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# Young people discuss what they want from mental health services







Featuring an interview with Deputy Minister for Mental Health and Wellbeing

Vender Lynne Neagle MS...



Consultation finds that Adferiad Recovery's stakeholders want joined-up services, action on stigma and rights to improved care and treatment

New Welsh charity Adferiad Recovery facilitated a huge conversation between its stakeholders across Wales - and beyond - during September and October to discover what they want the charity to achieve as it moves forward.

The "Talk to Adferiad" campaign engaged thousands of stakeholders including over 1000 members, 5000 service users and carers using Adferiad Recovery's services every day, hundreds of people who attended 24 local events and a final celebration event in Cardiff Bay, and hundreds of people who took part in its campaign surveys.

The message from stakeholders was clear. They said:

- All services for people with mental health, addiction or co-occurring problems need to be joined up: i.e., they need to treat the person as a whole and provide an integrated approach instead of pigeonholing people into specific services
- The stigma surrounding addiction, mental health and co-occurring diagnoses urgently needs to be addressed
- There is a need for improved rights to timely, wellresourced and patient-centred services for the charity's client group.

Specifically, when asked what priorities Adferiad Recovery should adopt in the coming years, participants said the charity should develop holistic services, be a workplace of choice, and be the voice of people affected by mental illness and addiction.





When asked what specific services Adferiad Recovery should be developing, participants said the following should be a priority:

- Befriending services and social groups
- Information and advice
- Services for people with co-occurring diagnoses.

#### A message for the Welsh Government

The consultation also asked stakeholders what Adferiad Recovery should be campaigning for, and how it should be holding the Welsh Government to account. The priorities for campaigning were identified as:

- Gaining more resources for services
- Improving waiting times
- Ensuring a new Mental Health Act in Wales is implemented in as progressive a way as possible.

#### Next steps

Adferiad Recovery's CEO Alun Thomas said: "I want to say a huge thank you to everyone who took part in our consultation. Adferiad Recovery belongs to its members and other key stakeholders and the trustees and management will act on what they have told us.

"In the coming years we are going to shape our new charity in light of the priorities identified by the consultation: this will include the development of ambitious new services for people with co-occurring needs, tireless campaigning to reduce stigma, and active lobbying to improve the rights of our client group.

"Exciting times are ahead. Watch this space!"

# NEWS

## No suitable places for young people in mental health crisis, warns Children's Commissioner

Sally Holland, the Children's Commissioner for Wales, has called for sanctuaries for young people experiencing a mental health crisis.

Professor Sally Holland said young people who reach a point of crisis with their mental health have nowhere suitable to turn. The only option for those at immediate risk of harm is to go to A+E departments or to call 999. The problem is most acute in the evening and weekends when community mental health teams are usually not available.

There are currently no dedicated mental health crisis centres in Wales for young people.

The Commissioner said: "Many of us will have experienced an adult A+E department. At night and on



the weekends they can get very busy with distressed adults who are often under the influence of alcohol or drugs. Despite the best efforts of healthcare staff, they aren't the calming and reassuring places that you'd want a young person experiencing a mental health crisis to go to for support.

"Everyone I hear from about this issue – young people, parents, clinicians – they all want somewhere suitable for young people to go to get this help when they desperately need it. They need somewhere accessible, calm and welcoming that offers help around the clock. They need a place of sanctuary where they can get the immediate help they need."

#### Read more at mentalhealthwales.net

### Ken Skates MS to chair new Senedd group on mental health

In October it was announced that Ken Skates MS will lead a new cross-party Welsh Parliament group set up to help improve the nation's mental health.



Mr Skates said: "Mental health is a subject close to my heart, and I'm pleased that the Welsh Government has dedicated more and more funding to it in recent years. I was particularly proud to see the First Minister appoint a dedicated Minister for Mental Health and Wellbeing in May.

"The last year or so has been an incredibly tough period for so many people, with real strain put on our mental health, so there has never been a more important time to ensure we keep this issue high on the agenda and keep coming up with ideas."

Read more at mentalhealthwales.net

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# **INTERVIEW: Jessica Lee**

We speak to Jessica Lee, Programme Manager at Youth Access, to talk about their work with young people, the future of young people's mental health services and the fantastic "Our Minds Our Future" programme.

