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About Mind Cymru

We're Mind Cymru, the mental health charity. We work nationally and locally.

Nationally, we campaign to raise awareness, promote understanding and drive change. We're also the first point of call for information and advice, providing mental health information to people in Wales over a million times every year. Locally, in communities across Wales, independent local Minds provide life-changing face-to-face support to more than 37,000 people each year.

Together, we won't give up until everyone experiencing a mental health problem gets support and respect.

- mind.org.uk
- @MindCymru
- f @MindCymruCharity

Introduction

As part of Mind Cymru's Stand For Me campaign for the 2021 Senedd elections we called on the incoming Welsh Government to:



Movelop a new Mental Health Strategy following Together for Mental Health, that listens and responds to people's individual experiences, cuts across the responsibilities of Government, and builds resilience to prevent poor mental health as well as support for those with more acute and enduring mental health problems. 99

We welcome that the Welsh Government identified mental health as a priority in its Programme for Government and is developing a successor strategy. Equally it is positive that it has been seeking views from a range of organisations, groups and people with lived experience to inform its approach.

As part of this we wanted to enable people with lived experience of mental health problems to grasp the opportunity to shape national action on mental health for years to come. This report summarises

findings from lived experience engagement conducted by Mind Cymru in June and July 2023 to explore what should be prioritised and addressed in the Welsh Government's next mental health strategy. It also draws on the extensive work Mind Cymru has undertaken with a variety of people on a range of issues over the last few years. Drawing together all this knowledge to provide an overview of what those we spoke to determine to be the priority for the next mental health strategy.

This report sets out what people told us matters most to them across all areas of life – from accessing the mental health system and the role of nature and communities, to workplace support and what happens in a mental health crisis.



Prioritising at a time of financial constraints

It is impossible to set out a realistic vision for the future of mental health in Wales without recognising that the new strategy is being developed in the context of serious constraints on the public purse, with health boards and other public services being tasked with finding significant savings in their budgets.

We heard loud and clear from the people we spoke to that they need more support and staff to cut waiting times and have the capacity to deliver quality care. In the economic context that the strategy is being developed this means ensuring all investment is having the biggest impact. At the moment we know too many people are falling through the cracks and not getting the help they need in the way that they would like.

We recognise that we are calling for change in an environment where difficult decisions must be made about priorities. There needs to be balance between recognising the long term benefits of investing in early intervention along with acknowledging that people seeking support from the health care system in Wales are not always having their needs met. The whole system needs to be looked at to determine where investment will make the biggest impact both now and in the future.

Our most recent engagement work focused on listening to what people told us and reflecting back the most urgent, strongly felt themes in our recommendations. However, over a number of years we have listened to people about their various different experiences, whether of moving from young people services to adult services or of waiting for talking therapies. It is important

Prioritising at a time of financial constraints



to note that listening to experiences and shaping the strategy according to them will ensure the investment made into the mental health system has the greatest impact. It is not economically viable to continue to deliver services with limited understanding of the outcomes for those who are receiving support. We need to know if people are getting better - and if not, why not. We have consistently highlighted how an effective output and outcome data set for mental health services is urgently needed in order to be able to analyse where the system is effectively supporting people as well as where there are challenges that need greater focus or change. Whilst we welcome the steps taken to progress this work in recent years, there is a need for the new strategy to recommit and deliver this refreshed data set within the first stage so that a picture can be transparently shared and challenges in the system identified.

We know that not all the solutions lie within the mental health system and that without true and meaningful cross-government action, the social and economic determinants of mental health will continue to drive wider inequalities in wellbeing and access to support. This means that appropriate cross government outputs and outcomes need to sit at the heart of the strategy, so that across government every mental health related investment is making the biggest difference.

Investment in children and young people is also an investment in healthier, happier adults who understand their own needs and will know where to turn for the support they need at an early stage. We know from the young people we have spoken to and the research we have undertaken that despite an increased focus on their experiences, too many young people are being let down by the system.

