

time to change

let's end mental health discrimination

Stigma Shout

**Service user and carer experiences
of stigma and discrimination**



rethink



Time to Change

Time to Change will change the culture of mental health forever in a ground-breaking four-year programme to combat the growing problem of mental health stigma and discrimination. Mental Health Media, Mind, Rethink and our evaluation partner the Institute of Psychiatry, King's College London have been awarded £18 million from the Big Lottery Fund and Comic Relief to run a programme that will publicly challenge attitudes towards mental health in England and counter discrimination against people who experience mental ill health.

The initiative will:

- Create a 5% positive shift in public attitudes towards mental health problems.
- Achieve a 5% reduction in discrimination by 2012.
- Increase the ability of 100,000 people with mental health problems to address discrimination.
- Engage over 250,000 people in physical activity.
- Produce a powerful evidence base of 'what works'.

The four year programme includes:

Open Up – a mix of 32 local and eight national service user-led projects to tackle discrimination in local communities. It will develop a new network of anti-discrimination champions, who will support other users and groups to tackle discrimination within communities.

Social marketing – use of the latest proven techniques to challenge attitudes and shift behaviour amongst those groups of people who impact on the lives of people with mental health problems.

Get Moving – an annual mass participation event that will bring people with and without mental health problems together around physical activities.

Legal Minds – to search out and support high-profile test cases that will change the way the law protects people from mental health discrimination.

Our website – to provide information, share models of good practice, and engage the public and stakeholders.

Anti-stigma training – aimed at medical students and trainee teachers to support new generations of practitioners who directly influence how these people think and behave in the future.

Community action – with 28 locally-based projects reaching out to provide practical support to individuals and communities.

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Introduction

Stigma and discrimination is receiving increasing attention across the world because its impact is devastating on individuals, communities and society.

Stigma and discrimination

- prevents people seeking help
- delays treatment
- impairs recovery
- isolates people
- excludes people from day-to-day activities
- stops people getting jobs.

The World Psychiatric Association's *Open the Doors* programme, operating in 20 countries, national initiatives such as *Like Minds, Like Mine* in New Zealand and *See Me* in Scotland and a host of community initiatives have been created over the last 10 years in recognition that 'something has to be done'.

In England, the approach has been more piece-meal. The government's National Service Framework for Mental Health encouraged mental health promotion to sit alongside service reform and established two programmes *mindout for mental health* and *Shift*. Individual NHS Trusts, national charities, pharmaceutical companies' advertising campaigns and local initiatives, including service user forums or local voluntary sector providers added to the mix.

'I've stayed away from many parties and other social situations because of a lack of confidence/fear of stigma. It has also stopped me applying for some jobs and joining sports clubs. I have often hesitated to disclose my history.'

'The easy way out is not to admit to friends that you have a mental health problem. This is very significant as I am sure that it delays recovery.'

The research community has been contributing to a growing knowledge base of 'what works'.

The ideal model emerging from this international and local experience includes some key factors:

Sustainability

There are no quick fixes and no instant solutions. Breaking down the prejudice, ignorance and fear surrounding mental health requires years of focused activity.

Multi-layering

Countering myths with facts and figures and people's real-life experiences may help to increase knowledge, but are better heard when underlying attitudes are firmly challenged and supported by clear incentives to change behaviours. Individuals, organisations, communities and governments all have a role to play.

Direct involvement

People directly affected by the stigma and discrimination – people using services and carers – need to be at the centres of the planning, delivery and evaluation of initiatives.

Targeting

People think and behave very differently in different circumstances. Understanding why people and organisations discriminate provides the key to unlocking more positive attitudes and behaviour.

Stigma Shout

People directly affected by mental health problems experience discrimination in a variety of ways from a range of individuals and organisations.

As part of the planning for the social marketing element of Time to Change, we wanted to understand people's experience and to identify who the campaign should target.

The Stigma Shout project was led by Rethink's research department. It included the largest ever survey of almost 4,000 people with direct experience of mental health problems and in-depth workshops involving over 100 people.

We received 3,038 responses from service users and 661 from carers to our survey. These identified where stigma and discrimination takes place and from who.

Our survey findings were then used with 86 service users and 24 carers who took part in our workshops at 10 sites across England. The workshops looked in depth at the behaviour of people identified in our survey and where the behaviour was happening.

Taken together, the Stigma Shout survey and workshops have identified a number of audiences for Time to Change to target.

'Making new friends, I hate the reaction I get from people when they ask what I do for a living, some people ask questions they would not ask if my son had a physical illness, other friends have stopped contacting me. I cannot go on holiday with my son because people stare when he behaves "differently".'

'Keeping in touch with friends - reaction is usually one of shock, horror, followed by avoidance; most people have no idea how hard it is. This leaves me feeling very isolated and with low self confidence.'

Who took part?

Our survey

Stigma Shout surveys could be completed on-line or on paper.

- 1,790 service user responses were received on paper and 1,248 online.
- 397 carer responses were received on paper and 264 online.

The service user survey sample was made up of respondents who were 60% female and had a mix of ages, though 54% were aged 35-54.

