

The Potential for Attitude and Behaviour Change Driven by Mental Health Professionals: A Scoping Report for Time to Change

by Disability Rights UK

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Introduction

Stigma and discrimination are among the biggest barriers to people leading lives to their full potential – finding and keeping friends, partners and jobs and being confident that it is OK to talk about mental health and to seek support. Nine out of 10 people using secondary mental health services report stigma and discrimination in their lives, often in many aspects.

Time to Change is England's largest ever programme to tackle stigma and discrimination. It is a partnership of Mind and Rethink Mental Illness and has been funded for the past six years by Comic Relief, the Big Lottery Fund, and the Department of Health. It has helped to achieve positive attitude and behaviour change amongst the population for the first time, with a 3.6 per cent positive shift in public attitudes and reductions in reported discrimination, through the delivery of a multi-layered programme.

Analysis of the annual Viewpoint survey findings, by the Institute of Psychiatry at King's College London, has shown that whilst levels of discrimination reported by people using secondary mental health services reduced most significantly in the areas of family, friends and social life (between 2008 and 2011) it remained almost static in relation to mental health and health professionals.

Stigma and discrimination can affect particular groups and communities in different ways, dependent upon things such as their type of diagnosis, their gender and their ethnic background. African and Caribbean communities, for example, can experience services as discriminatory on grounds of ethnicity.¹

Time to Change has a new pilot project called 300Voices which aims to influence 900 statutory staff and to empower 300 young African and Caribbean men who are using services in the pilot location of Birmingham. This pilot is part of a wider programme

¹ <http://www.time-to-change.org.uk/news/black-and-minority-ethnic-communities-faced-double-levels-discrimination>

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of work at community and national levels aimed at reducing mental health stigma and discrimination experienced by people from African and Caribbean communities.

In recent years, we have started to see professionals from a range of sectors being open about their experiences of mental health challenges. However it is well-recognised (and documented) that there is a reluctance among people working in the mental health sector (and the wider NHS) to speak about their own experiences of mental health problems.

Time to Change contracted Disability Rights UK (DRUK) between January and March 2014 to conduct a three-month scoping study to inform any future work in this field and potentially some development work in 2014/15. The remit of any potential future work in this field would be to secure attitude and behaviour change amongst mental health professionals, with the ultimate goal of reducing levels of discrimination experienced amongst people using services.

This scoping study and future activity are a timely opportunity to secure leadership and ownership of the issue, in order to change attitudes and behaviour among professionals working in the mental health sector.

The scoping study included:

- a literature review
- a roundtable event with key stakeholders
- analysis of quantitative data from the annual Viewpoint survey (Institute of Psychiatry, King's College London)
- a brief review of qualitative analysis of 50 of the most recent Viewpoint survey interviews (McPin Foundation)
- interviews with stakeholders from statutory and voluntary services and representatives of users of services.

This report sets out some conclusions and recommendations.

Background

Literature review

DRUK conducted a literature review during January and February 2014.² The review identified and screened 1263 articles touching on stigma and/or discrimination in relation to mental health staff and service users. The researchers reviewed 216 articles in detail.

International and UK studies find inspiring and empathetic staff attitudes, for instance Grausgruber et al³ found that mental health staff were less likely to attribute mental health problems to “weak character” than were the general public and less likely to see service users as dangerous.

However, many more articles paint a more negative picture. Studies of people with lived experience of mental health challenges showed some common themes:

- People were disheartened by pessimism about their future: the implicit or explicit message they would never recover and might commit suicide.
- There was a perceived lack of empathy – people felt reduced to a diagnosis; that professionals had no interest in “me as a person”.
- People felt that they were not listened to, taken seriously or respected: there was diagnostic overshadowing in primary care and assumptions by mental health staff they were incapable of making decisions

Some people also felt that they were affected by an unspoken threat of coercion: “I felt very upset, resentful, but I wouldn’t show it because I knew if I did, they would section me.”

There were indications of different experiences relating to certain more highly stigmatised diagnoses – such as schizophrenia, personality disorder, eating disorders, drug and alcohol dependency.

For African or African Caribbean people, services can be characterised by containment, cultural insensitivity - or service avoidance. The Care Quality

² Watson, E., Hudson, M., and Sayce, L. (forthcoming, 2014) ‘A literature review of the attitudes and behaviours held by mental health staff toward those they serve and interventions which may alter these’, Disability Rights UK.

³ Grausgruber, A., Meise, U., Katschnig, K., Schony, W., & Fleischhacker, W. W. (2006) ‘Patterns of social distance towards people suffering from schizophrenia in Austria: A comparison between the general public, relatives and mental health staff’, *Acta Psychiatrica Scandinavica*, 115, 310-319.

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Commission (CQC) reported⁴ no material change in ethnic differences in admission, compulsory detention or seclusion since 2005, with numbers still disproportionately high.

Other dimensions of identity also appeared to correlate with compound discrimination, for example lesbian, gay, bisexual and trans people continue to report that their sexuality is judged or pathologised.

Research in the UK and other countries among mental health professionals shows that they experience a “them and us” culture just as service users do. Some studies find mental health staff say they would perceive stigma if they themselves were diagnosed and would be reluctant to seek help.

Mental health professionals also often report that they would not date someone with mental health challenges or let them look after their children.⁵ Some studies find clinicians hold more pessimistic views of recovery than the general public.

In terms of structural issues identified by the literature review as leading to actual or perceived discrimination, risk assessment processes – with no right to challenge the outcomes – feature. The rising use of compulsion - in hospital and through community treatment orders – is seen as a “discriminatory” aspect of mental health law. The CQC talks of “cultures of containment”, demonstrating how structures and systems can affect culture, behaviour and attitudes.