The pandemic shone a light on the inequalities that have been present in our health system for many years. The new strategy needs to ensure investment and strategic drive is focused on reducing and mitigating these inequalities with tangible action. These inequalities are only likely to widen with the financial challenges many people, families and communities are currently facing, which will only increase the mental health need on a wide range of support services.



Together for Mental Health, the Welsh Government's 10 year mental health strategy that is coming to an end was a well intentioned strategy which set goals in areas that needed to see urgent improvement. Positive progress has been made in a number of policy areas including crisis care, primary care and perinatal mental health support. Together for Mental Health underwent a review which highlighted some lessons to be learned in the development of a successor.

The biggest weaknesses of the previous strategy have arguably been patchy governance, unclear accountabilities, and the delay of several years to the launch of the Mental Health Core Dataset, which would have contained far richer service performance and outcomes data than that which we have access to currently.

Looking back on the full lifetime of the last strategy, we would challenge whether a 10 year strategy is flexible enough to remain relevant and fit for purpose for it's full duration, without regular points of review on progress and emerging issues. This was particularly highlighted by the pandemic but even prior to 2020 the three year delivery

plans often had priorities that weren't part of the original strategy with limited annual updates. The lack of a published mid-point review also meant the changing landscape and understanding around mental health had to be reflected in action plans rather than strategically reflected in the direction of travel for mental health support as a whole. We would expect any future strategy to have clear review points.

The issue of whether another all-age strategy could be effective must be explored thoroughly, as Together for Mental Health effectively became an adult strategy in practice and has not delivered the improvements to child and adolescent mental health support that are desperately needed. We heard strong feeling through our engagement work that people of all ages want to see children and young people's mental health prioritised and supported.

Tackling deep rooted inequalities has to be central to any new strategy, with firm actions and clear accountability for delivery. This should also reflect that some of the communities that experience this inequality the root causes are the responsibility of other parts of government who need to clearly recognise this, identify relevant actions and adopt appropriate output and outcome measures.

Recommendations for the next strategy

Access to the right support

A range of measures are needed to tackle access to support – from support outside of working hours to ending postcode lotteries and increasing choice in how people can access help.

- Waiting times must be tackled, and we must ensure people are receiving therapies appropriate to their needs, for as long as they need it. This will only be achieved with significant growth in the workforce, a diversification of the workforce to improve cultural competence and the comprehensive collection of outcomes data for people who seek support.
- The availability of support should be expanded for those who struggle to access appointments including GP and therapy appointments during traditional weekday working hours. This should include options for self-referral.
- The Crisis Care concordat should be reviewed to ensure its continuing relevance, legacy and assess where gaps remain in supporting those in a mental health crisis, such as 'sanctuary' type service models.

Mental health inequalities

We know that particular groups in society are more likely to struggle with their mental health, less likely to access support and also often have poorer experiences when support is delivered.

- Data collection across mental health services urgently needs to be improved to better understand how and why mental health inequalities persist. We must be able to assess not just access to services, but also outcomes and experiences for groups we know are facing inequalities.
- The next strategy should include a specific anti-racist area of work to tackle the quality of support and access to support for racialised communities, including looking at developing a Patient and Carer Race Equality Framework as recently launched in England.
- Children and young people should be a specific focus of the next strategy. If it is an all-age strategy, it will need to prioritise the need to improve support for children and young people across all areas of life including education, the transition to adult services, inpatient care, crisis care, support for neurodivergent conditions and eating disorders.
- Mental health stigma and discrimination still endures and efforts to tackle it need to continue, in particular with a focus on racialised communities and mental health problems that are more stigmatised than others such as schizophrenia, bipolar disorder and personality disorders.

Recommendations for the next strategy

Cross government action

We will not see a step change in the mental health of the nation without meaningful cross government action.
Wider factors like poverty, insecure employment, racism, community environments and housing insecurity are key determinants of wellbeing and improving mental health services will have a limited impact while the wellbeing of so many is under threat from difficult and preventable life experiences.