11% of the sample were from black and minority ethnic communities and 13% were gay, lesbian or bi-sexual.

25% (737 people) reported additional health disabilities, the most frequently cited being physical health problems (33%), learning difficulties (13%), hearing problems (8%) and dyslexia (8%).

There was a good regional distribution of responses with 33% living in rural or semi-rural communities.

A mix of diagnoses were also reported, including 63% of people living with depression and anxiety and 50% living with severe mental illness such as schizophrenia or bi-polar disorder.

The carer sample was predominantly female (80%) – mostly mothers (52%) or wives (11%). One in three carers were aged 55-64, 57% were aged 45-64 and 92% were of white UK ethnicity. The average length of time people had been in a caring role was 12 years.

There was also good geographical dispersal of carer responses, with 42% residing in rural or semi-rural areas.

As with the service user sample, there was high reporting of disability in this group at 25%, with most reporting a mental health problem (54%).

In terms of diagnosis of the person supported, both schizophrenia and depression/anxiety were frequently cited (50% and 40%).

In the carer sample there were more responses from people supporting a person with severe mental illness (74%) than people with a severe mental illness in the service user sample (50%). This is important as we did find, as other studies have reported, that diagnosis impacts on stigma and discrimination experiences.

'Stigma makes me afraid of telling my work colleagues, telling my fellow volunteer colleagues, telling certain friends as I am uncertain of their reaction.'

'I'm signed off work currently, but embarrassed to be seen out at shops or wherever by people who know me because I don't LOOK ill.'

Our workshops

In total over 100 people took part. Each workshop lasted three hours, with participants' views being recorded individually and through a mark sheet to set group priorities.

There were seven groups made up of service users, one group of carers and two mixed groups of service users and carers (see table one).

Table one: Stigma Shout workshops

Attendees	Location	Number
Service users	London: Tower Hamlets	9
Service users	Taunton	9
Service users	Mid Herts	10
Service users and carers	Birmingham	12 (10 and 2)
Service users	London: Old Street	8
Service users	Grimsby	13
Carers	Beverley	13
Service users	Croydon	11
Service users and carers	Cambridge	11 (7 and 4)
Service users	Maidstone	11

The locations ranged across England, with the London workshop attracting people from within London, Kent and Hertfordshire.

Half of the service user participants were men and half were women, with 21% of participants coming from black and minority ethnic communities. As with our survey, there was a spread of adult ages and diagnoses, with an average of 18 years living with a mental health problem.

Women accounted for 67% of the carer participants, with 48% of all carer participants in the 55-64 age range. The average number of years in the caring role was 17.

The people we didn't reach

Our survey was promoted through Time to Change partners and networks and available to people for six weeks. The majority of our workshops were held during the day and all participants were recruited through Time to Change partners. This means that people who have direct experience of mental health problems, but who are not connected in some way with a Time to Change partner or did not come across the survey through an online access point, will not have been included. People with mental health problems and carers who work during the day will have had limited opportunity to participate in our workshops.

Stigma Shout therefore also used the results of desk research carried out over the previous two years by Rethink's research team to also shape our decision on who to target with the social marketing campaign. This desk research reviewed available international evidence including studies from across England and the UK.

'I have not always been able to take time away from work to care for my partner during periods of mental ill health. Sometimes I have had to lie about the reason I'm away, saying instead I've had a stomach bug or something.'

Table two: Reported level of service user experience of stigma and discrimination.

Question	Number	Percentage
Have service users been treated differently (in a negative way) because of their mental health problems?	2093 – Yes	69%
	509 – No	17%
	410 – Not sure	14%
Does stigma and discrimination stop service users from doing the things they want to do?	2122 – Yes	71%
	639 – No	21%
	249 – Not sure	8%
Does the fear of stigma and discrimination stop service users from doing the things they want to do?	2208 – Yes	73%
	617 – No	21%
	183 – Not sure	6%

Table three: Reported level of carer experience of stigma and discrimination.

Question	Number	Percentage
Have carers been treated differently (in a negative way) because of their mental health problems?	283 – Yes	43%
	276 – No	42%
	99 – Not sure	15%
Does stigma and discrimination stop carers from doing the things they want to do?	348 – Yes	53%
	273 – No	42%
	36 – Not sure	5%
Does the fear of stigma and discrimination stop carers from doing the things they want to do?	265 – Yes	41%
	336 – No	52%
	43 – Not sure	7%

What we found

The Stigma Shout survey confirmed that stigma and discrimination is all-pervasive, with close to 9 out of 10 service users (87%) reporting its negative impact on their lives. Two-thirds have stopped doing things because of stigma and two-thirds have stopped doing things because of the fear of stigma and discrimination (see table two).

These proportions are significantly higher for women, people living with severe mental illness, people who are gay, lesbian or bi-sexual, those with additional disabilities and the middle aged service user population. Multiple layers of discrimination are clearly a problem, although we did not identify any differences based on ethnicity.