#### Tell us a bit more about Youth Access and its aims:

Youth Access is a national membership organisation. We work with and on behalf of our 180+ members who provide integrated, young person-centred information, advice and counselling services, also known as 'open-access hubs'. These hubs provide a range of wellbeing and mental health interventions with other types of support such as employment and financial advice, money management, and accessing benefits or legal entitlements. We know that, invariably, young people who are seeking these types of support will be experiencing a combination of intersectional and complex social issues, and our aim is to ensure that every young person has access to free, age appropriate, holistic support when that time comes.

Earlier this year, your "Our Minds Our Future" programme saw hundreds of young people come together to outline their vision for what mental health services should look like. What were their key messages?

Almost 2,000 young people from across the UK worked with programme partners (Hafal and Pro-Mo Cymru in Wales; NCB in Northern Ireland; SYP and SAMH in Scotland; and Youth Access in England) to create their version of a mental health charter. Designing and developing these charters has empowered young people to raise a collective voice and advocate for the

"Our aim is to ensure that every young person has access to free, age appropriate, holistic support."



kind of transformational change they want to see in the mental health system in their communities. One of the best things about this programme is that delivery partners have the opportunity to work cohesively with young people, and everything we do aims to centre and empower young people's voices. As such, young people in each country were able to create meaningful charters which set out their requirements for change.

All of the charters had different key messages but there were four common themes from across the UK. Young people want:

- Services that listen
- Reduced waiting times
- Flexible support
- An end to inequality and discrimination.

You can find all of the charters on the Our Minds Our Future website here. "In order to provide the most appropriate support for young people, we need to involve them in what that care looks and feels like."

## What impact does the "Our Minds Our Future" programme hope to have?

Our Minds Our Future is a five-year programme which aims to support young people with lived experience of poor mental health to lead a transformation of community-based mental health provision in their communities. To achieve this, we are coordinating a powerful partnership of 10 UK youth and mental health organisations to bring young people together with Voluntary and Community Sector (VCS) providers, practitioners working in the statutory mental health system, and key decision-makers to co-design more effective ways to ensure young people can access the early mental health support they need in each country.

## How do you think we can empower young people to have a say on their own care, and services in general?

Throughout the Fund the Hubs campaign and our wider day-to-day work, Youth Access, alongside our members and programme partners centre young people's voices as lived-experience experts. We do this by including young people in conversations about service design and delivery and through their charters, they've told us what needs to happen to ensure transformational systems change. Services can only provide appropriate, accessible support for young people if we consult with them and respond effectively to their needs.

Over the past two years of the Our Minds Our Future programme, this is exactly what we've been doing. Young people across the UK have been taking the lead to promote their charters and advocating for the

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importance of changes to services in their communities. Young people have received bespoke training (e.g. about their Human Rights, media training, and how to engage with decision makers); been interviewed by a prominent news channel; led UK-wide social media takeovers; and most significantly, young people have had the opportunity to meet with key stakeholders in each nation - most notably at youth-led roundtable events across the UK.

We are, therefore, already effectively empowering young people to have a say about the care and support they receive, but we can't do it alone. The true cost of the pandemic on young people's mental health and wellbeing is yet to be determined and so it is vital, now more than ever before, that we prioritise our young people and actively seek to train and support our colleagues to ensure necessary and overdue system changes happen.

To find out more about the Our Minds Our Future programme, register your details here.



# INTERVIEW: Lynne Neagle MS, Deputy Minister for Mental Health and Wellbeing

We ask the Deputy Minister about her plans to improve mental health services for young people in Wales, the future of CAMHS and how we enhance support provided to young people by non-mental health professionals...

What are your aims for improving the mental health of young people during the sixth Senedd?

My aim is to focus on prevention and early intervention to prevent issues from escalating but also to ensure specialist services are accessible when needed. I have been an elected member of the Senedd, formerly the National Assembly for Wales, since its inception and have been advocating for children and young people's mental health rights throughout each of its six terms and continue to do so in my role as the Deputy Minister for Mental Health and Wellbeing.

The past 18 months have been extremely challenging for many of our young people. Coronavirus and the necessary restrictions have impacted significantly on the lives of children and young people, this includes worrying about periods away from school, clubs, family and friends. I think it is important that we recognise that most young people won't need specialist mental health services but we need to ensure that there is a range of support available across both the public and third sectors.

