Loneliness and isolation is huge.
- A Managed Practice in Flintshire has Trans / Gender Re-assignment identified as one of their specialisms. There are none in Gwynedd. [CHC will raise this with BCUHB Primary Care Team and say there is a need for somewhere for people to go to and feel understood.]
- GPs should be educated. The awareness amongst staff isn't there.
- There are approx. 300 young people on the list at the youth service in Conwy, and the list is getting bigger and bigger. Not sure if there is a similar youth service in other

areas across North Wales. They have been in touch with the young people throughout the pandemic, and have started to do door-step visits for some young people and their parents. The age range for the service is 11 – 25 yrs old.

- I work with those from MSM Community (Chemsex) – there is very little support for this community from Public Health Wales.
- No LGTBQ+ specific support from Mind Bangor – they say that they help everyone, but they do not advertise for specific LGTBQ+ so people won't feel comfortable accessing help. They should be actively engaging.
- North Wales Chemsex support group invited people from Mind to attend, but they just didn't turn up.
- BCUHB – great that they've got the Stonewall award, but that's more for Staff. There is very little promotion to encourage LGTBQ+ to talk. There is very little acknowledgement of LGBTQ+ community even in the sexual health clinic.
- In our support group Mental Health is the biggest issue we speak about. Health Workers need to understand individual needs.
- GP's – no acknowledgement and understanding of LGTBQ+.
- Service user needs in North Wales as an LGTBQ+ person is not reflected.

COVID-19 and Mental Health – 22nd February 2021

- Was discharged at the beginning of first lockdown – received a phone call from CPN saying was discharged and was given a leaflet. Since the services resumed, have received 10 minutes telephone calls by unknown members of staff. I have been given a new CPN, and have had to re-tell my story. Been discharged again last week as I have been offered counselling from my employer.
- Re-telling your story isn't great, you don't want to be telling your story again over and over.
- People were discharged from the MH team without having been assessed, which has caused major distress. The third sector organisations have been left to pick up the pieces. Third sector are seeing a lot more people over the past year that have complex needs as there is no one else available to help them.
- Third sector orgs transferred their services to online/ telephone when the lockdown started, they are the ones who actually care for the people through all of this.
- Actively taking part in DDC (?) course, and was discharged. My conditions got worse and I had to seek secondary care services. I self-harmed for 5 months, and there was no one available to help me. The only support I received was from Hafal as I am also a Carer.
- RNIB have commissioned a research paper with Bangor University to look at Mental Health provision for people with impaired vision. The RNIB have arranged for counselling sessions to be provided to its service users – something that should be a statutory service provided by the health board and NHS.
- It's difficult for people with impaired vision to access support or services.
- Transition from CAMHS to Adult services is poor. There is no overlap. Social Care is taking up a lot of the slack.
- Isolation – Covid-19 and lockdown have meant that people have lost their safety mechanisms. This has meant that conditions such as PTSD and OCD have become a

lot worse, and to be discharged from the MH service as well was catastrophic. Covid-19 constant changes to the rules also makes these conditions worse and increases anxiety.

- Husband has dementia, I am the only person he has to communicate with since lockdown. It resulted in him becoming violent towards me and I had to leave the house. I received no respite at all because of Covid. I needed someone to help me. Husband was becoming more and more distressed as all the help / assessments were over the telephone and he couldn't understand them because of the language barrier and because it was over the telephone. The level of care given to this patient is felt to be inappropriate. (*the CHC will be taking this up as a formal complaint*).
- Isolation means for some that they are being locked down with their abuser. People's safe spaces have been closed down. There has been an increase in domestic and sexual violence.
- Some other departments of BCUHB are using videoconferencing with patients, but not all. It would be much better for clients.
- Telephone calls are no good for some MH patients, a video call would be much better.
- CAMHS and Physio can do video calls, why can't CMHT?
- There is a need for the health board to contract appropriately with third sector organisations.
- Mind Conwy had a number of people who were discharged from the MH service contact them for help. Communication is poor – appointments not being kept and patients not informed, when patients telephone the service there have been instances where the receptionists are rude, been put on hold for a long time, not being taken seriously. It has made people feel they would rather struggle on their own than having to find support.
- There is a lack of humanity in the service. Services are only interested in gatekeeping.
- Mind Conwy are receiving constant inappropriate referrals from CMHT. The referrals are so vague. It is really disheartening. Have tried to engage with the CMHT regarding the inappropriate referrals or about a concern regarding a patient, they don't want to engage, and will not put anything down in writing.
- There have been occasions that when contacting the Duty Officer you are told to call the police, who tells you to call 999 for an ambulance. But there is no medical need. People need help early to prevent them from becoming worse and needing secondary care.
- Been told over the phone when needing help to 'go for a walk'
- Calling the CMHT at the end of the afternoon on a Friday is problematic, the service closes at 5pm.
- CMHT, taken adults over to them twice and been told no one could see them. Taken them to A+E and they enter psychosis on a trolley, staff could not handle them. Very distressing for patients. The CMHT are hoping the police will attend to these people and 136 them, it's lazy.

