Not just another statistic

Life in Wales for people with mental health conditions

Contents

Who we are

The Equality and Human Rights Commission aims to reduce inequality, eliminate discrimination, strengthen good relations between people, and promote and protect human rights.

November 2010
©Equality and Human Rights Commission

Introduction

"It's surprising in this day and age just how stigmatised people with mental health issues are"

In October 2008 the Equality and Human Rights Commission in Wales published **Who do you see?** This was a report based on the first major survey of attitudes in Wales towards race, religion, gender, sexual orientation, transgender, age, disability and human rights.

The survey revealed a Wales that is largely comfortable with people from different backgrounds. But it also found significant pockets of negative attitudes and prejudice. The most persistent negative attitudes centred around four groups of people – one of these groups were people with mental health conditions.

In responding to this the Commission in Wales undertook qualitative research to explore the real life experiences of people with mental health conditions.

The findings have provided a fascinating insight into the lived experiences of people with mental health conditions and how they are treated by society in a number of different settings.

Participants

In total, fifteen people with mental health conditions were interviewed. The interviews took place across South, Mid and North Wales and included both men and women. The sample included people with the following mental health conditions: clinical depression, agoraphobia, bi-polar disorder, obsessive compulsive disorder, and anxiety.

The aim of this report is to provide an overview of the individual experiences of people with mental health conditions. Given the in-depth and qualitative nature of the research, the sample is not intended to be representative of the composition of the participant groups. Rather, it is intended to be broadly reflective of the different circumstances faced by people with mental health conditions.

Experiences of people with mental health conditions

This section explores in-depth the experiences of people with mental health conditions and the impact of the discrimination they were faced with.

Overall people with mental health conditions described feeling powerlessness and shame in relation to their condition. For some their condition had a serious impact on their family relations as they felt unable to disclose their condition. Interviewees described feeling helpless in getting the help they needed, both from the healthcare system and from the benefits system. The findings reveal how this led to financial hardship, further isolation and a worsening of their condition.

There was a general consensus that there was a negative attitude towards people with mental health conditions. It was felt this often stemmed from a lack of understanding and negative media coverage. There were also examples of experiences of discrimination from those that were, or had been, in employment.

Family and friends

"I've got five children, there's four that know nothing. Four of them do not know I take tablets or have taken tablets…"

There was a strong feeling of stigma associated with having a mental health condition, due to a lack of understanding and negative attitudes in society about mental health. This led many participants to only disclose their condition when absolutely necessary and, in some cases, to keep it a secret from family and friends.

One man who lived in a small town described how he had many friends but was extremely concerned about people discovering he had experienced depression and anxiety. He was very secretive because he knew what friends and acquaintances said about other people who had mental health conditions. He did not want the same to be said about him, or for people to act differently towards him. This concern about people finding out about his depression and anxiety extended to his children.

Another person told us she was unable to talk to anyone about her obsessive-compulsive disorder other than her immediate family. When the condition was at its most severe, she feared how she would be viewed by others.

We heard how one woman family had disowned her. The female participant also described how she had lost friends due to her condition and because, as she described, "'I don't fit into their world'…". This led to her not telling her closest friend about her mental health condition. She also felt that she was unable to rely on her mother or friends for support at a time when she most needed their help.

Other people described how the attitudes of their family and friends could have a negative impact. One woman felt her mother did not understand her illness and told her to 'just get on with it'. These types of comments made her feel isolated and insignificant, illustrating the distressing effects that discrimination from families and close friends can have on individuals.

For people with mental health conditions, the language and attitudes of those around them had a profound effect. Whatever the intention, jokes and negative language increased their feelings of isolation and powerlessness.

The result of the negative associations with mental health conditions was reported to have a significant impact on people's ability to manage their lives. For one mother this led to a fear of having her children taken into care.

However, other people described how supportive and understanding family and friends had been. One participant described how people at the religious meetings she attended had been accommodating and helpful. This enabled her to participate in activities and enjoy the time she spent at the meetings.

"I felt I couldn't share that [severe phase of obsessive-compulsive disorder] with anybody because I still feel there is that stigma"

"She says 'you're mental in the head' when I'm having a bad day"

"The closest friend I've got, she doesn't even know I'm ill. I haven't said anything"

"It just reinforces all those feelings that I should be over this, I should sort myself out, that I am a waste of space...it reinforces all those feelings of I'm useless and worthless"

"I know that's crazy but there was this deep inner feeling that I had to be seen to be coping when really I was falling apart"

"I have had jokes from friends...they are saying it as a joke but part of them I think means it... 'I am saying this as a joke' but they smile and 'You can't be trusted' attitude as well. I have had that from family and friends, because of the mental health problems and 'you can't be trusted with that because you are a bit of a loony'..."