The literature review identifies some possible ways forward:

- Breaking down the “them and us” divide between staff and people using services and reducing inequalities.
- “Contact” on at least equal terms, collaborating on common goals (eg working together – a critical mass of peer support workers, colleagues being open about lived experience; processes such as co-production).
- Trialogues,⁶ “expert patient programmes”, Recovery.

⁴ Care Quality Commission. (2011) ‘*Count Me In 2010*’.

⁵ Hansson, L., Jormfeldt, H., Svedberg, P., & Svensson, B. (2011). ‘Mental health professionals’ attitudes towards people with mental illness: Do they differ from attitudes held by people with mental illness?’ *International Journal of Social Psychiatry*, 49. 48-54.

⁶ ‘Triologue’ groups help change the perception that only those who work in the field of mental health are the experts in mental health. They do this by creating spaces where communities can gather to develop their understanding of mental health issues, the challenges of maintaining mental health and how to develop better services and healthy communities. Triologue meetings welcome anyone with an interest in positive mental health in the community.

<http://www.trialogue.co/>

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- Not single interventions – such as a training programme – but a fresh purpose for services, requiring substantial change, for example:
 - distributed leadership
 - a culture of innovation
 - a changing workforce
 - new roles and relationships
 - deliberately reduced use of coercion
 - a clear cycle of planning and review.

Roundtable event, 24 February 2014

The Time to Change roundtable event drew together 45 experts from different parts of the mental health and wider health and social care sectors to consider what staff can do to help tackle stigma and discrimination.

The aim was to help inform any potential future focus of the Time to Change programme, including the new 300Voices pilot project, which works with 900 statutory staff and aims to empower 300 young African and Caribbean men using services in the pilot location of Birmingham.

The agenda (included at Appendix 1) included short presentations and table discussions on the following topics:

- Beyond ‘them’ and ‘us’: overcoming stigma together - what are the best approaches to building empathy and breaking down the ‘them and us’ divide in services?
- Leading change: what can the leaders of mental health organisations and professions do?

Issues discussed include:

Service users’ experiences of stigma and discrimination

There is a variety of attitudes among professionals: some are positive; some less so. Where attitudes are more negative than among family, friends and the general public, continuous exposure to pathology is what is different: seeing people largely or only in crisis, when they are a danger to themselves or others; not seeing “the whole person” or people when they have recovered. Clinicians are often pessimistic – they see people at their most “ill”. Meeting the same people later and speaking to them about what they needed and wanted from services is very powerful.

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In addition, a need to separate from and provide clear blue water between “them” and “us” may be a response to the pressures of the job.

The medical model of mental illness remains a very negative force – underpinning:

- stereotyping by diagnosis
- perceptions of incapacity, weakness, being high-risk or manipulative
- pessimism about recovery.

Leaders need to tackle pessimism and stereotyping – about particular diagnoses and the possibility of recovery.

Mental health laws, policies and services

“There is stigma and discrimination at every level of the system.”⁷ NHS England is determined to change this.

For some groups of service users, spiritual beliefs can be seen as “wayward thinking”; passion can be seen as aggression. The criminal justice system can be particularly problematic for some people based on their ethnicity, gender, class or sexual orientation/identity.

Being treated as worthless and untrustworthy or dangerous can influence your behaviour, which then fuels a vicious cycle. Structures, systems and services need to be humanised.

There are problems with training for non-clinical staff: with as little as 15 minutes spent on mental health issues.

The lack of holistic treatment, a human as opposed to risk based response, and ‘social prescription’ is problematic – not being listened to and valued is counterproductive to recovery and successful treatment. This is exacerbated when there is a lack of understanding and respect on grounds of ethnicity, gender or sexual orientation/identity. Feeling insignificant lowers self-esteem.

Signs of “them and us” include locked doors, separate patient and staff toilets, uniforms, separate mugs and eating areas.

Changing this and handing over power to patients can be challenging, particularly for hard-pressed staff. Many staff think their role is to stabilise, contain and medicate –

⁷ Kate Schneider, Assistant (Design & Delivery) to National Clinical Lead, NHS England.

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or feel they have little time for anything else. The model is maintenance not recovery.

Change requires influencing commissioners, so that they commission for quality and innovation and make national requirements such as people with mental health challenges having regular physical health checks; making information transparent and visible; providing training and education for GPs who are commissioners; making crisis settings as unrestrictive as possible; ensuring that Health Education England takes the right approach.

At the same time, humanising contact by reconfiguring services need not be expensive. Wardipedia⁸ contains many examples of good practice on wards, such as staff and patients doing ordinary things together. Such simple human contact is crucial to creating a therapeutic relationship and indeed an alliance to support recovery.

What distinguishes good services is when staff get to know “who you are as a person”,⁹ which includes your cultural background and your beliefs. When this is neglected, people can have bad experiences.

The parity of esteem strategy on fairness in approaches to physical health on the one hand and mental health on the other provides an important agenda for tackling stigma and discrimination.

We need to consider resources – taking money from mental health and community services is discrimination. We must reverse that decision.¹⁰

Resourcing has an indirect effect on the effectiveness of services: when expectations of services are not met, people feel worthless, impeding recovery. Coproducing ward house rules, cooking together, sharing recovery stories, welcome and good luck cards – these are not expensive but they are reflective of a positive and empathetic culture and likely to bring savings.

We need to start with the question of what our mental health services are for. Are they for containment, for cure or to help people to retain or regain lives of value? What’s needed is not another strategy but a conversation about why we are all –

⁸ <http://www.wardipedia.org/>

⁹ Raphael Shervington, user of services in Birmingham.

¹⁰ Sue Bailey.

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leaders, professionals, service users – here; not directives from on high but multiple different messages and a narrative to join the dots.