"My aim is to focus on prevention and early intervention to prevent issues from escalating but also to ensure specialist services are accessible when needed."



Our research has found that the CAMHS referral system often doesn't work quickly enough for those in greatest need. How can we ensure that only appropriate referrals are made to CAMHS so that those with acute illnesses get help quickly?

I completely agree that we need to ensure that referrals to CAMHS should only be made when that level of support is the most appropriate solution for the young person. The NHS most definitely should not be seen as the first and automatic choice for referral which is why our whole system response is centred on ensuring there is an offer of emotional mental health support outside the NHS. I want to see support situated within services already familiar to young people, carers and families.

We have seen fluctuations in the average wait time for children and young people to access specialist CAMHS during the pandemic due to both the restrictions and a significant increase in referrals between October 2020 and January 2021. We also know that waiting times have continued to increase across many NHS services through 2021. "We need to ensure that young people themselves are at the front and centre of the design of the services we intend to provide."

We will continue to work with Primary care, including GPs, and to work with teachers through the CAMHS In reach programme in schools to facilitate a better understanding of when young people need a CAMHS referral and when other support can be more constructive.

Bearing in mind that CAMHS are there for a minority with more serious mental illnesses, how can we ensure that other young people who seek help for their mental health receive a positive referral to more suitable support?

I agree this will be key to ensure our CAMHS services are sustainable in the future.

We now have single points of contact within each CAMHS service across Wales. This means that when a referral is received within the NHS, the young person's case is considered by professionals, in some areas this will be by a multidisciplinary panel. Following consideration, sometimes young people won't be added to the list for a CAMHS appointment but will be signposted to more appropriate help elsewhere.

We have been developing better support in schools and youth clubs for a few years so many young people will already be able to access services such as school/community counselling or emotional wellbeing services provided by third sector organisations. But to build these type of services and ensure they are available wherever young people need them in Wales, we are using the NEST Framework. This framework will help regions to develop services based on what is needed by young people in their area.

Many young people have told us that when they are experiencing difficulties they would prefer to turn to people they already know and trust (such as their teachers). Is there more we could do to improve support provided by non-mental health professionals?

We have listened very carefully to young people and are continuing to support and train trusted adults in a variety of places ensuring teachers, youth workers and parents are well equipped to teach and support young people to find the right solution for them and to build

#### their own resilience.

Our Framework for the Whole School Approach has been developed to support good emotional and mental wellbeing by promoting a positive cultural environment. We want our schools to provide an environment where children and young people can form positive relationships with staff and other learners, with other professionals working with the school and with the wider community that surrounds the school. We know it is important that young people have clear routes to ask for support.

After successfully piloting our CAMHS in-reach project in areas of Wales during 2019 and 2020, we are rolling out the service to all areas. This provides access for staff in schools (not just teachers) to support pupils' mental health and well-being and improve schools' access to specialist liaison, consultancy and advice when needed.

Another example is through the Youth Support Grant. We also provided funding for local authorities to work with the voluntary sector to reach a wider range of young people where they are already spending their time. This will support youth workers to deliver early intervention and prevention services for those with low-level emotional mental health and wellbeing issues, and be available all across Wales.

#### We increasingly live in a world where people view their experiences through a 'mental health lens'. How can we work to avoid the "medicalisation" of experiences such as living through the COVID pandemic and growing up?

I consider the best way we can ensure we avoid medicalisation of growing up and design the right support for young people is to ensure that young people themselves are at the front and centre of the design of the services we intend to provide.

We need young people to get involved in their areas, to reflect their clear views and keep us on track. The Nest framework will be delivered through Welsh Regional Partnership Boards. There are seven of them in Wales and each of them already has or will shortly be creating a young person's subgroup/stakeholder group. Organisations such as Children in Wales with their Young Wales Programme and the Children's Commissioner's Super Ambassadors programme provide you with the opportunity to share your views and be a champion for young people's views. Of course there is also the Welsh Youth Parliament that allows you to become part of the activity to make sure the way we design and provide services are right for you and your friends.

# YOUNG PEOPLE TALK MENTAL HEALTH

# OUR MINDS OUR FUTURE



### Laura:

"I want to see transitions made easier and waiting times shorter, so that you feel like you aren't forgotten about. I was discharged without being told and had to wait for another referral from my consultant psychiatrist to see a psychologist. More understanding of trauma is also needed: although I knew I was struggling, no one picked it up as anything serious for a long while.