"It has not bothered me, but I think people still view anything to do with mental health as bad. It has got a negative feeling about it...I wouldn't feel comfortable telling people who I didn't know very well. Not because I am ashamed, but just because I don't like the reaction you get"

"I hide it from her [close friend]...I don't bother phoning her. Maybe she has sussed but she doesn't say anything"

"To be honest, I didn't tell many friends because you do feel ashamed. I am ashamed to say I felt a shame, but you don't want people there, because it is such a terrible place to come. I was on a locked ward…I wasn't sectioned so my visitors were locked in and out. If we wanted to go to the café or when I was a bit better to the local village, it was like getting out of prison"

"I find a reluctance to tell people how much I struggle with OCD and things when it's bad, except for very close friends who know me"

"I have had experiences with friends whereas because of my mental health issues I have had to pull myself away from certain friends, who when they were pulling me down through their own issues and they didn't know how to be around me. They didn't know how to behave with me, they would watch what their comments would be just in case it said something that would tip me over the edge… and I felt quite isolated throughout"

"If I can't go to the meetings, they have got a link up system where you can listen in on the phone and they will keep a chair at the back because they know I don't want to feel like I can't get out"

Carers

"I think there should be more help for the families because there is so little that is said or done for them…even children, I think. It definitely changes their lives"

Many people we spoke to told of the ongoing impact of their conditions on carers. It was often felt there was little or no support for those providing care for them.

We were told that carers for people with mental health conditions often felt confused and powerless, which impacted on their ability to manage their lives and finances. This led to feelings of guilt and frustration for the person with the condition.

People with mental health conditions are often carers themselves. One woman who had depression and Bipolar disorder used to be a carer for her son, who had severe depression. She felt that she had not received any help or support and that her views were not listened to by her son's doctors even though she was his carer. The guilt and stress she felt about this also impacted on her ability to manage her own depression.

"She has to take me places and then there are arguments around the house because she has to be somewhere and then she has to take me to an appointment"

" …and I want to claim for disability living allowance and carer's allowance for her to have something in her pocket for looking after me because cars don't run on air. I can only walk so far and if somebody is with me"

"She does help me a lot and she gets nothing in return for it. It is very unfair...It is discriminating to her. I am being discriminating to her in a way, but I can't help it because I haven't got the money to give to her"

"I don't think people think about the carers as important...there was no backup. I never had any offer of any help...I felt guilty because I neglected my other two children because everything was [about son with severe depression]"

Media portrayal and social stereotypes

"People think they are crazy and there is always jokes on the telly about crazy people...like there was something about OCD, you know, on the telly and it was just a big joke and yet people suffer with it, don't they?"

Many individuals felt there was a lack of understanding in society about mental health issues and consequently, the general public had a negative attitude towards people with mental health conditions. This lack of understanding and negative attitude was felt by many to be fuelled by the way that people with mental health conditions were portrayed in the media.

There was a general acceptance that people had their perceptions of mental health shaped by outdated beliefs and stereotypes and misleading media stories.

But these representations rarely reflected participants own experiences and lives. Many of the attitudes reported reinforced people's feelings of isolation and for some increased their feelings of worthlessness.

One person described how he thought that lack of understanding about mental health conditions arose, in part, because of the 'invisibility' of mental health issues compared to the 'visibility' of physical health conditions.

The hidden nature of mental ill health was seen by a number of people to make things more difficult. Some also thought there was a lack of knowledge in society about the different types of mental health conditions and the variations within each type of condition. There was a sense that this lack of understanding allowed people with mental health conditions to be perceived as a homogenous group, often characterised by extreme behaviour.

Many thought reports in the media portrayed people with mental health conditions as unstable and as a threat to others. It was felt that each time a report was featured about a person with a mental health condition having committed violent crime, the media stereotyped all people with mental health conditions as dangerous.

Negative media representation of people with mental health conditions and the lack of positive coverage meant that there was no perception of people with mental health conditions living functioning, successful, happy lives.

However, one man spoke very positively about a television programme that featured Stephen Fry talking about his experiences of Bipolar. The participant had been having problems with his doctor in getting diagnosed with depression. As a result of watching the television programme, he was able to self-diagnose and discuss his symptoms with his GP, which led him being diagnosed with depression.

One of the results of dealing with these perceptions was a negative effect on individuals' well-being and increasing the disadvantage they experienced. Improving media representations of people with mental health conditions was seen as important to transforming public understanding. Many we spoke to wanted people with mental health conditions to be seen in a more positive light and not as a threat.