We need to monitor what we want to change. If it isn't monitored it isn't done. Punishment is a lousy way to change behaviour. We need to start noticing the jewels, the little innovations.

CEOs can create the right climate to ensure that services are developed and change as they need to; leadership is crucial. It needs to include frontline leaders as well – ward and team managers make or break services.

Effective and humanising services benefit service users, staff and budgets. Self-injury and seclusion are reduced; moving on increases; assaults on staff and staff sickness reduce¹¹.

Role of mental health staff in tackling stigma and discrimination

From the Viewpoint survey we should note that most people report that the attitudes of mental health staff have been good. This should be acknowledged. However 38 per cent of the 50 service users interviewed say they have experienced “a lot” of discrimination.

The sector should not beat itself up about poor results from the Viewpoint survey. It should publicise and celebrate what works.

Openness about lived experience

Staff are cautioned on the professionalism of sharing lived experience. It is seen as a sign of personal weakness and vulnerability, especially in a time of reducing resources: “Don't bleed in the water when there are sharks around.”¹²

Human resources staff within services are ill-equipped to deal with mental health issues. It can be middle managers who block openness and support for staff with lived experience.

¹¹ Dr Rachel Perkins, experience from Implementing Recovery through Organisational Change (ImROC) programme

¹² Lakhvir Rellon, Director of Community Engagement, Birmingham and Solihull Mental Health NHS Foundation Trust.

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Leaders can make clear that lived experience enriches practice, whether by individual staff or by systems and services generally. Where people are confident to be open, this should be seen as a sign of courage and valuable to services.

We need to begin by tackling self-stigma by professionals: “compassion starts within us”.¹³

Lived experience needs to inform practice. This is not just for the “mad ones” but for everyone, so that they can be their full selves at work. In no other service are shared experience and positive relationships so central to achieving objectives.

With a project such as 300Voices, it shouldn't even be defined as 900 professionals (some of whom will have lived experience) and 300 services users. It is 1200 people having conversations.

Successful initiatives to build empathy

“If you want to get rid of stigma, you need more shop fronts run by users.”¹⁴

Coproduction of policies, services and cultures can play a helpful role. Coproduction is not about the CEO talking to user representatives but about frontline staff talking to service users directly to design and create better services together. The process will be therapeutic for “them and us” – deliberately creating relationships that build common humanity, self-esteem and a feeling of being valued.

The training agenda is also crucial and needs to focus on empathy and compassion, with time for reflective thinking. We need to “unlearn” stuff – taking things out of training that are harmful.

Next steps for Time to Change

The challenge is to create a step change across systems and to enable work from the bottom up. All leaders ought to be accountable for actions on stigma and discrimination. Each of us has a sphere of influence. It needs to be done under the Time to Change banner, with core principles, but in a collective and diffuse way. Time to Change is the facilitator but it needs to be coproduced across agencies.

We need something as structured and supported as the public-facing aspects of Time to Change and we need to apply the successful elements of the programme so far –

¹³ Lisa Rodrigues, CEO, Sussex Partnership NHS Foundation Trust.

¹⁴ Sue Bailey OBE DBE FR, President, Royal College of Psychiatrists.

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like basing our approach on audience insights - to mental health professionals. However, while Time to Change is the vehicle, the drivers will be 'leaders' at different levels across the sector.

Positive messages are that tackling stigma and discrimination, creating supportive empathetic services reduces staff absence and burnout and helps service users towards recovery.

The tone of any approach to mental health staff from Time to Change must be positive and acknowledge the pressures that they face. An important message is that doing things differently may make a difference – a respectful, personalised, optimistic service will be a more effective one. Any resources and interventions need to be practical and helpful.

We need to capitalise on creativity on the ground. Amongst ward managers, for instance, there are "jewels". We need to notice and acknowledge their good work. By contrast, we need to recognise how "little indignities can erode the soul"¹⁵: separate toilets, cups, plates.

Viewpoint Data

The roundtable event (see below) included a presentation from the McPin Foundation on 'Discrimination and mental health staff: findings from the Viewpoint study'. These findings are provisional, as they are based on interim data.

The Viewpoint study is carried out by the Institute of Psychiatry, King's College London working with five mental health trusts in England to interview 1000 people using secondary mental health services (excluding dementia and learning disability). The survey has been commissioned annually by Time to Change since 2008.

Additional qualitative research with 100 of the latest Viewpoint survey participants was commissioned by Time to Change and carried out by the McPin Foundation in collaboration with the Institute of Psychiatry.

Participants are aged 18-65, living in the community and have had contact with a Trust within the past six months. The survey records self-reported experiences of discrimination.

¹⁵ Dr Rachel Perkins, Senior Consultant, Implementing Recovery through Organisational Change (ImROC) programme.

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The following table demonstrates changes in reported discrimination between 2008 and 2011 (for each year, topics are listed according to the percentage reporting it):

2008	2011	
1 Being shunned (57.9%)	1 Being shunned (50%)	(-7.9%) Signif
2= Friends (53.3%)	2 Family (43.7%)	(-9.6%) Signif
2= Family (53.1%)	3 Friends (39.4%)	(-13.7%) Signif
4 Social life (43.2%)	4 Social life (31.5%)	(-11.7%) Signif
5 Mental health staff (34.3%)	5 Mental health staff (30.4%)	(-3.9%)
6 Dating (30.9%)	6 Physical health staff (28.9%)	(-0.7%)
7 Physical health staff (29.6%)	7 Benefits (24.9%)	(+5.9%)
8 Neighbours (25.3%)	8 Safety (24.8%)	(+5.2%)
9 Finding a job (24.2%)	9 Neighbours (22.7)	(-2.6%)
10 Privacy (21.6%)	10 Dating (22.1%)	(-8.8%)

While there have been some significant improvements in experiences in relation to being shunned, friends, family and social life, there has not been a significant shift in experiences with mental and physical health staff.