"In the future I hope to see: written reports given to patients after their appointment; less stigma; and more specialist services tailored to a range of conditions.

### Laura's Demand: "We want to see services working well together to help us, using a holistic approach"

"Personally I am receiving this in the services I am currently using, but I also understand that many don't. When I was transitioning from Child and Adolescent Mental Health Services (CAMHS) to adult services, I was dropped because my illness wasn't 'serious' enough. I felt that I wasn't being treated as a person."



### Tessa:

"Having a good support network around you is really effective in recovery. Also having a good and clear recovery plan that you're happy with can have a big impact as it's something to follow and work towards.

"I feel like young people's voices are sometimes listened to in shaping services, but not nearly enough. It feels as though young people's opinions are asked for a lot but never utilised. I hope that young people's services are easier to access in the future and are more welcoming, inclusive - and the patronising and uncaring attitude goes!

# Tessa's Demand: "We want to access face-to-face and online settings that are safe, welcoming, and respectful"

"I think having a safe, welcoming and respectful setting to access face-to-face and online services is vital. When you are opening up, vulnerable, and not feeling well you need to be in a setting where you can feel comfortable and at ease. I have been sat in rooms with chipped paint on the walls, no decorations and just two chairs and a table, making it feel more like an interrogation than the support I needed to recover. As a result, I never felt comfortable enough to open up and really talk about what was important. After talking to many people my age who have gone through similar things I know that this is a common issue faced by people accessing services."



### Jess:

"I don't think mental health services can currently acknowledge or accept that young people who experience mental illness cannot be placed into boxes; everyone's experiences are different and so not everyone presents the same way. From my experience this means that professionals don't always take those who don't have a 'typical presentation' of an illness seriously. I found this difficult in my recovery because I wasn't treated with kindness or compassion - and because my symptoms looked 'different' I wasn't offered the support I needed. Instead I was treated with contempt, stigma, and discrimination which in the end made me more poorly. Kindness, compassion, empathy, and an acknowledgement that even though on the outside I was functioning, I was struggling on the inside would have really supported me the most in recovery.

### Jess's Demand: "We want influencers and decision-makers to listen to us, hear our voice and be accountable to us"

"No matter a person's age, everyone deserves to be listened to – including young people. Young people often have very different needs, ideas, and wishes, which means there cannot be a 'one size fits all' approach, especially when it comes to mental health. I often found it difficult to articulate my thoughts and feelings, and found that even when I managed to do so, they were dismissed – which then made it more difficult to articulate myself the next time. I felt like my voice wasn't heard, no matter how loud I tried to be. But my voice should have been heard, and so should every other young person's voice.

"We need influencers and decision-makers to hear us so that we can help shape the future of support for those who are unable to shout as loudly. But listening is not enough – we need influencers and decision-makers to advocate for us and be accountable, to ensure young people are at the centre of any decisions made about them. I think some young people are likely to fall through the net because their voices aren't heard: having someone who is accountable to us allows us to raise questions and challenges which reduce the likelihood of this happening."



### Stephen:

"I feel as though in some services young people's voices are heard, but not all. My own experience of young people's involvement has been really good as I am always listened to and sit on a panel of young people with the Our Minds Our Future project, which is at the forefront of demanding change for young people.

"In future I hope that services are easier to access for everyone because sometimes it feels as though you have to jump through hoops to get support. I also hope diagnoses are made quicker to enable young people to get the right treatment sooner.

### Stephen's Demand: "I want to see services working well together because this will allow young people to receive better support"

"Services working more collaboratively allows young people more choice and opportunities for a variety of support."

# Young people and mental health



Adferiad Recovery has published a new guide which explores prevention, early intervention, and the role of mental health services.



The new guide covers:

1. Promoting wellbeing

2. Getting through hard times – and preventing a mental health problem from developing

- 3. Lower level mental health problems – early intervention by non-mental health professionals
- 4. Referral to mental health services
- 5. Preventing psychotic illness
- 6. Early intervention in psychotic illness

This guide for patients, families, professionals, and commissioners draws on Adferiad Recovery's experience to show examples of what can make a real difference.



The new publication is available at: ADFERIAD.org.uk