"They think about workhouses and mental asylums. And media reports about people with mental health conditions killing people"

"The media don't help… I worked all my life. I know a teacher that was in hospital with me many years ago in the early seventies and he carried on and he's only just retired, so we're all the same…and not all of us [people with mental health conditions] are violent…"

"I think that happens with mental illness as well, people don't understand it, they think that it's self inflicted"

"I don't like anybody else knowing because it is a thing that people are very prejudiced against. I think people think I am going to go and stab them in my sleep just because I have had depression"

"That's the sad fact of it, that Joe Public can't see the illness…to them it's 'Oh, he's bloody nuts…Christ, he's round the bend…he needs a good kicking'…"

"Because if they can't see it they don't think there is anything wrong with you"

"You say to people 'I've had some mental health problems' and they think you've just come out of Broadmoor"

"Mental health issues is such a broad spectrum. You get the Dennis Nilsen's of this world who are going around stabbing people and need to be locked up…and then you get people with a bit of depression…yes, they are a total mess for a couple of weeks but after that they recover and get better, and a whole spectrum of people in between. Unfortunately you are all shoved into a band together. Even myself, if somebody said to me 'I have had mental health issues'…I don't necessarily think they have had a bit of depression. You do think three steps from Broadmoor…you say mental health issues and it looks bad. It feels bad even to people who have had them, themselves. It is the society that we are brought up in, the prejudices that we have been taught"

"You say to somebody 'I have had mental health issues' and that is what they imagine…they don't imagine a week locked in your bedroom crying your eyes out with depression"

"I don't know, maybe because it is like I said…it is the way it is reported on telly, if something goes wrong 'Oh he has got mental health problems'…"

"…I was gobsmacked with it…I thought that is me…so I went to have a word with the doctor…"

The community

"I wouldn't feel comfortable telling people who I didn't know very well. Not because I am ashamed but just because I don't like the reaction you get…you are judged on it"

As a result of the negative attitudes towards people with mental health conditions, people were often reluctant to disclose their mental health condition.

This meant when participants interacted with people in their community, they were often treated 'normally' because people were unaware of their mental health condition.

One person with depression and obsessive-compulsive disorder anticipated that lack of understanding about mental health conditions meant she would be treated differently to people who did not have a mental health condition.

In some instances participants did not engage or connect with their local community because their mental health condition affected their ability to interact. Often there was an anticipation of a being discriminated against by people within their community should they choose to disclose their mental health condition, rather than actually experiencing discrimination.

One woman had not been allowed to do jury service because of her mental health condition. She thought that in that situation she had been treated unfairly because she was capable of doing jury service.

"Because unless they [people in community] know you've got depression and treat you different, I can't really say whether they have treated me differently or not…"

"It's not something I talk about freely with everybody. I am an open person but…I still feel that not everybody understands mental health issues…It's very hard to explain, it's just that they would treat me differently, they would view me differently"

"Whereas today's society is so quick to brush it off, especially people with depression or it is 'pull yourself together, get over it'…and telling people not to worry about things…but with depression it is very hard to hear those words 'Well don't worry about it' because you worry ten times more"

"Today's generation doesn't understand how they can help, how they can find information, unless they have got the adequate facilities like the internet and they have got the understanding then, of knowledge in books and being prepared… then to go out and find out a bit more about their illness. So you feel very isolated from society"

"…I wanted to do jury service and you can't do jury service if you have had any mental health problems in the past…I was gutted that I couldn't do it"

Public services

Health

"I think mental health is known as a Cinderella service. I think it is easy to remove resources from people like myself because we can't fight back. I mean, if you have got anxiety conditions it is very difficult…you can cope with a lot, but it depends what frame of mind you are in at the time"

"I've lost all my trust in human nature. I used to have faith in the NHS, I don't anymore"

People were critical of the mental health services they used. Unreliable and inaccurate diagnoses were seen as a recurrent problem and many felt the quality of care they received from many health professionals was not good enough.

One woman described how, when she stayed in the local mental health hospital, she felt ignored and patronised by staff and was unhappy with the level of cleanliness in the hospital.

Another participants with agoraphobia felt that she had never received the support or information she needed about her condition. She had Cognitive Behavioural Therapy (CBT) for a time but was unable to continue with it after she was told she would have to travel to the appointments.

Many people we spoke to described not being listened to and having to fight to get the treatment they needed. When you have a mental health condition, you may be even less able to assert your rights. The impact of having to 'fight' for professional help meant that one woman felt like an annoyance and burden to her GP.

Others felt there was a basic lack of respect from staff. One man described a situation where he felt that NHS staff in a hospital had demonstrated a lack of understanding about mental health condition. He found the experience of sitting alone frightening and felt that it exacerbated his dislike of being alone in new places. This in turn, caused him to feel extremely uncomfortable about visiting the hospital again. This lack of respect and understanding increased his and others feelings of powerlessness and anxiety.

For some people the systems themselves were found to made things more difficult for them. This led, for example, to missed appointments and an increase in their symptoms. Some participants also discussed how difficult their conditions made it for them to express themselves. A need was identified for health professionals to be more understanding and to factor in additional time with appointments.

"I've lost all my trust in human nature. I used to have faith in the NHS, I don't anymore"

"There was urine on the floor, cigarette ends in the bathroom…they have these nursing auxiliaries that have about two days training…you are the lowest of the low and the staff treat you as though you have some contagious disease. They talk to you as though you are not there"

"I had a ridiculous conversation with them on the telephone saying 'I am agoraphobic. I can't get to you, could I have a visit?' and they won't do it"

"Can you imagine if you have got depression? …. You can't deal with washing your dishes so how do you say 'I demand this. This is my right'…?"