- The two-way relationship between mental health and poverty should be a focus of Welsh Government's agenda to tackle poverty, including child poverty. The next mental health strategy must address access to support for people facing poverty and track the outcomes of support being delivered.
- Mental health must remain high on the agenda within educational settings; in particular young people still feel that staff in schools need a better understanding of mental health to create a supportive environment.
- Welsh Government must recognise the importance of resilient communities, and an active voluntary sector that supports mental health and wellbeing. This will require sustainable, long-term investment.





Methodology

Between June and September 2023 we conducted three focus groups, one in partnership with Llanelli Mind, one with members of Mind's Youth Voice Network focussing on young people's priorities and experiences, and another in partnership with BAME Mental Health Support which focused on how the next strategy could be effectively anti-racist and address the challenges faced by racialised communities.

We also ran a survey where people could feed in their priorities for the strategy which received 347 responses. The data for this engagement was entirely qualitative, with free text boxes accompanying each question to allow open responses. We undertook a thematic analysis of the responses, coding each response according to themes to draw a comprehensive picture of priorities and experiences. Responses that covered multiple themes were assigned multiple codes to capture the full span of the response.

The other reports and evidence referred to in this report can be found on the Mind website.

What we asked

?

Thinking about your own mental health and wellbeing, what's most important to you for good mental health?

6 Opportunities to spend time outdoors with family. Quality time. Identifying that the current work/education structures no longer suit 21st century life. 99

Kellie, 40

The two most prevalent themes within responses to this question were access to timely and appropriate mental health support, and having support networks such as friends and family for informal support. Throughout the sessions we held there was a powerful theme about building communities that can support people outside of what they are receiving or waiting to receive from the NHS in Wales. Investment in community and third sector organisations to facilitate and build these communities is vitally important if we are to successfully continue to support people who experience poorer mental health in their community.

Mind's joint report with the Co-op Together Through Tough Times¹, echoed many of these themes when it looked at what creates resilient communities. It highlighted the importance of an active voluntary sector that can welcome people to the community and provide opportunities to volunteer, as well as the need for community assets that allow people to meet and develop relationships.

6 Bare minimum to survive. If I am not worrying about my next meal, I can prioritise better. 99

Arthur, 20

Stability and security of finances, housing and employment – and the impact of poverty on these areas - were highlighted often. These are only likely to become more prominent in the coming year as financial uncertainty continues. There is a need for support to be better co-ordinated, recognising that people may have multiple needs and it is unnecessarily traumatic to have someone tell and retell their stories multiple times.

To feel safe and secure in a home, to know I can settle and build friendships and a life and have security. To know that a landlord cannot just evict you because they want to sell or give the property to a family member. 99

Carys, 55

Working conditions were also often cited, particularly the impact of stress, not enough time for rest and/or family life, and not having access to paid time off when unwell.

 $^{1. \ \} www.mind.org.uk/media/9426/togther-through-tough-times-main-report_en.pdf$

Emerging themes

In order of prevalence, the top 10 themes that emerged on what was most important to individuals for good mental health were:

- Access to services
- Support networks, socialising and hobbies
- Purpose, a balanced life, life satisfaction and routine
- Working conditions, workplace wellbeing and support in educational settings
- Community, access to nature and being outdoors
- Health, exercise, diet and sleep
- Security of housing, finances and work
- Feeling heard by professionals or friends and family
- Empathy, understanding and the absence of stigma
- Third sector and community services





What changes to NHS services could make sure everyone gets the support they need, whenever they need it, including in a time of mental health crisis?