In addition to the regular collection of quantitative data, in 2013, a qualitative survey was conducted as part of the evaluation for Time to Change. Three of the Viewpoint interviewers recorded all of their interviews in the final two months of data collection: a total of 84 interviews. The interview questions were the same but respondents were probed for further detail on examples where discrimination had been reported. Fifty interviews were selected for analysis, based on the clarity of the recording and the number of examples given. The analysis is still at an early stage so results are provisional.

The interviews include some examples of discrimination by mental health professionals, in around one third of cases.

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The examples include both individual and institutional responses. The individual responses include:

- **Lack of support**

“I was in hospital because I’d been sectioned. A consultant there made certain promises and never followed them through. These promises were silly things. ‘If you’re sectioned, you can’t go anywhere, you’re locked up.’ It’s like: ‘Yes, we’ll let you go out for a ten minute walk: somebody else supervising and somebody else with you.’ These promises were made then they were not followed through.... [I felt] imprisoned and... I’m trying to think of a word that’s worse than worthless; just I didn’t want to live. [...] I think this chap just did it because he could do it.”

- **Not being listened to**

“It was the actual dealing with the psychologists that I found quite difficult. [...] What I felt from the beginning and has continued really was that I wasn’t really being listened to. [...] I was able to see the report that the assessor had done and she put in that that she felt that I tried to control the interview [...] Then I was assigned a psychologist and I felt that as a result of that initial assessment that the psychologist has always worried about me being controlling, you know. [...] And that meant then that I couldn’t be open and upfront [...] I never got to the heart of what my issues are. [...] In fact in the end I actually ended the treatment, you know. I stopped going.”

- **Lack of understanding**

“And then I also saw a psychiatrist a couple of months ago who basically just said: ‘You need to get a job and that’ll sort your life out.’ [...] She just turned around and said to me: ‘Your BMI’s not low enough’. Like: ‘We don’t need to worry about you.’ And I was, like: ‘I’ve been ill for eight years. Like, I do need... it is time to worry about it.’ [...] It was horrible, because obviously as a person with an eating disorder I’ve got a problem with, like, my weight and someone saying your weight is too high for... too high for treatments. [...] And she said: ‘We’ve got plenty of time.’ And I was like: ‘I don’t have plenty of time. It’s ruined eight years of my life.’”

The institutional responses include:

- **Resourcing**

“I know [...] the National Health is under pressure and all the rest of it. We started off having treatment in a really nice house with a lovely garden. [...] It didn’t feel like a

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hospital; it felt like a nice place where you could relax. [...] Then the NHS sold the house and we moved into a really crappy, dilapidated old hospital that was horrible. [...] You start off thinking that people genuinely want to help you and you believe in the service; you have to because that's all there is. [...] And then you start to question how effective the service actually is. And ultimately you start to say, 'Does anybody really care', you know?"

"I mean, they're overstretched. There are not enough resources and I do understand that there are people in more urgent need than I am at certain times. But that doesn't mean that I should be completely forgotten about."

"The problem is that mental health services are under so much pressure. They're seriously under-staffed. They've got serious staff sickness problems, certainly down here, and I would imagine probably throughout the country to a greater or lesser extent."

"Sort of let down by the system. I can see it from their point of view: that they can't give you the time. [...] I feel, sometimes, is it me? Am I being selfish and critical? The mental health teams are very overstretched. They're kind of maxed out on the amount of people they have per worker. They're very busy. They're underfunded. There's a lack of, you know, services that are available. They're always closing..."

- **Access**

"I didn't get to see a psychiatrist for three months after I was starting having problems, and that turned out to be someone who'd just graduated. [My GP] was keeping a really good check on me, and in the end he wrote a letter to this psychiatrist to say that his attitude was wrong. [...] And, finally, now, nearly a year down the road, I've got to see the proper psychiatrist, who's absolutely great, and put me on the right medication. So I've been waiting all this time when I could have been better, and not gone downhill so much, if I'd been given the right people to see in the first place."

"There was a mix-up over an appointment. I phoned them, my mum phoned them, my CPN [community psychiatric nurse] phoned them ... They never returned one single phone call. Then I got a letter telling me that if I wanted to be seen I would have to be re-referred, which means going to the bottom of the waiting list. [...] They basically denied having phone calls from me or my mum, or my CPN, at all. [...] I just felt that they were actually using my own mental health against me, because she basically implied that perhaps I thought I'd phoned but I actually hadn't."

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- **Discrimination?**

There is a question mark for some over whether what they are experiencing is about the mismatch of expectations with what is available or discrimination:

“It’s a difficult one that one, because I think sometimes you get, you have your expectation of what you’re going to get and they don’t meet that expectation. So it feels like you’ve been treated unfairly.”