"I am pretty convinced that my problems were all based on hormones initially…I have just recently finished fighting with my doctor to get that looked into and I am actually getting somewhere with them now…but I have had to fight"

"It makes you feel like you are being a nuisance and that you are being belittled, because she obviously feels there is nothing wrong or that I am just time-wasting, so you feel a right nuisance. It is really horrible"

"There was no respect and nobody ever asked me why I was depressed which is a very simple question. I mean, they were horrible"

"...I had to strip down to my boxers to be examined but I was waiting half an hour, sitting in a small cubicle by myself"

"And the power they had…. I mean the power to…to keep you there. She asked what medication I was on, so I had to recite this medication… I said '[medication]' and the next thing, you are on another one"

"You are the lowest of the low and the staff treat you as though you have got some contagious disease. They talk about you as though you are not there"

"When they take you into a ward like that, you are powerless"

"If you had one bad experience of the mental health team, they tend to hold it against you. If you miss appointments, then it is very hard to get back in the system. As well as that then with the bulimia and the depression, my stress levels don't cope very well"

"Well I think for me with the mental health side of things, if I get stressed out, I can't sort of emphasise myself enough…I can't explain myself to the degree that somebody who hasn't got mental health problems can. Even interacting with people is very difficult and because of that, you feel discriminated then, because you think to yourself well you know 'I am just hitting myself up against a brick wall' because as soon as you say 'Oh yes I've got mental health problems' it is a case of 'we don't want to know'

"So it is very hard to get into the system, and getting people to understand unless you have got mental health issues yourself, how can you relate to somebody else, which is very hard"

"I think initially when people go to their GP's, the doctors don't have time to explain what is going on because it is complicated and obviously each individual is going to have a different set of symptoms"

"Some are going to understand what they have been told a lot easier than others. But because of that, I think they need to be referred to someone who can explain what is going on"

"Just to be there, because initially the symptoms are absolutely terrifying, and if you don't understand them, a lot of people do think they are about to choke, or stop breathing or have a heart attack or die. If there was a system where they could pick up the phone and get some counselling there and then to calm them down and help rationalise what is going on…"

Finance and state support

"But the problem is on the forms it says can you walk far and, yes, I can but the problem is I am not like that everyday where I can walk...and I'm never going to fiddle because I don't want to get into trouble for fiddling. No way, I don't believe in that"

People with mental health conditions described the difficulty with the Disability Living Allowance Claim form. Participants spoke of their worry and difficulty in completing the form due to its length and the type of questions included. Some felt it was hard to provide an accurate representation of how their condition affected their lives, due to the fluctuating nature of the conditions. There were further concerns about giving misleading information and therefore, people tended to understate the impact of the conditions on their lives.

Completing the forms and getting access to financial support was felt to be made worse by staff attitudes and lack of awareness. The result was not only feeling unfairly treated, but very often the participants families ended up living in financial hardship as well.

Many found lengthy forms and processes complicated and expressed a need for the systems to be simplified. It was generally felt there was a lack of appropriate information to help people with mental health conditions through the systems.

"You really don't feel listened to half the time and it can be very stressful and very difficult"

"The attitude from the DWP can be horrendous"

"You do feel discriminated against...I'm just another statistic, I'm just another person on the end of the phone"

"Another of my bugbears is when they try and help people get back to work. Useless for me. I was assigned someone and I never heard from her again. I know why...because she didn't know how to deal with the fact that I couldn't go out for an interview or that the job would have to be at home. There was obviously nothing set up to deal with people like me"

"You know as far as they are concerned, they have work and when they have finished their work, they go home then to their family. So I feel quite discriminated then against that...that I can't do things then with my family that other people can because of the lack in benefits then you are unable to meet your bills. I do feel discriminated now, because I haven't got that income coming in, that I can't even you know...buy the kids a pair of shoes when they need it, pay the bills when I need to"

"I think it is harder for people with mental health conditions because they can't express themselves fully. They can't get themselves heard in the way that they want to express themselves. Because of the mental health side of it, the understanding of the vocabulary and just communicating with people can be quite hard in itself…and that can be quite daunting at times"

"Forms that are actually catered for those who really are mentally ill…to make it easier to understand"

"Because they are just a pain…I can't, I can't get it, I sit there and my mind goes blank. I think what on earth are they on about here, you know…"

"And then they might ask a question on one part of the form, and then ask sort of the same question again on another part of the form, and you think…it might have been worded different but I've already answered that bit, you know?"