Elin, 27

There was strong feeling from respondents that waiting times for things such as assessments and talking therapies were leaving people to become increasingly unwell with no support in the interim. These reflect issues Mind Cymru has raised through our reports Too Long To Wait, which looked specifically at adults experiences of waiting for NHS talking therapies, and our ten year analysis of the Mental Health Measure, which highlighted that children and young people were having to wait longer than adults for access to assessment and treatment at primary care level.

We also heard widespread recognition that funding for mental health services, and recruitment of staff were the core challenges to tackling waiting times.

66 In depth exploration of mental health instead of being prescribed anti-depressants instantly with no further support. I've been on and off anti-depressants since I was 16, no opportunity for talking therapies, cbt or counselling just constantly offered mindfulness despite telling doctors multiple times that it does not work for me. 99

Beth, 24

Many respondents indicated that an ability to self-refer to mental health support without needing to go via a GP could not only cut waiting times but also make it easier for people to seek support. Such services aimed at supporting people with mild to moderate mental health problems are often delivered by the third sector through a selfreferral model. Many of these, such as Mind's Supported Self Help service, collect robust data on outcomes which can demonstrate the value of such programmes, tracking scores on anxiety, depression and wellbeing. The Supported Self Help programme has supported over 17,500 people since 2020 and has collected outcomes data which can be broken down by multiple population groups.

Barriers to seeking support commonly highlighted included people feeling they weren't being taken seriously when seeking support, and logistical barriers such as being unable to access support without needing to make phone calls or leave the house. These were things respondents highlighted as often difficult due to their mental health. Training for staff on how to support people with mental health issues, as well as increased availability of digital systems and support options were frequently suggested. In our focus group with Llanelli Mind continuity of care and being able to develop relationships with staff rather than having to retell mental health histories to multiple different professionals was raised as a priority.

We heard a strong desire for more care outside of working hours, both from GPs for those who aren't in crisis but struggle to access appointments due to working hours, and for those in crisis. The availability of crisis care, quality of the care itself and follow-up care after a crisis were all areas in which we heard of poor previous experiences.



The Crisis Care Concordat has been very effective in providing a focus for sharing accountability, progress and challenges on both a national and regional level. The recognition of shared accountability across agencies has been crucial in taking a solution focussed approach and placing the person in need of help at the centre of decision making and action. Whilst the Concordat should probably be reviewed due to it being in place for a number of years now and in order to ensure it continues to be relevant to the ever changing mental health environment, its impact on bringing agencies together to improve responses to mental health crisis cannot be underestimated.

6 Patients need to be able to get to and from appointments and have the opportunity to receive support around other commitments such as family, work and school. I know people who have had to turn down support because there is no flexibility in when people can attend appointments. 9

Jenna, 36

The Concordat has also driven a significant increase in commissioned sanctuary provision within the voluntary sector in Wales, which provides an alternative to A&E for people who are experiencing mental health crisis. We saw this with our focus group with Llanelli Mind, as we explored what service users most valued from third sector provision locally. An out of hours service called the Twilight Sanctuary was raised as being particularly vital and valued. It seemed to fill a gap that statutory services and traditional mental health service models weren't considering; that out of hours support for those who are wanting to talk to somebody quite urgently but are not at a crisis point could prevent an escalation of poor mental health into a crisis. One participant summed up what they felt people needed more of from services as 'hospitality not hospital'.

Emerging themes

In order of prevalence, the top 10 themes that emerged on what changes individuals wanted to see to NHS services were:

- Waiting times and the availability of support while being on a waiting list
- Access to appropriate therapy, choice of therapy and an end to people needing specialist care being offered only low-level interventions
- Availability of 24/7 crisis care and the quality of crisis care
- Workforce recruitment and increased funding for mental health services
- Staff training for staff across mental health services, primary care and wider NHS services
- Support for children and young people, CAMHS support and transition between child and adult mental health services

- Joined up care, links between physical and mental health support including for disabilities and long term conditions
- Services focused on prevention, early intervention, self-management and peer support
- Equally prevalent:
 - A) Greater out of hours primary care provision and GP appointments outside of working hours
 - B) A more holistic approach to care
- Closer collaboration between the third sector and the NHS, or more availability of third sector services



Thinking about equality, and making sure everyone can access the services they need, what are the main issues that need to be tackled? What needs to be done?