Agriculture & Rural Communities & Mental Health – 24th February 2021

- Availability of counsellors on the phone at the weekend (at BCUHB) is problematic, when people call for help.
- It's been a difficult time for the farming community – stressful and lonely.
- 80% of calls to FCN (Farming Community Network) helpline are because of stress. There is a need for 'out of office hours' support for the agriculture community i.e. evening and weekends.
- Brexit and Covid have been on people's minds.
- Sufferer of mild depression, last year was in crisis and had nowhere to go for help. No one could assist. People who work in agriculture don't know where to go to find help

and end up in crisis and suicide. In 2018 there were 83 suicides in the agriculture sector. There is no support out there other than private.

- Access to services is wrong. People are told to go to their GP – but those agriculture workers won't go to their GP with anything. Outreach work has now stopped because of Covid, but it's the only way to reach the farming community.
- Social prescribers at a GP surgeries are trying to find out what is out there in the 3rd sector as help.
- Went to see a GP with a MH issue, and was told that there were many weeks waiting list to see someone. Was signposted to 'Back to Work' Counselling service, but re. NHS support was only told 'you can wait if you want'.
- The MH structure within the NHS is all wrong. If feels like a 'cop-out' from the NHS, they pass you on to charities for support. The NHS should be there to support you but all they do is sign-post.
- Farmers work all hours, so there needs to be a service available 24 hours a day.
- The NHS could learn a lot from charities i.e. how the support is offered and the level of understanding and reach out.
- People would like to see proper contracts between the NHS and the 3rd sector organisations where patients are referred to for help.
- FCN offer a lot more than a 10-minute phone call when supporting families.
- Charities have a good baseline / foundation. Why can't the NHS work with them. When farmers reach out once, they need to receive appropriate care / information straight away, they will not reach out more than once.
- Those working in Farming need help 24 hours – crisis can be middle of the night for some.
- NHS professionals need to learn about how different the agriculture sector is. To be told 'Take time off' or 'take medication' is not appropriate. Blanket policy for everyone is not the right approach.
- First phone call is crucial. It is a massive step for farmers to pick up the phone and ask for help ONCE, if they don't get any help they will not call someone else again.
- Farmers have lost their social interaction with peers due to lockdown with markets and marts being closed.
- DPJ foundation visit marts, visited farms, rugby clubs, they also run Mental Health awareness sessions at Young Farmers Clubs. Work done by the 3rd sector need to be acknowledged.
- It is not a big ask to ask health professionals to have more awareness of how different the agriculture sector is. There needs to be training.
- It's not a job, it's their way of life.
- The cancellation of agriculture shows will have a huge impact, farmers have lost the social interaction.
- For 3rd sector organisations agriculture shows were vital. People would call by the stand for a chat, and would feel easier about asking for help informally face to face.
- Financial stress on farmers, but it is not the biggest cause of mental health. One of the biggest is the lack of control over much of the work (being reliant on market prices, brexit, weather)
- Next 12 months will be crucial, there could be a lot of stress related to brexit, and the NHS will need to be aware of this.
- There is a lot of talk and pressure for farmers to diversify. Some farms don't have the opportunity to do this, they cannot change from what they do now. Where does that leave them?
- Older farmers – they are not internet savvy, don't want to change, and can't change. Need to look carefully at how we support them.

- Befriending service – FNC offers this service, where a volunteer can visit someone from the agriculture sector in hospital for a chat.
- Welsh Language is very important – inpatients have a legal right to access services in Welsh and also in mental health services. There have been instances of people under section not offered a Welsh speaker or an interpreter, and as a result the quality of care given is not as good.
- There is still an attitude of ‘they can speak English anyway’. But people suffering from MH or other illnesses need to be able to communicate in their first language. Especially important for dementia clients.
- How do the 3rd sector advertise their services – letters, emails, end of text messages, posters, stickers on big bales. It was suggested that approaching the feed suppliers asking for a telephone number to be displayed at the bottom of a bill would be good.

