Legislation Committee No.3

LC3(3)-05-10: Paper 2

Proposed Mental Health (Wales) Measure

Written Evidence submitted by Mind Cymru

Summary

Mind Cymru believes the proposed Mental Health (Wales) Measure to be an appropriate mechanism for developing legislation in the devolved matters of health and social care as they relate to people with experience of mental distress living in Wales.

The evidence for the demand for this legislation is strong across Wales, from the individual, family, local and national perspectives.

Mind Cymru believes these proposed Measures to be the best placed mechanism for providing for the wider needs of people with experience of mental distress living in Wales, as full use of existing powers has already been made. However we still have concerns, which need to be addressed by the Government, including:

A general duty to provide independent community mental health advocacy must be included in the proposed Measure.

Timescales need to be used to ensure people receive the assessment, treatment and care to which they are entitled, in a timely fashion; together with a timeframed dispute resolution system.

Primary Mental Health Schemes have no standards and no measures prescribed within the proposed Measure. This needs to be addressed, either through guidance on the face of the Measure, or through Regulation.

Resources need to be in place to ensure effective staffing levels to implement the Measure, and ensure its long term benefits.

Where reference is made to Regulation, for example sections 43 and 44, these take account of the views expressed in evidence gathering, including the views of people with experience of mental distress and their carers.

Due consideration be given to the potential expansion of the proposed Measure to include provision for those under the age of 18.

Introduction

Mind is the leading mental health charity in England and Wales. Mind Cymru is Mind's presence in Wales.

Mind Cymru welcomes the opportunity to contribute to this consultation process. The views expressed within this response are the views of Mind Cymru and are informed by people with direct experience of mental distress.

Mind Cymru is well experienced in matters of legislation affecting people with experience of mental distress, living in Wales. One example of this was the facilitation of 13 events across Wales, in community settings, hospitals, secure units and prisons, to inform the Mental Health Act Code of Practice for Wales 2007.

Mind Cymru's key messages are that:

People with experience of mental distress inform all that we do.

Because people with experience of mental distress inform all that we do, we know what the real issues are.

We are determined to improve society's recognition, understanding and acceptance of people with experience of mental distress.

We value diversity and ensure inclusion is at the heart of our work.

General Comment

We have responded to each of the Committee's questions, with questions 2 - 4 building on our responses to question 1. We look forward to having the opportunity to discuss these matters in more detail on 22 April 2010.

1. Is there a need for a Proposed Measure to deliver the following aims: Providing local primary mental health services at an earlier stage for individuals who are experiencing mental health problems to reduce the risk of further declines in mental health, and in some cases, reduce the need for inpatient treatment and compulsory detention?

Mind Cymru strongly believes that there needs to be an emphasis on earlier intervention. In 2006 the National Assembly for Wales Audit Committee stated that:

"A further challenge will be to develop services which have a greater focus on the prevention and early detection of mental health problems. Although the importance of mental health promotion and early intervention is recognised in much of the Assembly Government's strategic and policy guidance, many service users and carers indicate that they can only obtain access to specialist support

if they are experiencing a mental health crisis. This is unacceptable and indicates that work is still needed to bring about cultural and organisational changes in the way services are delivered".

There is still an urgent need for investment in early intervention to assist in the prevention of inappropriate hospital admissions and other referrals to second tier services. Proper approaches to crisis prevention result in considerably less stress to both service users and service provision. The current insufficient funding for appropriate and supportive community services is resulting in delayed transfers of care from hospital, with many patients returning to hospital due to poor community provision.

There is much emphasis upon service provision once a person is in need of support, yet still insufficient focus upon the value and impact of prevention and mental health promotion.