More provision of support for groups who experience most inequality - people on lowest income or no income, young people and people of colour.

Greater investment in culturally competent treatment, and more funding to support third sector mental health and equity providers. 99

Megan, 19

Many respondents highlighted enduring stigma around mental health within racialised communities and a resulting reluctance to seek help, which is compounded by services that are not culturally competent or are discriminatory. Language barriers were also commonly raised as a barrier to seeking support or receiving adequate support.

The endurance of stigma across different communities and around particular mental health conditions was raised commonly both in our survey and focus groups. The current phase of the Time to Change Wales campaign focusses on tackling stigma in under represented groups, with a particular focus on black and minority ethnic communities. The campaign has successfully recruited champions from a variety of communities and organisations in order to create safer environments to start a conversation around mental health. We have heard very clearly that whilst great strides have been made around tackling mental health stigma and creating safe environments for mental health conversations to take place, this is not uniform and stigma continues to play a significant role for some people and communities. The next mental health strategy needs to ensure the work of Time to Change Wales as a campaign is not lost and there continues to be a focus on tackling this issue for all communities in Wales.



A lack of data and understanding around marginalised groups within mental health services was highlighted as an urgent area for action. This is something we have consistently raised in reports, evidence and consultation responses. This data, output and outcome, then needs to be analysed and used to drive improved experiences and address gaps in provision.

6 Equality, diversity and inclusion should be audited by the respective bodies. Mental health problems affect marginalised groups disproportionately. 9

Dafydd, 69

Groups that were most frequently identified as facing inequal access to services and inadequate support included racialised communities, people with disabilities and neurodivergent conditions, children and young people and people living in poverty.

There was a strong feeling of injustice that the issues of accessibility and waiting times for talking therapies resulted in a gulf where people who could afford to pay privately were getting the help they needed while those on lower incomes were left without help. In both our survey and focus groups, many also felt that postcode lotteries disproportionately affecting deprived and rural areas were severely impacting equality of access to services.

★ Lack of therapy and CBT, the wait times and lack of information is a big issue. Those with disposable income can access these services privately. But those who cannot afford it have nothing.

→

Amy, 47

The diversity of the workforce was highlighted by several respondents with suggestions that targeted recruitment of people from marginalised communities into the mental health workforce to make it more representative of the population could improve the quality of care and the likelihood of people from those communities seeking help when they need it.

Emerging themes

In order of prevalence, the top 10 themes that emerged on how individuals felt equality of access to services could be improved:

- Training for staff on equalities issues, tackling discrimination within services and improving the cultural competence of services
- Choice in treatment and support, including digital/phone support for those who would prefer it
- Equally prevalent:
 - A) Equal services and access to services across all areas, eliminating postcode lotteries and poorer access within rural communities
 - B) Communication about services and what to expect, and more joined-up services
- Equally prevalent:
 - A) Improved support for children and young people and CAMHS services
 - B) Accessibility of a range of NHS therapies
- Stigma around mental health including particular conditions

- Workforce recruitment
- Equally prevalent:
 - A) Availability of 24/7 crisis care and the quality of crisis care
 - B) Financial, housing and employment security
- More focus on prevention
- Equally prevalent:
 - A) Tackling stigma specifically within marginalised communities
 - B) Access to support for neurodivergent people and an understanding of the relationship between neurodivergence and mental health
- Mental health support for people with disabilities and physical health conditions



Thinking about all of the things that can impact mental health (such as good work, education, housing and safe communities), what could be done to protect mental health in these areas?

66 Better pay and support in work.

Abolish universal credit. Pay the teachers, nurses etc a decent wage and put mental health points in all schools and wards. Provide good quality, affordable, dry housing for everyone.