"They don't give you enough information on benefits and I don't think you know…sometimes when you apply for benefits you have to be disabled and you don't get the benefits that other people get when they're disabled because it is a disablement really"

"The discriminating part is I should be on disability living allowance. I am not disabled. I can walk. I can talk. I can do stuff. But my head isn't here…my head isn't in the right place. I am a very intelligent person but I can't get it out if you know what I mean. I am stuck with loads of things in my head all the time"

Blue badge parking permit

"If I had had one [Blue Badge] in the past when I was still getting out, it could have been that stepping stone for me to getting past it (agoraphobia)"

Two people had applied for Blue Badges for their mental health conditions. One had been refused a Blue Badge and the other was waiting for a response.

Both participants were aware that other councils had awarded Blue Badges to people with mental health conditions in order to help them to participate in activities and daily life.

It was felt that the eligibility rules were not consistently applied, and for the individual who had been turned down, this amounted to discrimination. There was believed to be a general lack of understanding of how beneficial parking facilities could be in helping to manage their conditions.

These two participants felt that being able to use accessible parking was vital in overcoming one of the barriers they faced with their mental health conditions, by enabling them to feel safer when out and about.

The impact of not having a Blue Badge was they sometimes struggled to leave the house, which made them feel frustrated and despondent.

"I've got a handful of friends that have got Blue Badges and I've got nothing"

"If I had had one [Blue Badge] in the past when I was still getting out it could have been that stepping stone for me to getting past it [agoraphobia]"

"There are other cases around the country of people with mental health conditions getting Blue Badges...because you couldn't have them for mental health conditions when I first tried...I know with other councils they have given Blue Badges for agoraphobics"

The workplace

"Yeah it helps my mental health to be doing something, because ... as I say I after a while and you know, you apply for jobs and you don't get anywhere and it really sort of, you know, affected me. So, so really work really is part of my therapy really"

For many of the people we spoke to, access to employment was really important, not only because it represented financial independence but because of its therapeutic benefits.

The majority of people with mental health conditions we engaged with were out of work. However, most had worked at some stage in their lives and some had faced discrimination in the workplace. There were, however, examples where they had positive work experiences and support from their employers.

For those who had problems with employment it tended to be seen to increase mental health issues. There was a general concern about revealing a mental health condition when applying for jobs in interviews. There was a feeling that disclosing mental health conditions when applying for jobs would be disadvantageous. Some described feeling trapped in unemployment. Participants were concerned that employers would think that they were unreliable, would take a lot of time off work for sickness and were a danger to other employees.

Disclosure was seen by many as a barrier to gaining and securing a job. Participants appeared to often be in a predicament as to whether or not to openly declare their mental health condition or avoid mentioning it at all.

Even where employers undertook positive action for disability including mental health conditions, there was a fear individuals would be at a disadvantage. Experiencing a mental health condition while in work was difficult for some participants and a lack of support from colleagues after diagnosis emerged from the findings.

One woman who felt she had experienced discrimination in the workplace had agoraphobia and worked as a professional gardener. She described how her employer had used her mental health condition to encourage her to leave the job after she had not returned her manager's advances towards her.

She was moved to work on different sites, but found this difficult because she was uncomfortable working in unfamiliar environments. This adversely affected her condition to the point that she felt like she was having a breakdown, so as a result, she had to leave her job.

A man, with Bi-polar disorder, told us his employer did not support him when he was diagnosed with depression. He had a physical job that was target-driven and stressful but his employer did not adjust the workload in order to help him. This meant that he had to work late and was subject to work pressures. He eventually had a breakdown and left his job. At the time, it had not occurred to him to challenge his manager as he felt the working practices seemed reasonable and that it was his responsibility to cope with the work.

There was anxiety about returning to work after time-off work. One person with depression was self-employed and worked with her husband in the entertainment industry. She decided not to tell her bookings agency she was taking time off work due to depression because she was concerned that it might affect the number of bookings she was given when she returned to work.

However, there were positive experiences. One man told us where others had personal experience of mental health conditions they had more sympathy for him and this resulted in more positive outcomes. He discovered the person who had employed him had had a mental health condition himself. He felt this was a significant factor in securing the job and went on to work successfully for the organisation for many years.

Two other people were working as volunteers and both had found the charities accepting and supportive of their mental health conditions. One individual volunteered for the animal rescue organisation and was responsible for answering telephone calls. This suited her because she had agoraphobia and was able to do her job from her home.

The findings show how these positive experiences helped people manage their conditions. But the negative experiences left them feeling disempowered and without support. Rejection and difficulties in work increased their vulnerability and, frequently, the symptoms of their condition.