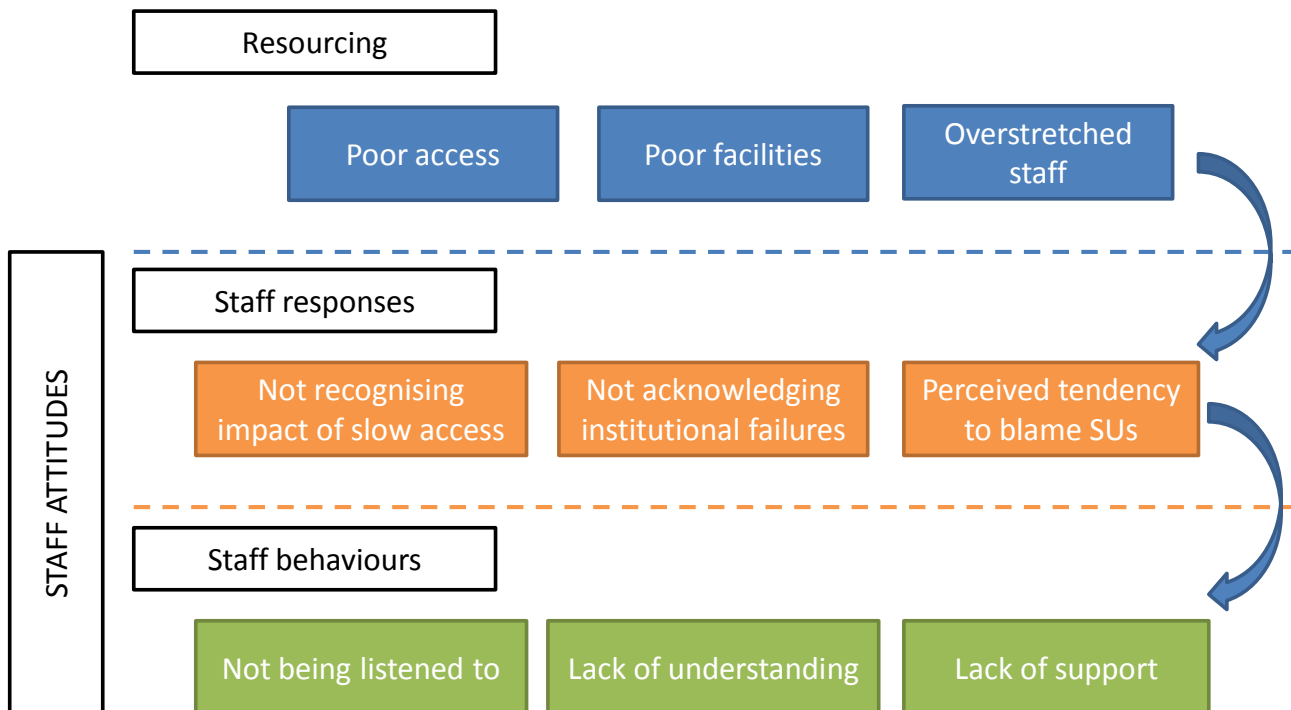
People’s expectations of support may include:

- support when it’s needed
- support that is efficient and effective
- support based on an understanding of them and their needs
- support delivered with respect and dignity.

These qualities will underpin successful support. However, there may still be a mismatch even in a well-resourced service between what is feasible and effective and what people want.

In terms of conclusions, Sarah Hamilton from McPin, drew out the following factors affecting the perception or reality of discrimination:

Discrimination?



Interviews with stakeholders

Interviews were conducted between February and April 2014 with the following people:

- Len Bowers, Professor of Psychiatry, King's College London
- Chris Butler, CEO, Leeds and York Partnership NHS Foundation Trust
- Mike Cooke, CEO, Nottinghamshire Healthcare NHS Trust
- Stephen Dalton, CEO, Mental Health Network
- Niall Dickson, CEO and Registrar, General Medical Council
- Stephen Firm, CEO, Oxleas NHS Foundation Trust
- Joyce Kallevik, CEO, Wish
- Kathy Roberts, CEO, Mental Health Providers Forum
- Professor Geoff Shepherd, ImROC, NHS Confederation
- Afuape Sola, Chair The Afiya Trust
- Neil Springham, ResearchNet Coordinator, Oxleas NHS Foundation Trust.

A topic guide was used to guide discussion. This is given at Appendix 2.

Time to Change achievements

Stakeholders agreed that Time to Change has been “a game-changer”,¹⁶ raising the profile of mental health. “In my 32 years of work in mental health, this has seen the most significant shift.”¹⁷ It had been very impressive in raising the profile of mental health in government and Parliament.

It has tapped into popular culture and the public psyche effectively. The poster and cinema adverts had high visibility and the use of well-known figures was normalising and destigmatising. The approach of short films could be used in a variety of settings, including with children.

Where people felt that Time to Change had been less successful was in tackling responses to people who were not managing their condition effectively, who had not recovered or who were not “a success”. There had been lots of focus on depression and anxiety and on bipolar, which were described by several interviewees as “the acceptable side of mental illness”. The danger of normalising the experience of mental health challenges is that it pushes further to the margins people with severe and enduring mental health needs. There was also a sense that the “acceptable face of mental illness” was a white middle class one. Some respondents mentioned that the programme did not seem reflective of a range of communities. At worst, Time to Change could be viewed as “unpalatably sweet” and irrelevant to people in settings such as prisons or police cells. Time to Change itself cannot simply seek to have a “BME voice” as an adjunct. It needs to allow for internal reflection and genuine coproduction.

Service users’ experiences of stigma and discrimination

There can be greater stigma against those perceived to be to blame, as in general healthcare settings. For example, people with drug and alcohol problems or other problems where dependency is exacerbating conditions and creating a chaotic lifestyle.

People with personality disorders are often judged rather than understood. Where people have a clear label (of depression, bipolar or OCD) which fits in with a category of NICE guidelines that often forms the basis for a better dialogue. With personality disorder or drug and alcohol dependency there is not the same level of

¹⁶ Stephen Dalton.

¹⁷ Stephen Firn.

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understanding. People are less able to empathise and communicate with someone with a disturbed upbringing, who self-harms or uses drugs. There is a perception of “it’s your fault. We can’t solve all your problems”.

Services are better attuned to people of working age but are not so good for children or adolescents. Often it is an adult service, information, etc, that is offered with little amendment to children.