Provide more social workers, care workers to help sort safe communities.

If you treat people better they have a base to climb from. 99

Susannah, 61

Calls for action within educational settings and workplaces were overwhelmingly the priorities in this area. There was a particular appetite for education around mental health literacy to begin at a young age. Within workplaces we heard both a strong call for support from employers to be expanded, but also legal protections for workers whose employers are treating employees poorly relating to mental health.

66 I think a universal basic income would help a lot of people. The link between poverty and mental health is huge and some people with poor mental health cannot work traditional jobs, so having a cushion of money so that you can at least pay your rent and buy food would be a huge help. It would also allow people to pursue personal interests, start businesses and study. 99

Catrin, 32

Similarly to themes from previous questions and from our focus groups, stability around finances, housing and employment were often cited as vital to good mental health. Many people suggested a Universal Basic Income would greatly benefit people with mental health problems, whose ability to work may fluctuate.



The proper funding of social services to create a reliable, shame-free safety net would be huge for protecting people's mental health. A sense of security can go a long way in daily life. 99

Aurora, 28

We heard many calls for support across the wider determinants of mental health to be located in one place, in a 'hub' style model to make support accessible and integrated in a way that reflects how intertwined these issues are.

Across our focus groups the importance of safe communities with environments that promoted wellbeing was emphasised.

Emerging themes

In order of prevalence, the top 10 themes that emerged on how individuals thought Welsh government should act on the wider determinants of mental health were:

- Support for children and young people within education and youth services, and education on mental health literacy
- Support from employers and good working conditions
- Good, safe communities and community services, such as community 'hub' service models
- Housing security and availability, and tackling homelessness
- Access to information and support across all the areas of life that can impact mental health
- Tackling the cost of living
- Tackling income inequality
- Tackling mental health stigma

- Equally prevalent:
 - A) Cross-government
 planning to tackle mental
 health across all these
 areas (such as good work,
 education, housing and
 safe communities)
 - B) Physical activity, leisure and social opportunities
- Equally prevalent:
 - A) Improved support and understanding for neurodivergent people
 - B) Improved social services and social care



Spotlight on:

Racialised communities



As part of our research we held a focus group in Swansea in partnership with BAME Mental Health Support to explore the experiences and priorities of people from racialised communities, and how the next mental health strategy could be an anti-racist strategy in line with Welsh government's commitment to make Wales an anti-racist nation.

Mental health means everything to me! 99

We asked how NHS support could be improved for people from racialised communities

Much of the discussion on this topic highlighted a need for training for medical professionals and changes to medical advice and research which is overwhelmingly designed around white people. Making the workforce more diverse, particularly among positions of authority was also a priority.

Suggestions for action included:

- Learning and re-learning: diversity training for health providers on how to tackle different minority issues
- Increasing the diversity of the workforce
- Research on service design and production to include more participants from racialised communities
- More people from racialised communities in positions of power and authority
- Addressing the way medical research and advice is mostly written by and centred around white people
- A system that supports the mental health of healthcare workers who are experiencing racial discrimination

We asked what government could do to make sure people from BAME communities are treated with dignity and respect when they are inpatients in mental health services

There was strong agreement that racial bias within mental health services contributed to negative experiences that caused major harm within inpatient settings, such as an assumption that black men were more likely to be aggressive and violent, which led to excessive uses of restraint. Staff training and representation as well as closer links with communities were highlighted as ways to tackle these issues.

Suggestions for action included:

- Action to eradicate the enduring racist stereotype of BBD ('big, black and dangerous', a term used as the subtitle of the inquiry report into the death of Orville Blackwood) within mental health services which results in the overrepresentation of young black men in inpatient and secure settings
- Appropriate restraint techniques, tackling the overuse of restraint and ending the use of face down 'prone' restraint

- Increased transparency and data collection
- Improved quality of care
- More funding & support for community organisations
- Awareness & integration of racialised communities
- Ethnic minority representation in administrative levels of the NHS

We would add that the Welsh Government and NHS Wales should look to develop and implement guidance for all health settings similar to the Patient Carer Race Equity Framework that is in place in England. This would ensure a more systematic approach to improving experiences of racialised communities in mental health settings in Wales.