'Equal Treatment: Closing the Gap' was a formal investigation conducted by the Disability Rights Commission (DRC) into health inequalities experienced by people with learning disabilities and people with mental health problems. The investigation covered England and Wales and came to 11 overarching recommendations, which apply to both countries albeit in slightly different ways. The DRC also produced a separate report specifically for Wales. This important report emphasised the need for early intervention and holistic treatment for people with mental health problems. However the recommendations have not been implemented in a coherent fashion across Wales. The proposed Measure will be an effective mechanism for translating vision into reality, improving the life chances of the citizens of Wales. Ensuring that all individuals accepted into secondary mental health services in Wales have a dedicated care coordinator and receive a care and treatment plan, and that service users previously discharged from secondary mental health services have access to those services when they believe their mental health may be deteriorating? Mind Cymru believes that mental health service users, regardless of the severity of their mental illness, are entitled to have their needs identified and met through co-ordinated support. Service users should be supported to identify their needs and wishes. The care and treatment plan should be based on identified need and not led by a diagnosis. Whilst some service users and professionals may find a diagnosis helpful, it represents an outline description of the needs of the service user, rather than the support that they need. The care and treatment planning process should be person-centred and needs led.

Contextual information such as the degree of social exclusion (homelessness, poverty and access to support networks for example) also needs to be considered within the proposed model.

Mind Cymru welcomes the proposal that previously discharged service users have a mechanism for access to secondary services, should they require them, without having to go through lengthy referral processes. We have evidence of service users being turned away, and told they are "not ill enough yet", leading to extreme anxiety and longer periods of severe illness. This is totally unacceptable in the 21st century.

Extending mental health advocacy provision beyond that which is currently required?

Mind Cymru agrees that mental health advocacy provision needs to extend beyond that which is currently required. However we are disappointed that the proposed Measure does not address the need for community mental health advocacy, outwith the provision for those subject to Community Treatment Orders.

In a mental health context, an advocate is someone who supports another person to express their views and concerns, access information and services, defend and promote their rights, and explore choices and options. For many mental health service users, the support of an advocate is essential in negotiating the complicated mental health system during periods of distress.

An advocate can also help to ensure that an advocacy partner is being effectively served by a range of necessary support services, including the mental health system, both in the community and in hospital. He or she may help to address issues about care plans, medication, and problems with the hospital environment or aftercare services. In many cases an advocate may also support the advocacy partner to access essential community-based or non-health related services, such as benefits or legal advice, or may help to find accommodation or childcare. The advocate plays no part in the provision of these services.

The provision of advocacy in a community setting can help and support people who experience mental distress to deal with problems and situations that may otherwise trigger contact with mental health services, and as such it also promotes social inclusion, equality and social justice. It is therefore essential that advocates must be trained to recognise and deal with discrimination, and also be aware of the effects of discrimination on mental wellbeing.

Many service users, when moving between the community, hospital - or in some cases, prison - have expressed concern that they have not received continuity of support, and that this lack of continuity has contributed to their distress.

Mind Cymru would therefore strongly support the extension of the proposed Measure to include:

A general duty on Health Boards and Local Authorities to provide independent mental health advocacy to all; without specific generalities; but with regulations specifying quality standards, equality standards and the like.

This should be implemented alongside much wider and more thorough access to information, in a variety of accessible formats, empowering people with experience of mental distress to make informed choices about their care and treatment.

2. How will the proposed Measure change existing arrangements, and what impact will such changes have?

Local Primary Mental Health Services

The importance of the role of local primary health services cannot be overemphasised. In any one year:

300 people in 1000 will experience mental distress

230 of these will visit their primary care practitioner

102 of these will be diagnosed with a mental health problems

24 of these will be referred to specialist psychiatric services

6 of these will become inpatients

The proposed Measure provides for access at GP level to mental health specialists. These mental health liaison workers already exist in some parts of Wales. However the proposed Measure would ensure greater parity and accountability of such services, to ensure they are used effectively to enable people with experience of mental distress to access appropriate and timely, treatment and care, on a person centred basis. Care will have to be taken to ensure that these workers do not become a "sticking point" in the process.

The duties placed on Health Boards and Local Authorities to provide those services identified in assessments should also strengthen the local support and provision for people living across Wales. The impact in rural areas and on minority groups receiving local, appropriate support could be of the greatest benefit. However service providers will have to be able to respond to individual need in a timely fashion, or the assessment will become a mere "wish list".