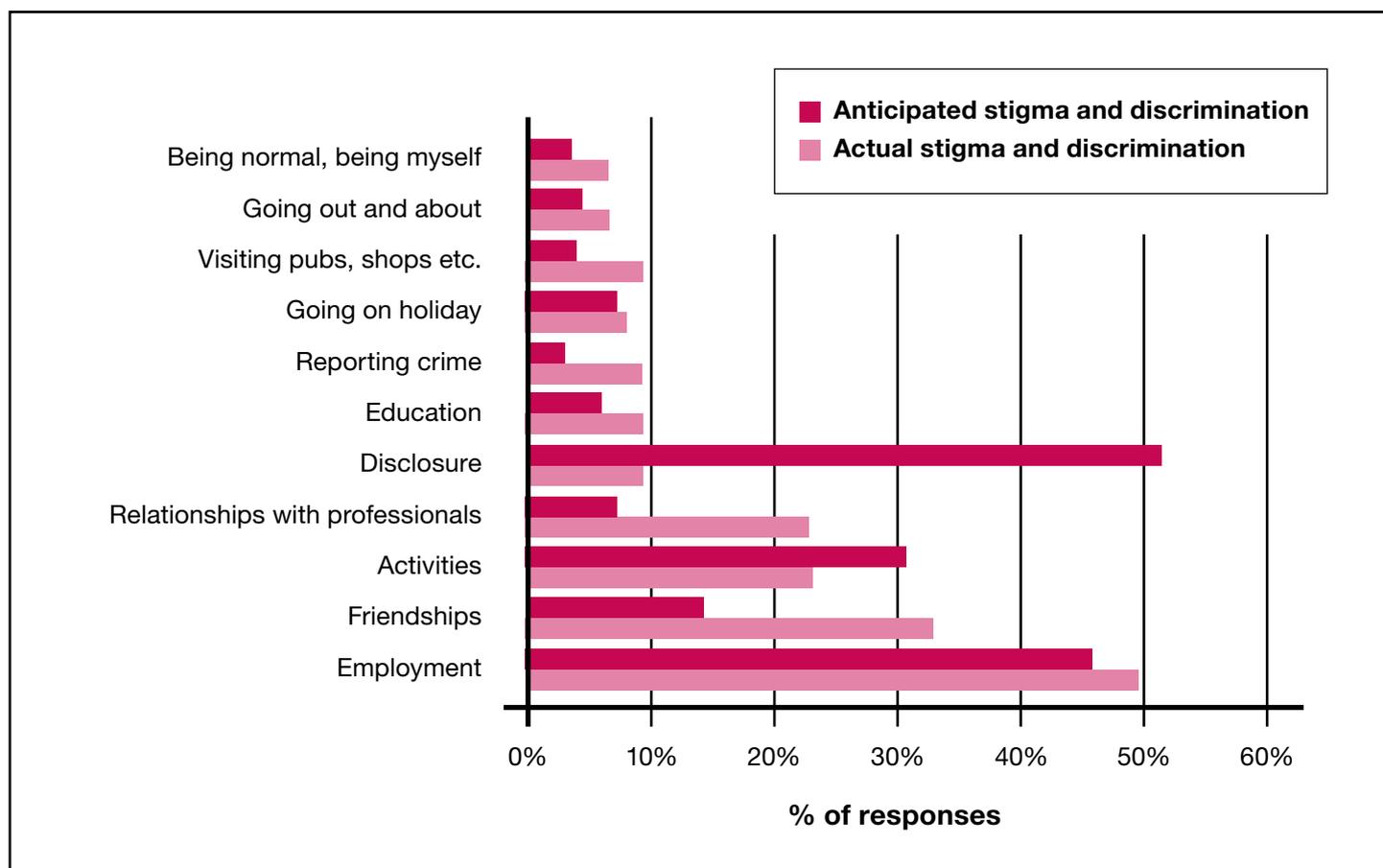
Lower levels of personal stigma and discrimination are reported by carers (see table three). Comparing aggregated stigma responses, 68% of carers personally identified with the problems of stigma and discrimination compared to 85% of carers who said that stigma and discrimination was a problem for the person supported.

For carers, ethnicity is seen as a key factor. Carers from black and minority ethnic communities reported higher levels of stigma and discrimination, as did those carers who also have their own disability.

Service users and carers report similar areas of their life that are damaged (see figure one, and figure two over the page), including:

- Employment.
- Building new and retaining existing friendships.
- Being able to join groups and take part in activities within the community.
- Feeling confidence to go out and about – visit the shops, go down the pub.
- Ability to openly disclose mental health issues for fear of being judged.
- Ability to challenge professionals, be heard by professionals or make requests for changes to treatment.

Figure one: What service users stop or fear doing because of stigma and discrimination.



Service users also highlighted:

- Being able to report a crime without fearing your testimony would not be believed.
- Difficulty accessing education.

Family carers also highlighted:

- Difficulty going on holiday because of reaction of other holiday makers to the person they cared for.

Both service users and carers acknowledged that often it wasn't stigma and discrimination that was a barrier but rather the illness itself or other consequences of living with a mental health problem such as low self-esteem or lack of motivation. We explored this further in our workshops.