We asked what actions could be taken on the wider social factors that can impact mental health (such as good work, education, housing and safe communities)

Similarly to the answers to our initial question on what matters most to participants' own mental health, there was a strong theme of the need for stability in areas of finances, employment and housing. Specific issues faced within those areas were raised such as social exclusion, discrimination at work, barriers to getting employment in the first place and private landlords creating barriers to housing affordability/access with unfair criteria.

6 Having the basic amenities and being stable in terms of a fulfilling job, inclusive environment and community. 99

Suggestions for action included:

- Providing relevant job opportunities tailored to accommodate visa conditions of immigrants from racialised communities i.e. 20 hours for international students
- Encourage transfer of skills and knowledge from our home countries
- Improve recognition of income contribution and cultural contributions of immigrants into Welsh communities
- Introduce regulations to tackle the housing crisis and create a fairer rental market
- Provide funding to community organisations which can be a refuge for racialised communities
- Ensure organisations and employers offer their staff regular EDI training to tackle isolation and discrimination felt at work by staff members from racialised communities

Spotlight on:

Young people

We held a focus group in September 2023 with members of Mind's Youth Voice Network from across Wales to explore the priorities and experiences of young people with mental health problems. We also analysed the responses to our survey from young people aged under 25, a sample of 221 young people, to see how priorities differed to older age groups.

It is worth noting that support for children and young people and beginning education around emotional wellbeing from a young age was a high priority across age groups, not just young people themselves.



What's most important to young people for their own mental health?

Acceptance and having a good support network were the most prominent themes; the makeup of an ideal support network ranged from informal networks of family and friends, to mental health support services and also community support networks for specific groups, such as young people, LGBTQ+ people, or people with specific mental health problems.

Having some routine and structure to my week with support when I need it. 99

Lifestyle issues like routine, structure, an understanding of how to meet your own needs and the ability to take space and time for yourself were also highly valued.

In our survey we saw little difference among young people compared to overall themes, but younger people placed more importance on lifestyle factors such as health, exercise, diet and sleep and were more likely to raise support and understanding around learning difficulties/neurodivergence as important.



What changes do young people want to see to NHS services?

- 6 Better understanding of autistic individuals and links to increased mental health problems such as anxiety and depression. 99
- 6 Having more mental health services in place to avoid very long wait times. 99

We heard strong feelings that the support many participants had received from NHS services as young people were often not appropriate to their needs, had long wait times and were not effective. This was particularly the case for people with neurodivergent conditions and eating disorders. Some had struggled with a lack of follow-up care after receiving an intervention that wasn't effective.

Mind Cymru's Sort The Switch campaign explored the experiences of young people moving from specialist young people services to adult services. We heard from young people who felt abandoned by the mental health system and left without support. The campaign made a series of recommendations to improve an area that has consistently been challenging for young people and their families to navigate. We would expect the next strategy to commit to a significant improvement in approach to transition for all children and young people.

A number of the young people we spoke to as part of Sort The Switch had experience of eating disorders and we heard further negative experiences through our engagement work. Participants reported not receiving mental health and psychological support, and of only receiving help if they met a particular BMI range. Whilst there has been a focus on improving eating disorder support the experiences we heard just demonstrates how much more needs to be in place to support these young people.



66 I had an ED diagnosis in January 2022, and didn't see a dietician until December 2022. I was only given physical interventions.

Enduring mental health stigma, and a need for more training in the primary care workforce were also highlighted. People are still telling us about experiences of stigma and discrimination from people working within health services, particularly for those with less common mental health problems, or co-existing mental health problems and neurodivergent conditions.