Women with complex needs are often not well-served. Many in prison have unrecognised mental health needs. If they are seen as unfeminine in their attributes – aggressive, unkempt, not nurturing – they can experience stigma and discrimination.

Lesbian, gay, bisexual and trans people and travellers were also mentioned as groups of people who experience extreme stigma and/or compound discrimination.

Several respondents mentioned the idea that “a little learning is a dangerous thing”, either in relation to contact only with people in crisis, leading to pessimism about recovery, or to stereotypes based on limited knowledge of ethnicity, culture or religion. Each of us is more complex than one or two aspects of identity. For example, a woman might also be a lesbian and a refugee. An African or Caribbean man might also be gay.

It’s important to recognise that staff themselves face unpleasant behaviour from patients. They can be verbally abused daily, threatened, occasionally stalked, punched, kicked, pushed, and throttled. In addition, racism in the mental health system can be patient to patient and patient to staff as much as staff to patient. Ethnic minority staff often face racism from patients. In London, for example, there are a high number of nurses from ethnic minority backgrounds and racism is an issue.

Some believed that people are quick to criticise professionals who often face complex dilemmas, for example about reducing harm to self or others. User and provider relationships can be characterised by anger and antagonism in both directions.

There was a sense that general health professionals, particularly GPs, who may have a limited range of tools for helping people with mental health challenges that are caused or exacerbated by social and economic issues, could find the level of mental health casework frustrating.

Mental health laws, policies and services

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For some, the perception of bias is most intense in relation to Mental Health Act compulsion, with suggestions that it is out of date and needs revising to reduce the culture of containment and coercion.

Some thought that the police are more likely to be the recourse rather than sectioning for men from ethnic minorities (although sectioning rates are also high and rising). There may also be issues to do with services not being or seeming inclusive and people not approaching them early enough and coming in crisis. There may also be cultural issues about mental health challenges in particular communities, which form a barrier to services.

The CQC report on the Mental Health Act was identified as implying that its use meant a failure of services, when in fact more use of the Mental Health Act might keep more people, particularly from some ethnic groups, out of the criminal justice system, which arguably might be a good thing.

Others felt that problems with the Mental Health Act were more about how it was implemented than the letter of the law.

If people are living with serious mental illness, there is a possibility that they will need health services. The policy framework doesn't do enough to prepare people for this. The introduction of 'choice' from April 2014 excludes people who are detained. It would be more positive if people who are predictably detained were encouraged to discuss this possibility and draw up advanced directives about their wishes.

The fact, for example, that African and Caribbean men are disproportionately subject to the Mental Health Act doesn't mean that we understand the reasons why or that it is in part or solely due to discrimination. Some interviewees thought more research rather than assumptions were needed. If things were not improving, the drivers could be inequality – not diminishing in recent years – and austerity as much as stigma and discrimination by mental health staff.

Role of mental health staff in tackling stigma and discrimination

They definitely have a role to play, alongside providing support and treatment. Equally, more positive attitudes from employers, the media and more broadly in the community are crucial.

One of the most common complaints about mental health staff is "You don't understand". However, this is at least as important in primary care. GPs are under

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enormous pressure. The model that they might adopt with a long-term condition such as diabetes, of a holistic prescription to enable and support people to recover and lead an independent life, is not one that is followed very often for mental health conditions. More could be done to support GPs and give them confidence.

Where people may have mental health challenges affecting or related to feelings of worthlessness, positive relationships with mental health staff can make a difference. The ‘Treat Me Like a Human, Like Someone that Matters’ report¹⁸ presents the findings of a two-month consultation with survivors of domestic and sexual violence who have also experienced problematic substance use and/or mental ill-health. It was conducted as part of the Stella Project Mental Health Initiative. It outlines a number of themes including:

- the importance of humanity
- consistent and trusting relationships
- the pivotal role of GPs.

This quote is included: “Asking for help is the most difficult thing you can ever do. And when you do that, you just want someone to say, “Look, it’s not your fault, and we’re going to get you some help, and you are not this worthless human being, you do deserve to live, you deserve to be a mother, you deserve to be happy, you don’t deserve this man smacking you round the face every time he has a drink”, you know what I mean? That’s the first thing you need, then practical help. But what you really need is for someone to treat you like you’re worth something; you’re not just something out of the gutter.”

When it comes to initiatives to change attitudes and behaviour of mental health staff, what is effective for the general public may not be so for health professionals. There is not a lack of information but too much of one sort of information – about people in crisis, not about the whole treatment journey and the whole person. A narrow and repeated experience of observing crisis tends to consolidate a negative view.

Leaders of organisations, even if they don’t have formal experience of mental health treatment, should not feel they have to be ‘heroic’ and always present a strong face to staff. Trust and security can be built by being honest about everyday feelings – say being nervous about a meeting or presentation. Everyone should be able to show that they are human and vulnerable, without it necessarily being a “them and us” divide of those with and without “lived experience”.

¹⁸ <http://www.avaproject.org.uk/media/99239/treat%20me%20like%20a%20human%20being%20-%20spmhi%20survivor%20consultation%20report%20june%202012.pdf>

Openness about lived experience

Lived experience amongst staff was felt to be beneficial to services and should be supported. Oxleas NHS Foundation Trust, for example, has a Lived Experience Network of 18 staff members who meet monthly, publicise resources to staff, revise policies and are a focus for Time to Change activities.

There is an apparent contradiction to services attempting to be positive and inclusive about staff with lived experience at the same time as recording and taking note of time off sick with stress. There are still “whispers in corridors” and a sense that staff have no right to be working in mental health if they haven’t “got themselves sorted out”.¹⁹ Unlike some physical health conditions, people with mental health challenges may be more likely to feel that their mental health experiences are core to who they are.