MS Teams Chat during the Safe Space Sessions:

- I am an organisation rep, have been a service user and am also a carer of a young man with mental health issues.
- I am a current user of MH services and I am also a N Wales Champion for the DPJ foundation. I am also training to be a Samaritan.
- I am the FCN (*farm community network*) co-ordinator for North Wales. We have just employed a part time development officer and we hope that will increase awareness of our services.
- Please keep me on the mailing list
- I live in Denbighshire, I choose not to access services as I have had very bad experiences and been traumatised by them. I have been sectioned twice, I was under Hafod for about 4 years many years ago. I was also North and Mid Wales manager for Hafal for 4 years. I was a service user representative on the national partnership board for Wales for 1 year and SU rep on the Time to Change Wales programme management board for 1 year too. I was Caniad co-ordinator for Conwy and Denbighshire for about 6 months before I was effectively forced to leave, I also volunteered for them until I was told I couldn't. I am currently a lived experience advisory member for Mind UK helping to develop their 5 year strategy. Maybe that is too much information. I would just really like to help improve things but feel I have been silenced.
- CALL helpline Cymraeg 24/7/365; mental health helpline for Wales community advice and listening line offering a confidential listening and support service. Freephone: 0800 132 737
- Sister helpline for Wales drug and alcohol helpline. Freephone: 0808 808 2234 or text DAN to 81066
- My Asperger's TED talk: https://www.youtube.com/watch?v=3Q211-b7Ee4
- Virtual HUBs in Conwy: https://conwymind.org.uk/how-we-can-help/virtual-hub/
- I found this forum very beneficial – being able to share and hear others experiences, look forward to hearing how the CHC are taking the issues forward.
- Thank you for giving us the opportunity to be heard. Happy to help with CAMHS consultation in January – you know where to find me.
- Thank you everyone, thanks Geoff and team. If you have any views or suggestions, please contact me on: nick.meakins@conwymind.org.uk
- This is our survey regarding young people if you have time: https://forms.office.com/Pages/ResponsePage.aspx?id=MN3QzqkdBkiuP7Cn_M5kGdhnQC7qs4NOjjV9QqcIBRUQTdHQ0gxUjdWTFNIWDFDUUY5VFBOWU8ySy4u
- Thank you Geoff and your team, this has been amazing!!
- I would like to leave info about our service for future reference: https://www.vestafs.org/ or https://www.vestafs.org/polishcounsellinginwales
- Feel free to contact me on email: agat@vestafs.org
- I would be interested to know who the activity co-ordinator is. It would be good to try and set up a virtual exercise session at one of these sites. My details: Rebecca.f.roberts@denbighshireleisure.co.uk
- I think there is an opportunity for the third sector to get involved in supporting / providing activities. But this needs funding. There is a view from BCU that the third sector can provide services on the cheap or free.

- Discharge support is a massive issue that needs changing.
- Thanks everyone, very interesting discussion.
- I work for TGP Cymru which is a children and young people's rights charity. We have a youth advisory board and participation groups which you could possibly link with for engagement events.
- My hope is for mental health to be taken seriously and for the services to be properly funded and integrated under a permanent director at Betsi.
- Very frustrating and demoralising. And very lonely.
- We have Shared Lives schemes across Wales, there is currently a Mental Health Crisis Project in South East Wales for adults. This project will provide an alternative to, or facilitate early discharge from, an inpatient hospital setting. Shared Lives is a community based service for adults (from 18yrs, we are trying to change this in line with England for 16+yrs). We are able to share stories we have gathered from people and young adults who are now living a Shared Life, we're able to access support during a time of crisis, whether short or long term. If you feel this is relevant please don't hesitate to contact me. We also have a Shared Lives scheme – PSS in North Wales providing support to people with MH needs.

Acknowledgements

We thank the people who took the time to tell us about their experiences and sharetheir ideas.

We hope they influence Betsi Cadwaladr University Health Board to recognise and value what they do well – and make improvements so that the things that cause very real difficulties for people using the NHS are addressed.

Feedback

We want to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.