Participants shared difficult experiences of both crisis and inpatient care. There was strong agreement that there was a long way to go before appropriate 24/7 crisis care was available to everyone and inpatient services met the needs of young people.

6 Crisis services especially need to be looked at. And inpatient services are often really difficult places to be. Like as a young person being on an adult ward with people 2 or 3 times my age. Plus having autism and being with people who might be loud is hard too. 99

In this part of our survey young people were more concerned with access and quality of support for neurodivergent conditions, and services' understanding of the relationship between neurodivergence and mental health.







We heard a range of opinions which reflected the differences often heard on this topic. Many felt that more medicalised language and diagnoses were helpful for some and validated experiences, as well as being a crucial threshold for receiving support and being taken seriously by services. Others felt the language was complex, hard to understand and lacked empathy.

- We need to normalise using terminology like depression rather than 'low mood'
 it can be really invalidating, and also builds stigma around having a mental illness/condition.
- 6 It can also be really helpful to have a diagnosis for when you attend other services that access your medical records as this may explain why you act a certain way. 99

6 Most younger people and most teens don't fully understand the terminology that medical professionals are using. 99

There was agreement that differences in language used even within different areas of health and social care - such as mental health teams, social workers and GPs all using different terms - caused confusion. There was some agreement that people had different preferences, and staff being aware of individual preferences was an important step in providing good care, rather than a blanket approach.



What support do young people want to see from schools, colleges and universities?



In our focus group a prominent theme of the discussion was a lack of understanding among staff in schools which led to students being penalised for issues related to their mental health. We heard an account of a student being placed in detention for running away while experiencing psychosis, others being penalised for absences and panic attacks and students struggling to receive reasonable adjustments relating to mental health problems and neurodivergent conditions.

It was agreed that teaching staff could benefit from training to spot early warning signs that a student is in need of support, and reviews of safeguarding policies. This should be central to the Welsh Government's statutory whole school approach to mental health. The guidance should be supported with comprehensive training and support for staff to create an environment where there is safety to talk about mental health and signposting to support is quick and non-stigmatising.

There needs to be much greater awareness and sensitivity to how the curriculum is delivered.

As an example we heard multiple instances of schools delivering education aimed at tackling obesity which arguably promoted disordered thinking around calories and could be triggering for students with eating disorders or at risk of them.

6 In PE lessons people were given a McDonalds menu and asked to work out the calories in their order. They then had to burn this many calories in the lesson. 99

...With BMI – we were asking to calculate ours in maths and then asked to share it with peers. 99

The new curriculum has the potential to be transformative for young people, not only through providing more focussed time for discussion about mental health but linking in with a whole school approach to mental health in order to provide a school wide response.

Some respondents had experiences of ALN schools and felt that despite a high number of pupils in these settings having experiences of mental health problems, the understanding among staff and communication with mental health services was poor.



Conclusion

The new Welsh Government mental health strategy is an important moment for all of us who need support for our mental health. It needs to balance strengthening the protective and preventative factors within communities with the need to ensure support is quickly available and meets the needs of all our communities in Wales. The work we have undertaken in recent years demonstrates that

when investment is made, trust is built and people can access support quickly amazing things can happen. We hope that the views reflected in this report will be listened to, included in tangible, measurable actions and encourages Welsh Government and the wider public sector to continue to engage with people about their experiences with the view of improving the lives of everyone.

Acknowledgements and thanks

This report is a reflection of the voices of around 400 people who took time to share their experiences and thoughts with us in rich detail, often retelling stories that were traumatic and difficult. We are a campaigning organisation that places lived experience at the core of what we do, and are grateful to everyone who shares their stories with us so we can effect change together.

Particular thanks to the services users of Llanelli Mind, BAME Mental Health Support and members of Mind's Youth Voice Network for taking part in our focus groups.

What's next?

Priorities for the Welsh government's next mental health strategy

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