

Lived experience in Time to Change

Position statement

October 2012

From its inception, Time to Change has recognised that people with experience of mental health problems need to shape and deliver the programme at every stage and level. The heart and soul of our work, and that of organisations we will work in partnership with, needs to operate in adherence to this key principle. This is not just a guiding principle but also how we achieve our mission – empowering and nurturing leadership talents that will help drive wider social change. We estimate that 60-70% of staff working on Time to Change have lived experience of mental health problems, and we state in job advertisements that this experience is desirable.

This is a summary of how people have been involved in the governance and delivery of Time to Change as well as how people with lived experience more widely have been empowered as a result of the work of the programme.

Phase 1: 2007-2011

Leadership and governance

In the first phase, a Lived Experience Advisory Panel (LEAP) of 12 people with mental health problems and carers provided strategic advice and support to the programme. Members of LEAP came from across England and included individuals from Black and Minority Ethnic communities. Their role included being part of governance and management groups; advising all projects and sitting on the evaluation steering group; being ambassadors for the programme; supporting and mentoring others with mental health problems to take part in the campaign; and undertaking strategic reviews of diversity and involvement. Members of LEAP were also crucial in developing the Phase 2 funding bid and securing funding.

People with lived experience delivering Time to Change

People with lived experience of mental health problems were involved in delivering anti-stigma work as part of Phase 1 in a range of ways:

- The Open Up project provided tools, training, resources and support including 29 small grants to people with mental health problems to deliver anti-discrimination activity. There is more information about the projects that were supported through Open Up at www.time-to-change.org.uk/speakout.
- People with experience of mental health problems helped to design and deliver events including 22 roadshows in the summer of 2011. Around 30 volunteers participated in each roadshow, with at least two thirds of these having experienced mental health problems. For many, it was the first time they had spoken openly to members of the public about their experiences. Volunteers were given training to help them speak out safely and confidently, and were supported by dedicated Volunteer Coordinators, most of whom also had lived experience. Hundreds of other events involving people with lived experience speaking to the public were also organised by Time to Change and by local organisations and individuals throughout the first phase.
- Involvement Workers with experience of mental health problems helped to design and deliver training to medical students, trainee teachers, and staff in schools and GP surgeries as part of the Education Not Discrimination project. Involvement Workers received training, which was accredited by Middlesex University and could be used to build up credits towards a higher education certificate, diploma or degree.

- People with lived experience advised the social marketing campaign, with a LEAP member sitting on the Campaign Advisory Group and the wider LEAP group feeding back on campaign strategies and concepts. People also featured in the campaign telling their stories, both in advertising and PR.

Wider engagement of people with lived experience

Time to Change also had a target of supporting 100,000 people with mental health problems to gain confidence to challenge stigma and discrimination. This was exceeded with 162,196 people being supported:

- As members of the Facebook community (In a 2010 survey, 84% of fans of the page had experienced mental health problems themselves. 83% said they felt more confident about tackling discrimination as a result of joining the page and 44% said they had tackled an instance of discrimination since joining).
- Through taking part in community projects as participants, volunteers and staff members.
- Accessing legal advice and information about rights in the workplace, online and through a telephone legal advice line.
- As ambassadors and campaigners through the Time to Change Champions scheme.
- Running their own anti-stigma projects through the Open Up initiatives scheme and attending the Open Up conference for people with lived experience actively challenging discrimination.

Evaluation

Academics and others with experience of mental health problems from SURE (Service User Research Enterprise) at the Institute of Psychiatry, King's College London were involved in the design and analysis of Time to Change's evaluation. Interviewers with lived experience were trained to carry out telephone interviews for the Viewpoint survey into reported discrimination. Researchers with lived experience were also involved in the design, data collection and analysis of qualitative interviews to evaluate several areas of the programme.

Phase 2: 2011-2015

Lived experience leadership and involvement in Time to Change was reviewed two years in to Time to Change, and the LEAP panel was reviewed at the end of Phase 1, and recommendations and learnings from this have been taken forward into Phase 2 to ensure that lived experience influence, experience, opportunities and visibility are now even more fully embedded in all aspects of Time to Change.

Some of the key learnings from these reviews include:

- The need for lived experience representatives to be linked to specific activity within the programme. LEAP members had the most influence and a more satisfying experience when working intensively on specific projects and activities, for example membership of governance and advisory groups, chairing events, mentoring others with lived experience to be part of the campaign, and supporting volunteers.
- The need to develop practical involvement resources for staff including guidelines for consistent payment of people with lived experience.
- The importance of bringing people with lived experience who were involved in different elements of the programme together (a series of lived experience networking events in 2010 and 2011 did this).
- The importance of lived experience expertise in supporting Time to Change to address diversity.

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- The need for regular reporting of involvement activity across the programme.
- The need for lived experience to be central to the design and development of Phase 2.

Taking these learnings forward, LEAP no longer exists in order to broaden leadership to include a larger group of people, but many members are still actively involved in Time to Change – as employees, in freelance roles and as advisors at senior management and governance level.