About staff being open about their lived experiences of mental health challenges, there were mixed views. Some saw it as entirely a personal decision and that no one should be encouraged to do it out of a sense of responsibility. It was in the nature of the experience not to broadcast it. Some people in public positions now feel a pressure to talk about their own experiences. There is a sense of criticism from Time to Change and others: why don’t CEOs talk about it. Some people talked about their children’s experiences. Did they have an explicit right to do so?

In addition, some felt that there was an emerging view that only those with lived experience could understand, empathise or offer a good service, which was wrong.

In some professions, such as general medicine, there is a high level of stigma attached to mental health challenges, particular problems such as easy access to drugs and anxieties caused by the regulatory framework and the culture that can make seeing help particularly difficult.

Successful initiatives to build empathy

IMROC was mentioned frequently. Introducing people with more experience of mental health challenges into the system creates a healthier environment and encourages empathy. National training and education are not quite right. More people with experience on Trust boards will also be helpful.

¹⁹ Neil Springham.

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Sharing personal information about neutral topics like favourite television programmes or music can build empathy between staff and service users. Some wards and some staff prefer to create distance and maintain the power dynamic as it makes them feel less vulnerable.

Wards in the 1980s were more egalitarian. Safety is a big driver. Sharing toilets would mean that staff were outside the view of other staff and there were concerns about risk in some settings. There are "appalling practices", such as staff putting plastic bags down on chairs, not sharing cups, etc. If toilets and other facilities aren't clean enough for staff they aren't clean enough for patients.

Having locked wards profoundly affects people's self-esteem. Experiments with leaving them unlocked found a counterweight to increased risk – with fewer suicides and self-harming. The evidence is there to encourage this approach but the politics says it's impossible.

In Oxleas there has been an initiative to bring service users back onto wards once they have recovered to meet staff who have only seen them when they were psychotic or otherwise in crisis. This has been very successful.²⁰ Many staff found it a very moving experience. They were able to step out of the duty of care and ask questions about how it had felt for the patient, what they remembered, what they wanted. As a result of this exercise, restraints were reduced on the ward.

Empathy and trust are built by small things – saying hello to patients on a locked inpatient ward, for example. "We should be prescribing oxytocin."²¹²²

Coproduction is crucial – Experienced-Based Co-Design, a King's Fund project, is very helpful. It shows how stigma can be stripped away from an acute ward by using service users' stories. Previously, there had been lots of complaints on the ward about staff attitudes. After the project, there were none for 19 months. Unfortunately, systems can destroy regular human contact and its benefits. "We

²⁰ <http://www.kingsfund.org.uk/projects/ebcd/case-study-1-running-ebcd-mental-health-inpatient-service>
<http://www.theguardian.com/healthcare-network/2014/jan/07/mental-health-toolkit-improves-services>

²¹ Neil Springham.

²² Often referred to as the "trust hormone", some research suggests that oxytocin may play a part in enabling us to forge and strengthen social relations and even to stave off some psychological and physiological problems as well.

should be commissioning human to human contact instead of throwing petrol [lack of time, empathy and respect] onto the fire [of mental ill health].”²³

But while there has been a dramatic increase in the professionalisation of services, potentially creating greater “them and us” distance, there has also been a growing acknowledgement of the value of peer support and other service user contributions.

This is best where it is direct and personal. However, short films, showing the raw material of people’s stories can be useful to broker discussions.

The General Medical Council has had a specific programme of work in relation to people with learning disabilities that could provide some useful learning.²⁴ Education and continuing professional development offer positive opportunities to tackle stigma and discrimination, with Health Education England and its equivalents an important focus for this, alongside the regulators and royal colleges.

Conclusions and recommendations

The literature review, roundtable, Viewpoint data and interviews all indicate that people with mental health problems experience some good practice but also experience stigma and discrimination within mental health services. This may be as the result of a “them and us” divide, sustained contact of staff with people in crisis and pressures on staff and resources.

Such experiences are detrimental to the therapeutic relationship and therefore undermine what services are supposed to deliver: facilitating people in their journey of recovery and supporting them to manage their mental health challenges.

The role of mental health staff in tackling stigma and discrimination

There is some evidence from the literature review and from Trust-led initiatives described during scoping project interviews on what works to change attitudes and behaviours:

- Breaking down the “them and us” divide between staff and people using services and reducing inequalities.
- “Contact” on at least equal terms, collaborating on common goals (e.g. working together – a critical mass of peer support workers, colleagues being

²³ Neil Springham.

²⁴ <http://www.gmc-uk.org/learningdisabilities/104.aspx>

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open about lived experience; processes such as co-production of policies, service developments and simple decisions in teams and wards).

- Recovery focused services (with staff offering expertise to individuals in their journey of recovery), Dialogues, “expert patient programmes”.
- Staff with lived experience being seen as an asset by their employers.
- Staff being encouraged to reflect on how seeing people only or usually in crisis may affect their attitudes to particular individuals and how their behaviour is judged.
- Not single interventions – such as a training programme – but a fresh purpose, distributed leadership, a culture of innovation, a changing workforce, new roles and relationships and a clear cycle of planning and review.
- Deliberately reduced use of coercion, which brings benefits such as reduced self-harm and aggression towards staff and reduced staff sickness.