For instance, service users reported close family members being over-protective or patronising while carers and service users said that psychiatrists and other health professionals often refused to

listen, refused to exchange information, or refused to recognise non-medical needs. How far these behaviours are a reflection or consequence of stigma and discrimination and how far they are a reflection of the complex dynamics found in any family or professional-client relationship can be difficult to judge.

When using this data to make decisions on how to target the anti-stigma campaign we have been mindful of the complexity of mental health and how stigma and discrimination interacts with other factors, including professional practice and the modern-day realities of all family life.

'It's not so much discrimination that stopped me doing things, it's more my anxiety in certain situations.'

Who should we target?

The survey asked about the groups and settings the Time to Change social marketing campaign should target to make a real difference. Who is the 'right audience' for this campaign, bearing in mind we can't reach everyone and segmented target populations are known to be the most effective approach for social marketing campaigns?

Immediate and wider family, friends, neighbours, work colleagues and GPs all scored highly in our survey, though with some difference of emphasis between service users and carers (see figure three).

Our workshops explored these groups in depth, asking participants to explore the actual behaviours of each group in turn.

'Disclosing my son's mental health problems to work colleagues as I fear being stigmatised for absences in times of crisis.'

'Disclosing my mental health situation to people who live in my community. The neighbours campaign has led to certain authorities not lending a sympathetic ear when I have made various complaints, even my psychiatrist who simply told me to "move home then".'

We wanted to understand why these groups had been identified and what type of negative behaviours were being displayed to help us decide which of the groups – if any – could be reached and their behaviours changed by the social marketing element of Time to Change.

On family, workshop participants rated highest the statement: 'They have lowered expectations of me; assuming I will achieve less, cope less well in specific situations etc.' When asked what families should do differently, participants rated highest the statement: 'Don't make assumptions about me, label me or be embarrassed of me'.

Figure two: What carers stop or fear doing because of stigma and discrimination.