"Yeah it helps my mental health to be doing something, because ... as I say I after a while and you know, you apply for jobs and you don't get anywhere and it really sort of, you know, affected me. So, so really work really is part of my therapy really"

"Obviously I think the employment procedure, application procedure, I think it does discriminate against people with mental health, well all physical disabilities. In England and Wales employers, you know, they are entitled to ask on your application form about your mental health, so you have got to put it all down haven't you?...then if you put down what you have had, got something, you know, it's 99 times out of 100...well you won't get an interview, you can't prove discrimination...you know that it's happening"

"When you get to the job centre, they have a little sign that says if you are on disability living allowance or you are disabled, you are guaranteed an interview if you mention it on your application form...so in a way it helps, but in a way it doesn't...because in my eyes, it pin points which of the people they are interviewing that are, they can tell them which ones have got problems and which ones haven't"

"Some of the comments you hear people are coming out with...there is no need for it...It's just hard getting a job these days. And I am damned if I do and damned if I don't kind of thing. If I don't tell the truth I probably won't get an interview. And if I do tell the truth, I will get interview but I am guaranteed not to get the job"

"Problems I have had in the past with work when I was working part-time...problems I had in that job caused problems with my mental health. I had problems looking for a job because I was very, very scared that the experiences that happened there would happen again"

"I think if I went for a job or anything, I wouldn't tell them [about the mental health condition] because of how they might judge me because of it"

"Yes, I think like if someone was to go for a job and they did ask you 'do you suffer with depression?' and the answer is 'yes', I honestly do think that would go against you"

"If I didn't have a cover story, I'd be very worried about telling future employers [about the mental health condition]. They think you're going to end up with a sickness record"

"If somebody said 'I am not going to give you this job because you have had mental health problems in the past and I believe that they might come back and you will end up with a sickness record' who would you go to?"

"With an illness like mental health, the fact that it might occur again would be in the forefront of somebody's mind...but they don't necessarily turn around and say 'you will be off sick so I won't give you this job'..."

"...the management turned on me and decided they didn't want me there. But they knew of my condition because I didn't keep that sort of thing secret, so it was used against me"

"...it was a gardening situation and we had lots of properties all over the place and they just moved me into all my zones of stress on purpose...they made me walk long distances to places...they just stacked up huge amounts of work on me...they would be watching me out of buildings and staring through the window"

"I can't say I had a breakdown because it was not diagnosed, but pretty much so..."

"I think because I had mental health [conditions], he gave me the job and I was there for twenty years"

Why justice not sought

"Well I don't think there is enough information put across about mental health issues and what the mental health issues are unless you have got access to the internet. There is that information there, but you don't have day-to-day materials on what mental health issues are, and how you can help somebody..."

The findings demonstrated an underreporting of discriminatory incidents. People with mental health conditions described themselves as feeling disempowered and not knowing how to use the systems available to them. None of the people we spoke to felt they knew where or how to get help and support. There was a general feeling information was unavailable, either to them or the public, in relation to mental health issues.

There was also a fear that trying to deal with the issues would increase their ill health.

"I am on edge all the time...instead of treating me as an individual and normal, it is as though I've got a label on my head...'I've got mental health issues' and it sends the alarm bells ringing and people just don't want to know. Instead of sympathising with someone they are very, very hard to judge them"

"And a lot of the employers now boast that equality and all this, but deep down they are just words, because they don't follow through with half of that"

"I wanted to take it further because I wanted it to stop, because I had seen it happen to other people. It had happened to me and I didn't want it to happen to anyone else. I wasn't in the right frame of mind to be able to cope with that…you need to be strong to be able to deal with that sort of thing. They know what they are doing, and you haven't got a clue plus I am agoraphobic, so I can't go anywhere…plus I was totally stressed to the hilt"

Practical measures and solutions

"People don't understand….they're a bit…well it's the stigma of it. They don't understand. I don't think people express it…they should be taught, or they should be shown what it's like to have a mental health problem"

As the people we talked to described the prejudice they encountered on a daily basis, solutions also emerged. Significantly the ideas on what needs to change match closely with priorities identified by many other groups the Commission has engaged with over the years.

Clear, simple information was seen as a critical first step in increasing awareness and improving relationships between people. Not only did participants want information and support for themselves, but also for their supporters and carers. It was seen to help create better relationships with, for example, those providing public services.

Overall, people wanted there to be high-impact awareness campaigns. Such campaigns were seen to change attitudes and behaviours and this was thought to be the key to better lives for everyone in the future.

Several solutions were suggested for helping people to have better access to justice. This includes the government telling people clearly where to turn for advice and who to approach for help in accessing rights. People with mental health conditions wanted support services that were tailored specifically to their needs and reported wanting help from specialists such as advocated and lawyers as they did not feel able to secure their rights alone.

Solutions for public services included simplifying systems and forms but also distributing better information about their services. In that way people would be clear about what needs to be done and how to do it.