Office contact details

Unit 11 Chestnut Court	Units 1B and 1D Wilkinson Business Park
Ffordd Y Parc	Clywedog Road South
Parc Menai	Wrexham
Bangor	LL13 9AE
LL57 4FH	

Telephone: 01248 679 284 or 01978 356178

E-mail: Admin2@wales.nhs.uk

Website: https://gogleddcymrucic.gig.cymru/

Social Media:

Presentation

Gwasanaethau Iechyd Meddwl yng Ngogledd Cymru

Digwyddiadau Ymgysylltu a Gwrando Cyhoeddus

2020 - 2021

Mental Health Services in North Wales

Public Engagement and Listening Events

2020 - 2021

NorthWalesCHC NWCHC NWCHC

Croeso

- Diolch i chi gyd am ddod
- Fy enw i yw Geoff Ryall-Harvey, Prif Swyddog Cyngor Iechyd Cymuned Gogledd Cymru (CICGC). Mae hefyd aelodau o staff ac aelodau gwirfoddol y CICGC yma heddiw

Welcome

- Thank you all for attending
- My name is Geoff Ryall-Harvey, Chief Officer of the North Wales Community Health Council (NWCHC). We also have members of NWCHC staff and volunteers here today

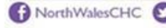
1

Cyflwyniad

- Digwyddiad gwrando ac ymgysylltu yw hwn i sicrhau fod llais y defnyddiwr yn cael eu clywed gan BIPBC yn ei adolygiad o Wasanaethau Iechyd Meddwl
- Byddwn yn cynnal cyfres o ddigwyddiadau yn ymwneud a pob agwedd o wasanaethau Iechyd Meddwl yng Ngogledd Cymru

Introduction

- This is a listening and engagement event to ensure the user voice is heard by BCUHB in its review on Mental Health Services
- We will hold a series of events to include all different aspects of Mental Health Services in North Wales



2

CICGC - Ein Gweledigaeth

- Bydd CICGC yn gweithio i ddatblygu gwasanaethau iechyd sydd yn cael eu dylanwadu gan farn a chyfanogiad cleifion a chyhoedd Gogledd Cymru
  - llais cyhoeddus cryf yn adlewyrchu'r hyn sydd gan bobl i'w ddweud am wasanaethau iechyd
  - cysylltu â'r rhai sy'n cynllunio ac yn darparu gwasanaethau iechyd yng Ngogledd Cymru er mwyn sicrhau eu bod yn croesawu ac yn dysgu o'r adborth a roddir

NWCHC – Our Vision

- NWCHC will work to develop health services which are influenced by the views and involvement of the patients and the public of North Wales
  - strong public voice reflecting what people have to say about health services
  - liaise with those who plan and deliver health services in North Wales in order to ensure that they welcome and learn from the feedback given

3

Beth nad ydym yma i'w wneud

- Trafod canmoliaeth, sylwadau, pryderon, cwynion ynglŷn â gwasanaethau y tu allan i Gwasanaethau Iechyd Meddwl yng Ngogledd Cymru
- Trafod unrhyw fater arall sy'n gysylltiedig gyda BIPBC y tu allan i Gwasanaethau Iechyd Meddwl yng Ngogledd Cymru

What we are not here to do

- Discuss compliments, comments, concerns, complaints regarding services outside of Mental Health Services in North Wales
- Discuss any other issue associated with BCUHB outside Mental Health Services in North Wales

4

Rheolau Sylfaenol Ground Rules

- Parchu barn eraill – efallai nad ydych yn cytuno – ond dyna eu barn!
- Cyfrinachedd – dim recordio, dim nodiadau mewn urnhyw ffurf am stori rhywun arall heblaw am CICGC
- Caniatáu i eraill siarad, bydd pawb yn cael cyfle

- Respect other participant's views - you might not agree - but it's their view!
- Confidentiality - no recording or notetaking in any form regarding anyone else's story except by NWCHC
- Allow others to speak, everyone will get an opportunity

5

Y Fframwaith

- Bydd yr holl gyfraniadau yn anhysbys, bydd angen i ni gael manylion cyswllt gan y rhai sy'n cymryd rhan – ond ni fyddant yn cael eu rhannu
- Bydd angen rhannu gwybodaeth pe byddai niwed difrifol neu gamymddwyn troseddol posib yn cael ei ddatgelu

The Framework

- All contributions will be anonymised, we would need to take contact details from participants – but these will not be shared
- Information would need to be shared in the event of serious harm or potential criminal wrong doing being disclosed

6

Y Fframwaith ...parhad

- Bydd CICGC yn cefnogi unigolion os oes angen cymryd pryderon neu gwynion ymlaen i BIPBC

The Framework ...continued

- The NWCHC will support individuals if concerns or complaints need to be taken forward to BCUHB

7

Heddiw

- **C**anmoliaeth, **C**omments (Sylwadau), **C**oncerns (Pryderon) a **C**hwynion
- **C**ynllunio Gofal a **C**hyflawni Gofal
- **C**yfathrebu ac Ymgysylltu

Today

- **C**ompliments, **C**omments, **C**oncerns and **C**omplaints
- **C**are Planning and **C**are delivery
- **C**ommunication and engagement

Dewch i ni fwrw iddi!

Lets get started!