Governance and management

People with lived experience of mental health problems have roles on all governance and management groups and project advisory groups.

- The Senior Management Group (SMG), Time to Change's strategic decision-making board, includes two representatives with experience of mental health problems (one from a Black and Minority Ethnic community).
- The Programme Advisory Board (PAB), which provides advice and expert opinion to Time to Change, includes one adult and one young person with lived experience.
- The Operational Management Team, which makes recommendations about budget allocation and project planning to the SMG, includes the Head of Leadership and Engagement, who has lived experience of mental health problems.
- Advisors with lived experience help to shape the development and direction of each individual project within Time to Change, either by sitting on Advisory Groups or advising on specific projects; and all projects have a budget to cover advisors' time.

Leadership, delivery, and engagement

People with lived experience continue to be involved at all levels of the design and delivery of all activity. In Phase 2 there are also aims to improve the social capital of people with mental health problems by increasing their access to social resources and to improve the confidence and ability of people with mental health problems to take action to tackle discrimination.

The table below outlines how people are involved in each level within all Time to Change projects.

Dedicated Social Leadership team

The Social Leadership team has the lead role in reaching out to people with experience of mental health problems across England and supporting people from a wide range of communities to become Time to Change Champions. The team also provides information, training and support to help all Time to Change staff engage with people with mental health problems as effectively as possible.

Thank you

Engagement and leadership of people with lived experience is a continually evolving process. We are committed to continuing to listen to feedback from those engaged in our activity in order to improve how we work. We would like to thank all those who have contributed to the development of Time to Change so far – those who have volunteered, shared their views online, worked as consultants and been open about their experiences as members of staff. In particular we would like to thank the LEAP group who worked with us throughout phase one and who hugely influenced the development of the phase 2 programme.

Project	Lived experience in strategic development and decision making	Delivery by people with lived experience	Building social capital and confidence of people with lived experience
Social marketing campaign	2 lived experience representatives on Campaign Advisory Group.	People with lived experience feature in advertising and PR material.	The primary target audience for the campaign is people without mental health problems, whose attitudes we aim to change. However 51% of people signing the pledge have pledged to disclose their own mental health problems (over 3000 people so far in Phase 2).
Community events	8 representatives, including 2 from Black and Minority Ethnic communities, on the national advisory group.	Hundreds of events across the country are organised by Time to Change as well as by other organisations and individuals. People with lived experience are trained and supported to speak to the public about their experiences at these events. The training sessions and resources are designed and delivered by people with lived experience.	Time to Change is evaluating improvements in confidence and social capital of volunteers taking part in community events.
Grants	2 representatives on the Grants Panel which makes final decisions about awards.	A key criteria for successful applicants to the Grant fund is evidence of lived experience leadership at all stages of project design and delivery.	An estimated 4,500 volunteers will have the opportunity to be involved in the delivery of these projects, which bring people with and without mental health problems together.
Children and young people	13 members of the Children and Young People's panel, which helps design all elements of the project. Parents Panel with 5 parents with direct experience and 12 parents of children with mental health problems.	Part of the project is a leadership training course which supports young people to become trainers, tell their stories in the media, work as researchers and run their own events.	The leadership training will build the capacity of 120 young social leaders, developing skills including communication, public speaking, decision making, sharing stories in the media, co-training and research skills.
Social leadership	Advised by Champions and freelance Coordinators with lived experience.	8 Regional Coordinators with lived experience deliver training and networking events for people with lived experience regionally.	There are currently 1100 Time to Change Champions with lived experience (10% from Black and Minority Ethnic communities). Champions

			receive regular newsletters with opportunities to get involved with Time to Change. So far 183 people have attended networking events and 71 have received training. We aim for 1680 Champions and 1500 people attending networking events over the Phase.
Media advisory service	4 representatives on advisory panel.	5 people have advised on TV soap and drama scripts. People with lived experience have contributed to a training film for media professionals and spoken at media events. These opportunities will continue throughout Phase 2.	18 people have already been put forward to take part in documentaries, including the recent Channel 4 '4 Goes Mad' season, with two appearing on screen. These opportunities will also continue.
Organisational engagement	Advised by consultants and advisors with lived experience.	A lived experience consultant is developing a health check for organisations. A team of people with lived experience is being recruited to deliver these health checks and make recommendations to organisations on how to improve culture and practice.	Champions will be supported to take part in organisational pledge signing events.
Digital	Advised by Time to Change Champions and Young People's Panel.	Around 144 bloggers per year supported to contribute to the Time to Change website. The digital team receives input from Time to Change Champions and other site users to develop the website.	Over 100,000 fans on Facebook sharing experiences and ideas for tackling stigma. In a Phase 1 survey, 84% of Facebook fans had lived experience.
Evaluation	Advisory group is being established to inform the development of evaluation tools for community based research. Evaluation led by the Institute of Psychiatry, King's College London (IoP) has input from people with lived experience via SURE.	People with lived experience of mental health problems are employed by the IoP and supported by Time to Change to undertake research interviews.	