Care Coordination and Care Planning

Mind Cymru welcomes this aspect of the proposed Measure, and believes this could make a significant impact, in an area of great uncertainty and uneven practice. It will ensure that both service providers and service users and their carers have a greater level of understanding of relevant roles, responsibilities and accountabilities and of planning their journey.

It should also allow for a greater level of coherence across health and social care providers, putting the service users' needs at the centre.

Assessment of Former Users of Secondary Services

As stated elsewhere, the biggest potential change this should bring about is more timely access to assessment, care and treatment for those people who are beginning to feel unwell. This will also have a positive effect on the economy of Wales as people will be more likely to get better quickly and return to, or retain employment.

Mental Health Advocacy

Any increase in levels of advocacy provision will increase access to assessment, care, treatment and informed choice for service users and their carers. However, we continue to have serious concerns about the scope of community advocacy provision under the proposed arrangements for those outwith Community Treatment Orders.

Other Areas

Part 5 sections 38 and 39, allow for cooperative and joint working, including the pooling of budgets, and the sharing of information, between Health Boards and Local Authorities. If fully implemented this could make a huge, positive difference to the lives of people with experience of mental distress living in Wales, with both better matched provision and economies of

scale creating more choice.

3. Are the sections of the proposed Measure appropriate in terms of achieving the stated aims?

(In considering this question, respondents may wish to consider the nature of the provisions in the proposed Measure that:)

Provide that there will be local primary case mental health services throughout Wales delivered by local health boards and local authorities working in partnership (part 1, sections 1-10)

Provide for care and treatment plan for individuals receiving secondary mental health care (part 2, sections 11-17)

Provide an entitlement to assessment by the providers of secondary mental health services for previous service users in particular circumstances (part 3, sections 18-28).

As outlined in previous question responses, we believe that this entitlement will be of great potential benefit to people with experience of mental distress, as earlier, more seamless access is likely to result in earlier intervention and a quicker return to wellness. It could also assist people in being able to stay at home, and to retain their usual patterns of community activity and employment, training etc.

However the lack of provision to community mental health advocacy made under the Measure, will hinder some people's access to this provision.

Make provision in relation to Independent Mental Health Advocacy schemes in respect of patients subject to the compulsory powers of

the Mental Health Act 1983, and 'informal patients' (part 4, sections 29-37).

Part 4, sections 29-37, will allow for the extension of mental health advocacy services, as intended. However as detailed in our response to question 1, and in the example regarding assessment for those previously in receipt of secondary services , we do not believe the proposed Measure as it currently stands, goes far enough with regard to an entitlement to community advocacy.

4. What are the potential barriers to implementing the provisions of the proposed Measure (if any) and does the proposed Measure take account of them?

As with any change, the major potential barriers are resource and will. With regard to resource, money has been set aside both for seed money and for ongoing additional resources, for example primary care staff, but there are other potential staffing issues, which are less certain. These would include a lack of clarity around care coordinators and advocates.

Also the timescales for training staff will potentially impact on how quickly the Measure can be implemented in the perceived timeframe.

With regard to will, historically the relationship between Health Boards and Local Authorities has been inconsistent across Wales. This proposed Measure affords an opportunity to learn from those who already work in partnership and support those who have tried, but encountered difficulties along the way.

The regulatory controls regarding staffing will be crucial to success, and we look forward to the opportunity to engage with this process in due course.

5. What are the financial implications of the proposed Measure for organisations, if any? In answering this question you may wish to consider Part 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the proposed Measure.

The Explanatory Memorandum clearly addresses this matter. If the proposed Measure affords earlier intervention and access to treatment, it is likely to succeed in reducing the reliance on long term and more specialist interventions. We support this and would expect the savings made to be reinvested in mental health services, thus supporting Wales to deliver first class mental health services, as appropriate to the diverse population of Wales.

6. Are there any other comments you wish to make about specific sections of the proposed Measure?

"In Carmarthenshire, there's no support for OCD. Service Users set up their own support group in Swansea, but it was disbanded due to lack of funding. Now, the closest group is Cardiff, in the Link Centre, which is too far to travel. There is nothing in my area, so for 15 years, I have travelled to Cardiff regularly, to go to this group. People travel from as far as Bristol and Torfaen to attend the group" (Service User Carmarthenshire).

