



let's end mental health discrimination

Involvement of people with lived experience of mental health problems

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 every level. 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. People with lived experience have been involved in the governance and delivery of Time to Change and, more widely, have been empowered as a result of the work of the programme.

The involvement of people with lived experience included, amongst others, the Lived Experience Advisory Panel, who have driven strategy, delivery and been a key part of decision making (sitting on governance and management groups and working as part of the team on the bid for our new funding). There were also the regional coordinators, who supported user led community projects; the involvement workers, who helped plan, develop and deliver training to influential groups of professionals; people who featured in the campaign and in media interviews; volunteers at events; and the Open Up project team, as well as many other staff members within the Time to Change team with lived experience.

A statement on the involvement of people with lived experience in the first phase and second programme is [available online](#).

Lived Experience Advisory Panel (LEAP)

In spring of 2008 a group of 12 people affected by mental health problems were recruited to help shape, govern and deliver the overall programme. This panel would help Time to Change make sure the needs of service users and carers were at the heart of its work. Known as LEAP, they provided specific guidance on service user and carer involvement and engagement across the programme. They also provided guidance on campaigns and projects, reviewed progress, and acted as spokespeople and ambassadors for the programme.

LEAP contributed an invaluable mix of experience, expertise and skills, particularly in diversity, and links to broader networks and communities, with a good geographical spread across England. LEAP worked directly with the programme management team, and had a representative on the Joint Management Group and Senior Management Team, which were the strategic decision making groups. LEAP members were also involved in the development of the phase two funding bid and a representative attended the bid assessment meeting.

LEAP members were commissioned to undertake an Involvement Review (2009), the first Diversity Review (2009) and were involved in the LEAP Review (2011).

Open Up



The Open Up project brought together people with mental health problems to challenge discrimination in their communities. The staff managing the project had lived experience of mental health problems, as did all the regional coordinators and people that ran projects. There were eight regional coordinators, all of whom had lived experience of mental health problems and were located in different regions across the country. Regional coordinators supported the 30 projects that Open Up funded that were developed and delivered by people with lived experience. Open Up was important to the programme as a way of increasing the visibility of people with lived experience, both inside Time to Change and in general.

Education Not Discrimination (END)

END worked with Involvement Workers, all of whom had experience of mental health problems, of caring for someone with mental health problems, or both. Involvement Workers worked with END to design, develop and deliver training to key groups of individuals. Their personal testimonies were a key part of sessions and received particularly strong feedback.

Staff members with lived experience of mental health problems

Although there wasn't a formal audit in Phase 1, we know that in the second phase between 60% and 70% of staff have lived experience of mental health problems, and the situation was similar in the first phase. The Programme Director, Sue Baker, has talked openly about her experience of depression, but not all staff disclose their mental health problems, even though many do. However, staff do use their mental health experiences to support their work and there has been a purposeful approach to creating a culture within all Time to Change teams that sees experience of mental health problems as a positive attribute.

Lessons learnt

Be clear on roles

It became clear that LEAP roles needed further clarification. This clarification was important not just for LEAP members, but also for project staff as it set out the remit of the Advisors and where roles were in an advisory capacity and where there was decision making capacity. It would have been better to have LEAP roles entirely clear from the beginning.

Clarify the nature of the group

Linked to the issue of roles was a need for a defining statement on the nature of the LEAP team. Were LEAP members a cohesive group that could be represented by one member; or a collective of individuals that needed engaging separately? This posed a significant challenge for LEAP representatives in senior management groups who were tasked with bringing a number of voices and views into the discussions and decision making, as well as feeding back to the group.

Begin with involvement

The original funding bid to the Big Lottery Fund and Comic Relief was informed by people with lived experience of mental health problems, after consulting the networks of the partners. Once funding was received, project teams needed recruiting and reporting and monitoring systems established as well as project delivery from the outset. Capacity of an interim team was stretched, resulting in a delay to the recruitment process to set up LEAP (until the post responsible for facilitating the LEAP group was in place). This gap meant that some projects made decisions that would have benefited from the experience of LEAP members. However views from people with lived experience was sought in other ways whilst the LEAP team was being established.

LEAP strived for the best

LEAP could act as a critical friend, highlighting areas to be improved as well as areas of strength. LEAP members were integral in many of the reviews carried out in the first phase, leading on elements of the Diversity Review (2009), the Involvement Review (2009) and the LEAP Review (2011), both of which led to changes in working practice. LEAP members were spread right across the country, so they could tap into their local networks and promote and support engagement locally as well as nationally.

Involvement needs to be meaningful

LEAP members wanted to be consulted and share the value of their knowledge and expertise. Difficulties arose when projects leaders, being unsure of consultation processes, presented updates rather than involving and consulting with LEAP members. Equally, the need for meaningful involvement could stifle people as they worried about not doing what LEAP advised. When advice wasn't acted upon, it was important to explain why.

Make sure your budget covers all potential costs

Budgets needed to take account of all potential costs associated with consultancy – not just the initial outlay. Budget limitations meant that at times it wasn't possible for LEAP members to do as much as they or projects leaders felt was necessary. Time to Change committed to consistency of rate of payment for LEAP members across projects in both partner organisations through a programme-wide document detailing suggested rates of pay and expenses.

People understand involvement differently

Across the partners, projects and teams, people had varying understandings of what was meant by involving people with experience of mental health problems. Part of the role of Time to Change was to help develop that understanding to be consistent and focused on empowerment. At the same time, it was important not to try and dictate what language people used, the models they worked to or the way they ran projects. Clarification was produced that highlighted examples of leadership versus engagement, consultation versus communication, and this was distributed throughout the programme.