"Raising awareness of this through some campaign. I think if you have somebody who is well known, who is willing to admit either they had depression or mental health problems or a family member and they said 'you should never say this' I think that would get through to people. I don't know how you would tell people otherwise. But people have got to bother picking it up and reading it haven't they? I would love to know that there was some way of getting through to people and saying 'don't say these things'…"

"I know for some it would knock them back for months if somebody said something negative like that because you would feel even less self-worth than you already had"

"There should be more support, more help available and make sure people know about it because there are probably services that are there to help people with mental health problems, but people aren't being told about them. Make you more aware of services that are available for people with mental health problems like help and support"

"Solicitors…they should set up places for mental health problems especially"

"I think there should be more awareness right down to school age"

"I don't know what else I could have done…I needed someone to fight my battle for me because I wasn't capable of doing it myself"

"You are not mad, you are not insane, you're not a nutter…it is just your nerves are gone and you are not in control and you need someone to…like to guide you. Put their arm around you in a mental way if you like…and guide you through this maze that you don't know which way to go"

"You can have all the laws in the world but the only thing that you are going to stop is them saying it…if you hide something, you are going to push it underground and I know it isn't that bad, but that is basically what you are doing. Nobody is going to be stupid enough to either say it or write it"

Next steps

The evidence gathered in this research gives a voice to people who are seldom heard and paints a vivid picture of life for those experiencing prejudice and negative attitudes on a daily basis.

Despite the challenges, everyone we spoke to suggested improvements that could be made, how attitudes could be changed and what steps could be taken to make lives better. In each section of this report we have included people's ideas.

As a top priority everyone highlights the need to change attitudes and behaviours through awareness-raising and through education. People feel that changing public perceptions of the issues is a task for a wide range of players.

These include the media, government, public service providers and employers. Making a concerted effort to promote positive images in all of these areas would transform lives.

People spoke about the good stories that could be told about the contributions they make to society and how these are rarely promoted. They spoke about the media and the workplace as key areas where this could make a difference. Personal contact is seen as the key to building understanding, trust and better relations within communities.

Most people talked about how important staff attitudes are in relationships with public services. They said that simpler systems acknowledging one size doesn't fit all would be a big step forward.

Many people spoke about the role of advice and advocacy as a life-line in coping with everyday tasks and in understanding rights.

Finances are very stretched for everyone. Nevertheless, there are opportunities for a broad range of individuals and organisations to take actions and make significant progress in achieving the positive next steps highlighted by those who participated in our survey.

The Commission's priorities are evidence based and outcome focused.

The Triennial Review, 'How Fair is Britain' will underpin all of our future work and the findings from this research add to our evidence in Wales and will contribute to shaping our priorities.

We will use our regulatory powers under equality and human rights law and this includes promoting understanding and effective practice. We will be sharing the findings from this research with a wider audience. We are organising conferences and events with specific audiences, such as the media, to promote change.

But the solutions that emerge do not necessarily lie in the Commission's hands. In many areas it is for other organisations and individuals to make the small changes necessary to tackle these issues. Together these will enable us all to make progress towards a fairer Wales – a Wales where everyone is confident and treated with dignity and respect.

Appendix 1

Methodology

GfK NOP conducted individual interviews with 15 people with mental health conditions.

Interviews took place between 7 January and 10 February 2010 in various locations across Wales. All interviews were conducted face-to-face. The interview approach encouraged open and honest responses and was best suited to the hard-to-reach nature of the sample.

Interviewees were recruited on a free-find basis (i.e. not through organisations).

Given the in-depth and qualitative nature of the research, the sample was not intended to be representative of the composition of the participant groups. Neither was it intended to reflect their geographic dispersal. Rather, it was intended to be broadly reflective of the different circumstances faced by people from each of the participant groups.

Participant Group	Location		No. interviews
People with mental health conditions	South	Cardiff	3 individuals
		Carmarthen	2 individuals
	Mid	Aberystwyth	5 individuals
	North	Wrexham	5 individuals

Overall 10 participants were female and 5 were male. Two participants identified as homosexual, while one Welsh speaker and four people with multiple disabilities were recruited. Given the way in which recruitment was conducted, it was not possible to consistently record the socio-economic group (SEG) of the participants in this research. Most of the people with mental health conditions were claiming Disability Living Allowance. A good spread of ages was achieved across the sample, as shown in the following table.

Participant Group	TOTAL	Age				
		16-21	22-34	34-49	50-64	65+
People with mental health conditions	15	3	4	3	3	2

A discussion guide was used in all interviews to direct the conversation and ensure key questions and areas for discussion were covered. This guide was developed by GfK NOP and the Commission and is included in appendix 2.

All participants were provided with a £35 incentive for taking part in the research. This was intended to thank them for their time and to cover any travel costs incurred in attending the interview. During the interviews, all participants were provided with an information sheet directing them to support services should they require these. This is also included in the appendix 2.

GfK NOP and the Commission would like to thank the following organisations for their interest in this project and the support they offered throughout it:

- Mind Cymru
- Disability Wales
- Gofal
- Awetu
- Stonewall Cymru

Appendix 2

Discussion guide

1.   CURRENT CIRCUMSTANCES   10mins

(Aim: to introduce the subject and find out about the respondent)

Moderator

- Thank respondents for taking part in the research, introduce self and GfK NOP

- Interview will last 1 hour, explain purpose of research:

    > *GfK NOP are carrying out research for the Equalities and Human Rights Commission Wales to explore your real life experiences of discrimination and prejudice as well as your thoughts on solutions.*

- Reassure re: confidentiality, recording and MRS Code of Conduct

- Explain importance of being able to say what they think, no right or wrong answers, need for honesty, validity of opinions, any questions?