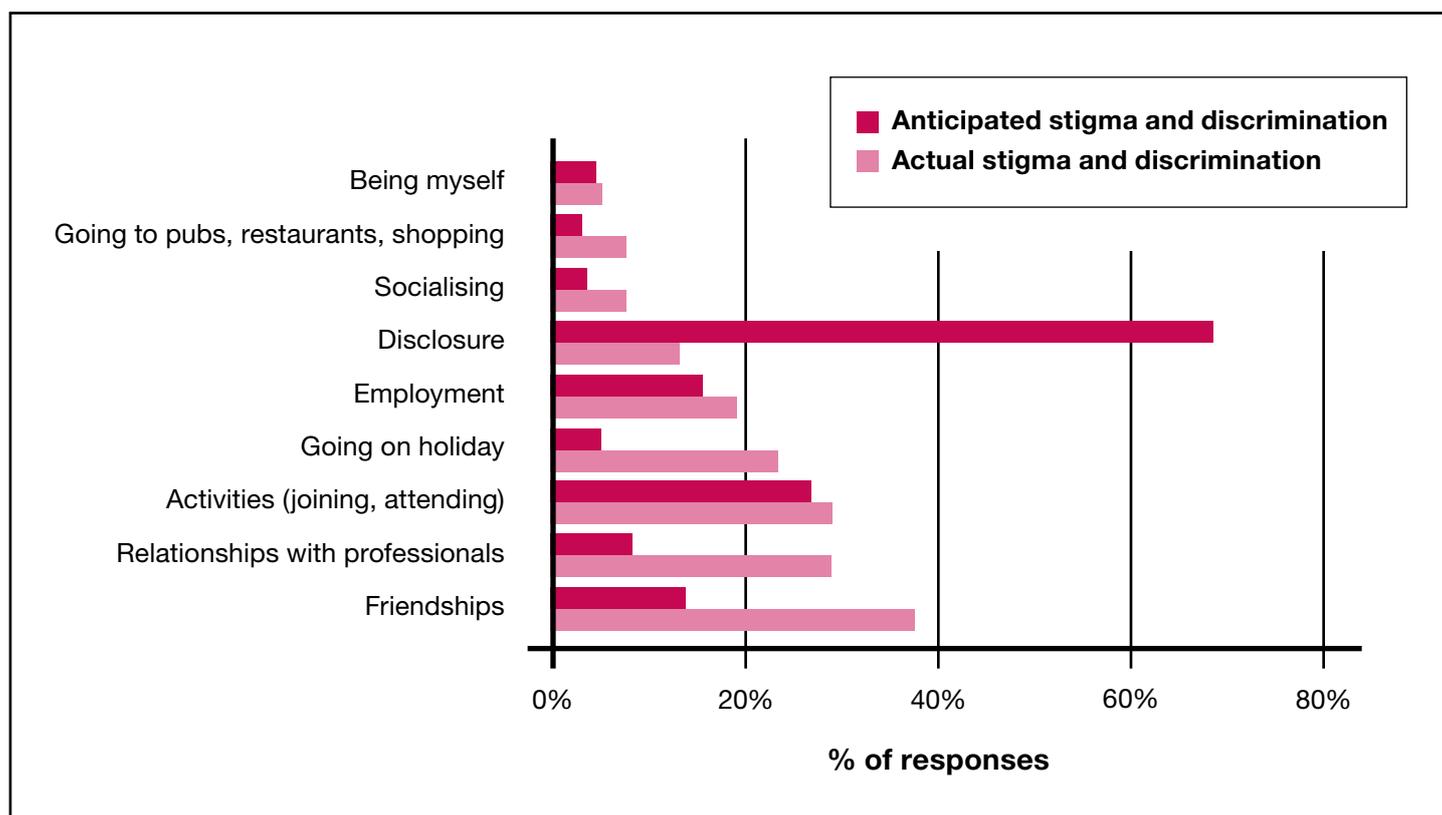
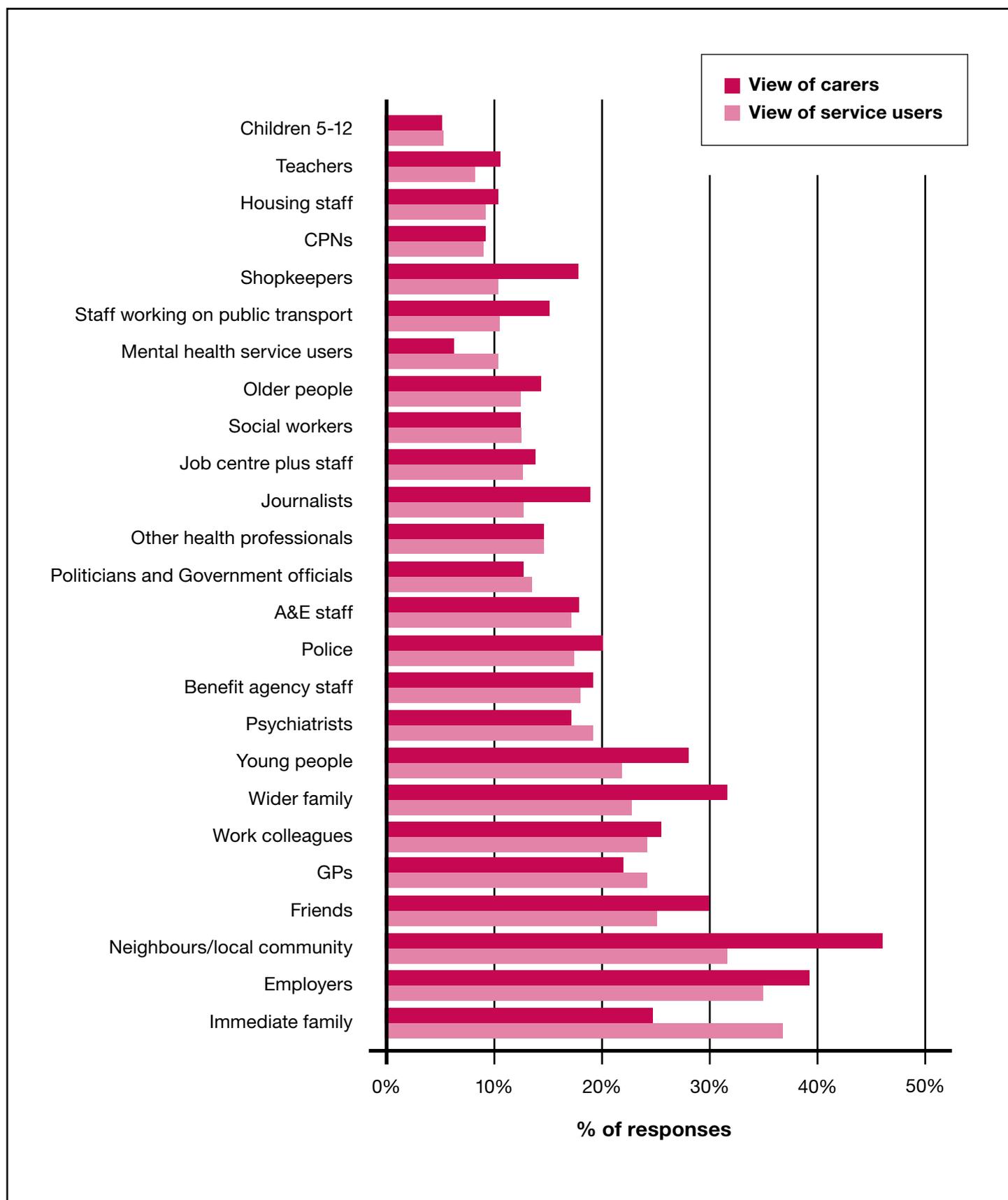


Figure three: Which group(s) should we target with an anti-stigma campaign?



On friends, participants said that they ‘don’t want to know me’ when the mental health problem is disclosed. People wanted friends to stay friends and ‘give me some support’.

On neighbours, participants were more evenly spread across the three alternatives – ‘they label me’, ‘they are afraid of me’, and ‘they are rude to me – they snigger when I walk by, they say and do bad things towards me’. Participants wanted neighbours to ‘understand mental illness’ and treat them as any other neighbour would be treated.

Work colleagues excluded participants from events and team meetings, and wouldn’t talk about the impact of a mental health problem. Participants wanted to see work colleagues ‘treat me like any other work colleague’, ‘include me’ and ‘understand mental health issues’.