There is some evidence that the range of community based services available in any one place is historical and often accidental. There is a need to ensure that community based provision meets the needs of changing and developing communities.

Evidence from our network of local Mind associations (LMAs) flagged up significant gaps, based on 18 year olds presenting to LMAs with mental health needs, typically not having been in receipt of services.

Once family clinic services have been exhausted there is often no follow up or support service for the young person or family.

It was reported that there was no consistent dialogue experienced in joint planning or local mental health forums relating to the transition to adult services for young people over 16 years.

The transitional nature of adolescence is not reflected in flexibility of service provision. Partnership working ranges from limited to no engagement with voluntary sector adult services.

The method of communicating information to young people was challenged by service users who acknowledge engaging young people requires creative communication methods and the use of information technology as current access points are ineffective.

The needs of young carers are poorly addressed. Parents experiencing mental health issues are concerned over joint working across sectors and services, with poor links to education identified as significant. Parents already experiencing mental health issues have been faced, for example, with prosecution proceedings about truancy whilst absence has been to care for the parent. This reflects the lack of a joined up approach to support the family and communication between education and adult mental health services.

"I went to the ....[asylum seeker clinic] for anxiety and depression as I miss my family. They gave me paracetamol. I was angry. They treat us like we're inferior. No one offered me someone to talk to, though I would have liked that. I was told to come back again if I felt the same. It was a waste of time"

(18 year old unaccompanied asylum seeker from Iraq).

People seeking asylum and migrant workers experience difficulties in accessing primary care services and are not adequately targeted by voluntary sector mental health service providers. A general improvement is required in all aspects of equality in access to services. Voluntary organisations operating at maximum capacity are not resourced to target individual groups or equipped to respond to demand.

Within the mental health assessment process there is a general lack of understanding of the background of female asylum seekers. In particular there is a lack of understanding in relation to their possible experiences of torture in their "home" countries. There are difficulties in relation to language and translation services when accessing mental health services. There is a lack of translators available, and again some of these translators will not be aware of the background from which the individual may have come. With women in particular there are cultural issues around "disclosure" when there is a male rather than a female translator.

There are particular issues around stigma within the BME community, that links mental ill health to "madness" and on occasions an assumption that mental illness is "God's punishment" or worse that mental illness needs exorcising. We have one example of a man with depression who was severely discriminated against in the Cameroon because he was Catholic and gay. This led to continuing depression in Wales, where he was unable to access treatments apart from medication. He believes that support from AWETU in South Wales saved his life.

Anecdotal evidence in Wales still shows that people from BME communities are offered little in the form of treatment outside medication. There is a dearth of talking treatments available in the language of choice. People from BME communities are also less likely to take up, or be offered options such as bibliotherapy or exercise referral.

Our understanding is that there are significant challenges faced by members of the Chinese community in Wales.

Service users attending open access resources reported feeling part of the community and less stigmatised by mental health issues. However some service users report being treated differently because of their diagnosis.

"Since I've had a diagnosis for a personality disorder, I have been treated differently because of this. I've been pigeon holed and everything I say is because of my diagnosis, not because it's my opinion. Whereas before, treatment was always an option, I now feel they have written me off because they view me as untreatable. Yet all that has changed has been the diagnosis, rather than the symptoms, and therefore I feel discriminated against because of my condition" (Service user South Wales).

Service users still report discrimination with regard to sexuality. Often their perception or fear is that the general public will behave in a discriminatory manner, but the attitude of some professionals is still a real cause for concern.

"There is a lot of stigma around mental health and homosexuality. People fear you won't get treated as well if you say you're gay. People still think its part of your mental illness. Some Psychiatrists use sexuality as route cause of your problems, so other possible causes relating to your mental health are often negated " (Young service user).

"I was afraid of discrimination from the community, because of my mental health problems, but if your sexuality comes in to it, I found that professionals discriminate against you too" (Older service user).

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