Mental health laws, policies and services

The findings of the literature review, borne out in comments from roundtable participants and interviewees, suggest that a focus for future work should be supporting a shift in the purpose of services – from treatment and symptom reduction to facilitating people to live the lives they want to live. This shift requires five key elements to be met:

- A different role for mental health services and professionals – moving from one ‘expert’ to two; valuing the expertise of lived experience, with professionals being ‘on tap’ not ‘on top’; putting their expertise at the disposal of people who may want to make use of it.
- Different relationships between mental health workers and those they serve – breaking down the ‘them and us’ divide, working from our common humanity – with professionals using both their professional expertise and their lived experience to facilitate and model recovery.
- Redefining user-involvement – moving to coproduction in service design, delivery and development.
- A different kind of workforce that includes the expertise of lived experience, through employing peer support workers – perhaps aiming for 50 per cent of the workforce to be made up of peers.²⁵
- A different relationship between services and the communities they serve: replacing a clinical approach to ‘fixing’ people, so they fit in, with a focus on the ‘right to live independently and to be include in the community’ (as the United Nations Convention on the Rights of Persons with Disabilities puts it).

²⁵ Sainsbury Centre for Mental Health (2008) ‘Implementing Recovery: A new framework for organisational change’.

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On this model, individuals have a right to the assistance necessary to support inclusion and prevent isolation and segregation.

Distributed leadership

Time to Change can facilitate dialogue on these service changes but change will only happen through “distributed leadership” across different organisations and professions and interest groups, and at different levels (from national to the ward):

“There are many leaders, not just one. Leadership is distributed. It resides not solely in the individual at the top, but in every person at every level who, in one way or another, acts as a leader.”²⁶

Leadership needs to be by service-user leaders, trade union leaders, professional and regulatory bodies’ leaders, opinion formers, professional leaders, etc.

A role for Time to Change

A practical role for Time to Change is a programme of work targeted at mental health staff which is driven by audience insight to help support the wider cultural change that will only come through distributed leadership.

A useful focus would be on breaking down the “them and us” barrier by featuring:

- staff with lived experience, demonstrating the benefits to outcomes, to staff and to patients of this approach
- ‘jewels’ of good practice, where ‘them and us’ cultures and practices have been changed through co-production. This might include, for instance, reducing the use of compulsion, or staff and service users uniting on common goals – with outcomes such as reduced aggression, seclusion, or staff sickness.

Time to Change would play a key role in:

- shaping this programme targeted at frontline managers and staff
- facilitating a movement of mental health staff with lived experience who through speaking out help to tackle stigma within the profession, encourage the use of co-production and peer support and demonstrate the benefits in effectiveness and efficiency of services.

In the absence of any large marketing budget for future Time to Change work, this programme would be delivered by leaders within professions and services and would

²⁶ Goleman et al. (2002) ‘The New Leaders’.

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develop learning sets on capitalizing on lived experience and promote the “jewels” that already exist within the mental health system. We suggest that a working group of senior professionals and people with lived experience could plan the next stages, facilitated by Time to Change.

Such an approach would build upon evidence of successful interventions (such as contact on at least equal terms; tackling systemic issues such as the negative impact of risk aversion and coercion).

In this way, Time to Change would play a small part in the ongoing dialogue within the sector about the purpose of mental health services and how equal human relationships play a crucial part in supporting people to manage their mental health challenges – and in promoting health, well-being and recovery.

Appendix 1. Leading from within: How mental health staff can help to reduce stigma and discrimination

Roundtable agenda

- 1pm **Welcome and opening remarks**
Roundtable Chair: Liz Sayce OBE, Chief Executive, Disability Rights UK
Sue Baker, Director, Time to Change
- 1.20 **Session 1: Beyond ‘them’ and ‘us’: overcoming stigma together**
- Lisa Rodrigues, Chief Executive, Sussex Partnership NHS Foundation Trust.
 - Sarah Yiannoullou, Managing Director, National Survivor User Network.
 - Lakhvir Rellon, Community Engagement Director, Birmingham and Solihull Mental Health NHS Foundation Trust.
 - Raphael Shervington, service-user.
 - Professor Sue Bailey OBE DBE FR, President, Royal College of Psychiatrists.
- 1.50pm Table discussions: What are the best approaches to building empathy and breaking down the ‘them and us’ divide in services?
- 2.40 Feedback of one top idea from each table
- 3pm Coffee
- 3.20pm **Session 2: Leading change**
- Sarah Hamilton, Research Manager, The McPin Foundation
 - Liz Sayce OBE, Chief Executive, Disability Rights UK
 - Dr Rachel Perkins, Senior Consultant, Implementing Recovery through Organisational Change programme.
 - Kate Schneider, Assistant (Design and Delivery) to National Clinical Lead.
- 3.45pm Table discussions: What can the leaders of mental health organisations and professions do?
- 4pm **Plenary discussion and next steps: Who can lead the change?**

Appendix 2. Topic guide

Time to Change is keen to explore how mental health professionals can help to tackle stigma and discrimination experienced by people with mental health challenges.

1. Are you aware of the Time to Change campaign?
2. If so, what do you think it has achieved so far?
3. How do you think health/mental health professionals can help reduce stigma and discrimination?
4. Do you think people with mental health challenges experience or perceive stigma or discrimination within health/mental health service?
5. If so, what forms does this take and how common is it?
6. Does it affect some services or parts of the system more than others?
7. Does it affect some people more than others – e.g. people with particular diagnoses, or people of a particular ethnicity, gender or age, or use of drugs and alcohol? What about Afro-Caribbean men?
8. Is there anything relating to mental health law or policy frameworks, such as containment or compulsion, that you think creates discrimination or the perception of discrimination?
9. Are there initiatives you think are helping – or could help – to build empathy and break down the sense of ‘them and us’?
10. How inclusive are mental health services of professionals with current or previous personal experience of mental health challenges?
11. What are the benefits of openness about lived experience of mental health challenges within the profession and services?
12. What might help whole organisations and professions to change, and overcome any conscious or unconscious discrimination?

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13. What can leaders of organisations and of the profession do to tackle stigma and discrimination? Who could take the lead?