‘When attending a job interview, I was explaining my home responsibility and that on a rare occasion I may need to take leave at short notice and I was told that my job should come first and that I was lacking commitment.’

On health professionals, we decided to include GPs within a wider category of ‘health professionals’ within our workshops. In line with our survey results, negative experiences of GPs and psychiatrists in particular came to the fore. However, workshop participants had more ambiguous views than our survey contributors, with many more positive experiences of contacts with both groups being highlighted. Positive experiences of Community Psychiatric Nurses and psychologists were also raised. Workshop participants rated highest the statements ‘they just see me as an illness, not a person’ and ‘they don’t actually hear what I’m saying – they don’t listen to me and they judge me’. Health professionals should ‘listen to what I’m saying’ and ‘see me, not the illness’.

‘Stigma and discrimination has stopped me talking to my GP about physical problems, they say it’s in my head.’

The survey data on which groups to target was also analysed to identify variation by service user ‘grouping’.

We found key variations by diagnosis, gender, age, ethnicity and additional disabilities.

This is important as it provides evidence of the varying ways stigma and discrimination impact on people’s lives and the subsequent recommendations people make to tackle these issues through targeting energies towards specific groups.

From our data we must be mindful that the campaign will not benefit all service users or carers equally.

In thinking through which groups the campaign could target, those groups who are seen as helpful, generating less stigma, are important to identify as they could be allies in the programme.

Further work will be needed to identify which roles they might best play but among the medical professions Community Psychiatric Nurses are less frequently cited, among social care professionals housing staff are seen to generate less stigma and in terms of a public audience the 5-12 age group are highlighted.

‘It has caused family and friends to “drop” me. My depression is not taken seriously by some GPs, psychiatrists and CPNs, which makes it hard to get treatment. I felt like an impostor in psychiatric hospital.’

Where should we target?

People were asked to recommend one location only for a successful campaign. Broad agreement between service user and carer responses is evident (see figure four).

‘I have no idea. This is such a big problem I would not know where to start.’

The data for location were again also explored for variations in service user view. There were no variations identified by age or ethnicity. But by gender, diagnosis and disability variation in preferred locations were reported.

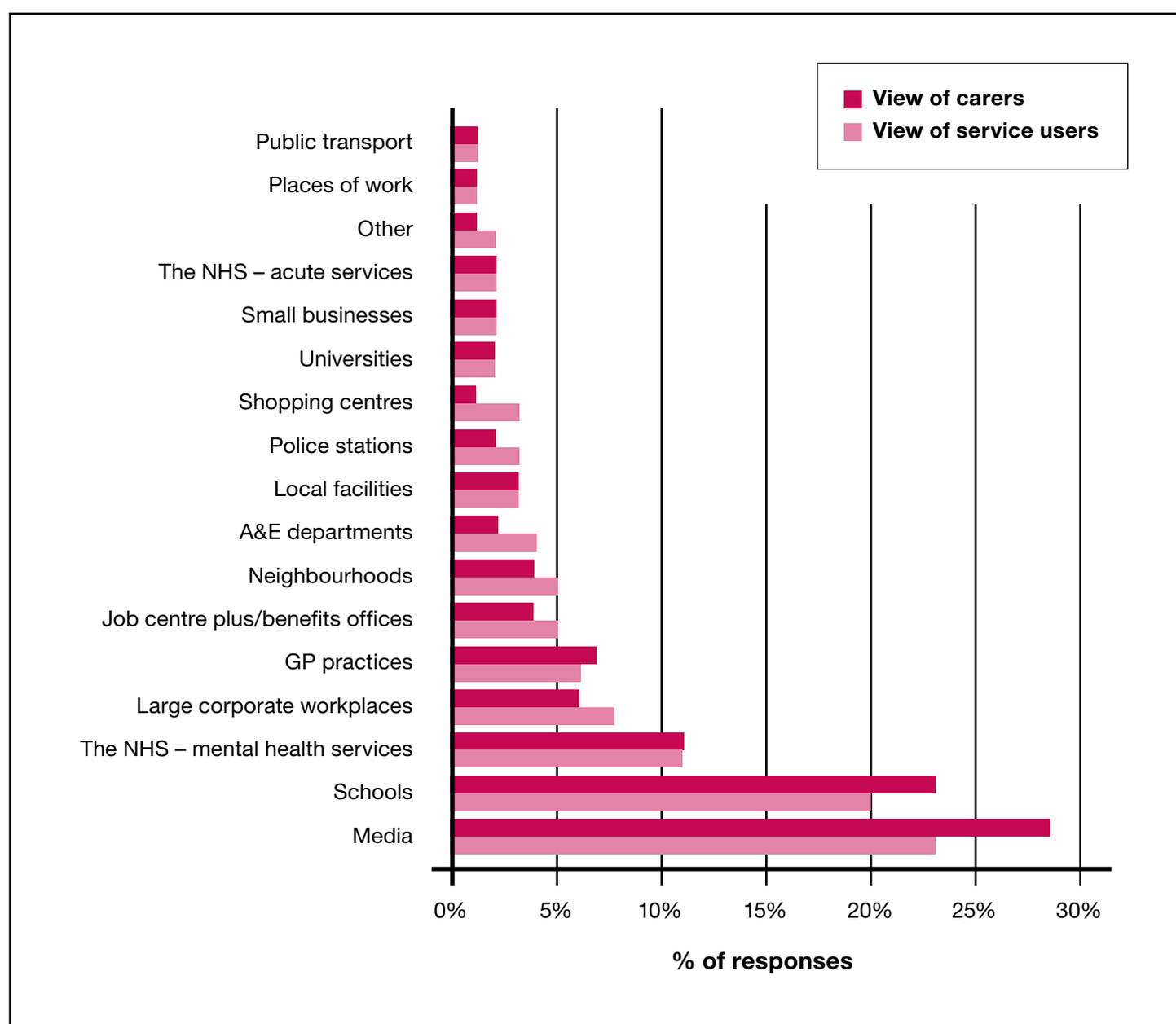
Again this highlights to us how different groups of service users will have very different preferences on where the campaign should target segmented groups – and whom those groups should be.