- Reassure that it's OK to say if they don't understand a question and to ask for it to be said differently.

- Provide recognition that this is a sensitive area and if you want to stop interview / need to take a break, this is absolutely fine.

Respondent

- Name, are you working or not working at the moment, what are your main activities during the day (if not working) , interests, where do you live

- Tell me about living in this area – what do you like/not like about living here?

- Tell me about the things that are important to you at the moment?

  Prompt: events, relationships, activities, interests, housing, education, money, work, etc

2.   EXPERIENCE OF DISCRIMINATION AND PREJUDICE   15mins

Understanding

As you know, this research is to explore your real life experiences of discrimination and prejudice. Thinking about this:

- What do you understand by discrimination and prejudice?
  - > How would you describe discrimination and prejudice?
  - > Where does discrimination and prejudice happen?
  - > When does it happen?
  - > What type of people face discrimination?
- *Moderator: Show Card B*
  - > What do you think of these definitions?
  - > How would you change them?
- Do you believe you have ever experienced discrimination and/or prejudice?
  - > Tell me about these situations – what happened, where did they take place?
  - > How often does this happen?
  - > Why do you think this happened?
  - > How did this situation affect you?
  - > What impact did it have on your life?
  - > *Moderator: Show Card A*
    - Have you experienced discrimination and/or prejudice in any of these areas of life?
    - Question as above...

Impact

- Thinking about the impact of discrimination and prejudice, how has being discriminated against and/or experiencing prejudice made you feel?
  - > How has it affected you?
  - > In what ways does the worry of being discriminated against and or facing prejudice stop you from doing things you want to do?
  - > In what ways does it make you do things differently?
  - > To what extent has this ever made you:
    - Do things you would otherwise not have done?
    - Not do things you would otherwise have done?

- Does the thought of being discriminated against and/or experiencing prejudice worry you?
    - \> If yes, in what situations / which areas of your life?
        - *Prompt using Show Card A if necessary*
    - \> If no, in what situations might being discriminated against and/or experiencing prejudice worry you?
        - *Prompt using dartboard / Show Card A if necessary*

3.   OUTCOMES OF DISCRIMINATION AND PREJUDICE   20mins

- Thinking about the situations where you experienced discrimination and prejudice:
    - \> Did you tell anyone?
        - If yes: Who did you tell? Why them? What happened?
        - If no: Why didn't you tell anyone? What made it difficult to tell someone? What would make it easier?
    - \> What action did you take? (What action did the person you told take on your behalf?)
        - If took action:
            - ➢ What prompted you to take action?
            - ➢ What was the result of this?
            - ➢ How happy were you with this result?
            - ➢ What result would you have wanted?
            - ➢ How could you have got this result?
        - If did not take action:
            - ➢ What prevented you from taking action
            - ➢ What could have helped you take action
- How can people who are treated unfairly because of who they are get the result they want?
    - \> What would have been the result you wanted?
    - \> How could you have got the result you wanted?
    - \> How confident would you have been in being able to get the result you wanted in that situation? What would have stopped you?
    - \> If you were in the same situation again, what would now prompt you / prevent you from trying to get the result you wanted?
    - \> What would prompt you to take action in future .what might prevent you from taking action in future?

4. PRACTICAL MEASURES & SOLUTIONS   15mins

- Thinking about the situations where you experienced discrimination and/or prejudice :
  - > What could have been done to prevent these arising in the first place?
- In each situation, what could have helped you to challenge the discrimination and/or prejudice?
- How could it have been made easier for you to challenge the discrimination and/or prejudice and got the outcomes/result you wanted?
- *Moderator: read out Show Card C:*
  - > What action would you advise this person to take?
  - > How would you advise them to get the result they want?
  - > What should the result of this situation be?
  - > What do you think you would have done?
- Why might people not challenge the discrimination and/or prejudice they experience?
  - > What might prevent them from doing this?
  - > What concerns might they have?
- What action could the following people have taken:
  - > Those behaving/treating you unfairly
  - > You (the one being treated unfairly because of who you are)
  - > The law / courts
  - > The government
  - > Any other individuals / organisations involved
  - > Citizens Advice Bureau
  - > Employer
  - > School, college etc
  - > Shop
  - > Other

6. SUMMARY   5mins

- Overall, how fairly do you think people in Wales are treated today?
- Overall, how fairly do you feel you are treated at the moment?
- Is there anything else you would like to say before we finish?
- Check whether respondent would like details of local support organisations. Leave card with details in case they want to add anything or get in touch

Thank & close

Contact us

You can find out more or get in touch with us via our website:

www.equalityhumanrights.com

or by contacting our helpline:

Telephone: 0845 604 8810
Textphone: 0845 604 8820
Fax: 0845 604 8830

waleshelpline@equalityhumanrights.com