These findings were further tested in our workshops, and broadly confirmed, with the media in its

broadest sense, being seen as a route to reach large numbers of people.

We also explored why schools were highlighted (figure four), despite school age children not being identified as a group who present stigmatising behaviours that impact on the lives of people affected by mental health problems (figure three). Two reinforcing views were given – adults who exhibited discriminatory behaviour would not change while interventions with children would ensure that not only they but future generations would be prevented from developing negative attitudes and behaviour.

Figure four: Which one location should we target with an anti-stigma campaign?



Our campaign

What should we say?

We were interested in the survey to gauge what key messages were important to people. Of those provided, the most popular were:

- We are people – see me, not the illness (service user 51%, carer 44%).
- Having a mental health problem is a common part of life 1 in 4 (42%, 45%).
- People with mental health problems can and do recover to lead rewarding and fulfilling lives (37%, 35%).
- We should have the same rights as everyone (37%, 33%).

There were strong calls for positive messages to be heard and this is consistent with how service users and carers described their ambition for the tone of Time to Change as a whole.

The top 10 words service users and carers used to describe the programme included positive, inspirational and respectful (see table below).

We also asked what else people would like us to say to change the way people behave towards people with mental health problems.

Table four: Tone of Time to Change.

	Service users	Carers
Positive	23%	22%
Respectful	13%	13%
Inspirational	11%	9%
Informative / educational	9%	10%
Inclusive	8%	9%
Recovery focussed	7%	7%
Reclamation*	5%	5%
Confident	4%	3%
Impacting / thought provoking	4%	3%
Challenging	2%	3%

* The sense of reclaiming derogatory words or behaviours.

We analysed responses using a 19 code framework generated by the research team. Responses were received from 52% of the service user sample and 64% carers. There was more agreement from carers than service users, who provided wide ranging suggestions.

The most commonly cited messages were:

- Show some understanding – increase knowledge and awareness (service user 13%, carer 41%).
- Treat us with respect (people need to behave differently towards us) (7%, 34%).
- Mental illness can happen to anyone (7%, 20%).
- Don't label us (5%, 9%).
- It's just like a physical illness (3%, 9%).
- Don't isolate us (3%, 9%).
- I am not threatening (3%, 8%).

We again tested these findings in our workshops and again participants reinforced the survey findings.

Campaign approach

The Stigma Shout survey shows that service users want the campaign to be factual (98%), hard-hitting (79%) and humorous (69%). It should avoid a lecturing style, being too gentle or shocking.

Service users were divided over use of controversy (50% agreement, 50% disagreement).

The views of carers were similar – voting for a factual (99%), hard hitting (80%) and humorous (63%) campaign that avoided a lecturing approach. Fewer carers were in favour of controversy than in the service user sample (42% agreement versus 50%).

Mental health is the subject of lots of jargon and the phrases used to describe the issue itself – mental 'illness', or 'problem', or 'distress' and so on – can be hotly contested.

In our survey, we found that the largest agreement among both service users and carers was over the use of the term 'mental health problem' as a generic description.

What we've learnt

Stigma and discrimination has a profound impact on the lives of people with mental health problems. The overwhelming majority of people with mental health problems report being misunderstood by family members, shunned and ignored by friends, work colleagues and health professionals, called names and much worse by neighbours.

In short, people are being denied opportunities to be people.

The findings from our survey, the largest of its kind ever carried out, and our in-depth workshops have produced a wealth of material to help inform both the social marketing element of Time to Change and the programme as a whole.

1. Stigma and discrimination is a massive issue. It impacts on every part of people's lives and although some people learn to combat or ignore stigma and discrimination, for the majority it is an additional burden to cope with alongside the symptoms of living with a mental health problem.

2. Stigma and discrimination stop people engaging in everyday activities – going shopping, visiting the local pub, taking a holiday, obtaining insurance, making new friends, joining a local club, talking openly with family about problems – the list is endless – as well as preventing effective engagement with health professionals, applying for work for fear of discrimination from colleagues or employers and accessing educational opportunities.

3. There are some groups of service users and carers who are more affected by stigma and discrimination than others. Although it is difficult to make generalisations from our sample, we see trends that should be followed up.

- We found that multiple discrimination is experienced by those living with a mental health problem and another issue that can attract public prejudice, ignorance and fear in particular on grounds of ethnicity or sexuality.

- We also found those living with 'severe' forms of mental health problem such as schizophrenia, psychosis and bi-polar reported more problems than those living with depression, anxiety or phobias.
- That is not to say the difficulties experienced by those with more common mental health problems are not 'severe' personally or that stigma has less impact but research does show that public attitudes towards different mental health problems do vary. Data from the Office for National Statistics shows more understanding towards dementia, eating disorders and depression than schizophrenia or drug and alcohol addiction.
- For carers, those living in black and minority ethnic communities and those with disabilities themselves reported higher levels of stigma and discrimination, as did the 'middle-aged' population 35-54.

4. We also found that people's solutions to the problems of stigma and discrimination in terms of whom we should target and where we should place our energies again varied.

We explored variations in views in the service user sample and found that diagnosis, gender, age, ethnicity and disability impacted on who people thought we should target and where that targeting should take place.

Some of these findings are intuitive:

- People with severe mental illness are more troubled by the police and more likely to have contact through the sectioning process and by mental health professionals such as psychiatrists.
- Those of working age are more affected by staff in benefits agencies and job centres.

However, other findings highlight some key concerns for particular groups with, for instance, women reporting more difficulties through A&E and GPs, men experiencing more difficulties through neighbours, teenagers and the police.

It is clear the anti-stigma campaign will not impact equally on all people affected by mental health problems, and we need to be upfront about that from the outset.

5. The survey explored two types of stigma and discrimination – actual and anticipated. We did find differences here – with disclosure being a greater problem because of the fear of doing so (including disclosure on job application forms) prevented people from talking about their illness or applying for a job.

There was less evidence that disclosure experiences in social settings were negative in practice. There was considerable worry about talking to friends, but less actual discrimination from friends.

Other actions were experienced as negative, but not feared to such an extent – such as relationships with professionals and difficulties with the way friendships are made, maintained and change as a result of living with a mental illness.

This has implications for Time to Change which needs to address people's anticipation of stigma and discrimination as well as its reality.

6. It is acknowledged that some of the consequences of mental illness are routed in stigma and discrimination – the attitudes and behaviours of other people towards those with mental health problems, and the consequences of one's own anticipated-stigma beliefs.

However, service users and carers also reflected on the difficulties of distinguishing the impact of stigma from the impact of the illness.

- Do I shy away from applying for a job because I feel I will be discriminated against or because I don't feel well enough to return to work yet?
- Do I decide not to join the gym for fear of how people will view me as a 'mental health service user' or because I don't believe I am well enough to go regularly?

As with many areas of mental health the causal links between events are not clear cut.

7. The key message that service users and carers want communicated to successfully combat stigma and discrimination is very grounded and humane – 'we are people – see me not the illness'.

They also ask for people to 'show some understanding' – which requires greater awareness and knowledge of what mental health problems are and how they impact on people's lives.

Reflecting on the tone of the campaign services users and carers feel it should be factual to achieve this goal as well as hard-hitting to ensure it has impact.

There was a strong sense that Time to Change must be positive, respectful, inspirational and informative.

'I always fear telling anyone, friends, new employers etc about my mental health problems. This makes it difficult to make new friends or join any kind of social group, as questions are always asked.'

'Stigma and discrimination has stopped me making a complaint, going out, making friends and keeping them and going out to functions.'

Next steps

The findings from the Stigma Shout survey and workshops will be relevant across the whole of Time to Change. In the first instance, they are being used to identify the target audiences for the social-marketing campaign that will launch in England in January 2009.

Between now and then, the social marketing campaign will work with people from those target audiences to understand from their perspective what gives rise to stigmatising and discriminatory behaviours and what would help them change their attitudes and behaviour.

Acknowledgments

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We are grateful to everyone who took part in the survey and workshops and who opened up their lives for this research.

Author Paul Corry.

If you would like more information on Time to Change, what's going on in your area and how you can get involved, please visit www.movingpeople.org.uk or contact us:

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time to change

let's end mental health discrimination



Mental Health Media is a unique organisation working in the fields of communications and mental health. We want to bring about equality and respect for those who experience mental distress. So we work to reduce discrimination on mental health grounds by promoting diversity, visibility and expertise of people who experience mental distress.



Mind is the leading mental health charity in England and Wales. We work to create a better life for everyone with experience of mental distress. Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively, and with respect. There are 200 local mind associations throughout England and Wales.

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Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. Our aim is to make a practical and positive difference by providing hope and empowerment through effective services, information and support to all those who need us. We help over 48,000 people every year through our services, support groups and by providing information on mental health problems.



The **Institute of Psychiatry** is the leading centre for mental health research and teaching in Europe, and is a health school of King's College London. Our mission is to pioneer research into the understanding and treatment of mental and neurological disorders, and to make this knowledge widely available to improve mental health care.