Invited commentary

Time to Change from the perspective of a family member. Invited commentary on . . . Evaluation of England's Time to Change programme

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Summary

This commentary views the Time to Change programme from a triple perspective: that of a concerned family member, an academic investigator and an American. The programme's results are both encouraging and sobering. Progress has been made in employers' views, but mental health professionals remain a source of discrimination. Future initiatives must have realistic objectives, be multifaceted and avoid overzealous promises.

Declaration of interest

None.

I belong to a family in which many individuals have struggled with serious mental disorder.¹ In large measure because of such experiences, I am also a researcher in the areas of developmental psychopathology and the stigmatisation of mental illness. Furthermore, I am a resident of the USA. As a result, my reactions to the incomparable series of articles in the *British Journal of Psychiatry* supplement emanate from a triple perspective: that of a concerned family member, an academic investigator and an American who is awed by the scope, depth and rigour of Time to Change (TTC) and its evaluation, particularly in contrast to the lack of comparable US efforts.

To begin, I highlight the sheer financial investment, planning, effort and time involved in the expansive and multi-pronged TTC programme (Henderson & Thornicroft, this supplement).² I also laud the effort's clearly stated goals and objectives, with clearly demarcated and appropriately framed targets regarding reductions in stigma and discrimination. Systematic evaluation of the programme's many facets was intended from the outset; such a commitment to formative and summative appraisal is exemplary, as evidenced in each of the supplement's seven specific articles.³ Overall, TTC is characterised by an admirable range of targets for anti-stigma efforts (ranging from the general public to more focal groups, such as employers or medical students), of means of reducing stigma and discrimination (spanning social marketing and planned contact with individuals experiencing mental illness to efforts to alter media coverage or promote changes in employers) and of potential benefits of the programme's efforts, including enhanced public knowledge, attitudes and social distance/intended behaviour, as well as reduction in experienced discrimination on the part of the people who use mental health services.

Assessing the effects

As both a family member and a scientist, I immediately jump to the question of whether the programme's multifaceted components worked. Despite the complications and nuances that inevitably surround such a varied programme, the term I find myself repeating with respect to the overall results is 'modest'. Although individuals with mental disorders did report clear reductions in the amounts of experienced discrimination across the evaluation period, and although intended positive behaviours towards individuals with mental disorders showed a small increase across the population, the general public's overall attitudes, knowledge and actual behaviour revealed no reliable change across the several years of the study. Moreover, early gains were not maintained: initial signs of attitude change among the general public appeared to backslide (perhaps as a result of worsening economic times); medical students' immediate post-intervention improvements had been lost half a year later; and discrimination reported by people using mental health services showed clear improvement during the programme's earliest phases, but this trend then flattened or slightly reversed.

Of course, the evaluation task facing the TTC team was overwhelming: in terms of the general populace, how could a randomly assigned or matched control group be created of citizens *not* exposed to key programme efforts such as social marketing? The evaluators took pains to document, in fact, whether respondents had actually noticed and registered key elements of the media/social marketing campaign, but the proportions were not encouraging.^{4–6} Moreover, response rates among those using mental health services, representing the population of people with mental illness, were extremely low. In addition, as several papers in the series aptly point out, such important secular trends as the deeply felt economic downturn that began not long after the inception of TTC may have been just as influential (if not more so) as any specific TTC intervention components in terms of ultimate influence on the public.

Was the effort worth it? Evans-Lacko *et al* (this supplement) report fascinating results of economic analyses that hint at the potential savings to the economy – not to mention improvements in personal and family suffering – from relatively low *per capita* cost social marketing efforts.⁵ We must remember that change in fundamental social attitudes and entrenched behaviour patterns will take time, and that, far down the road, a more tolerant society may well become a more productive society.

A relative's perspective

From my perspective as a family member, what do I take from the findings? First, employers must continue to be a target of anti-stigma intervention. Encouragingly, Henderson *et al* (this supplement) found greater realism in employers' views about mental illness, greater appreciation of employees' struggles and improved tendencies to grant reasonable accommodations.⁸ All family members know that the economic viability of a family, as well as the self-worth of the individual struggling with mental illness, is highly dependent on meaningful work. Second, family members are often exquisitely sensitive to the attitudes and practices of mental health professionals, who remain an important source of stigma and discrimination despite the sea changes in scientific beliefs about the causes of serious mental illness in recent decades.^{11,12} Distressingly, Corker *et al* (this supplement) found no significant change in discrimination by mental health professionals experienced by those using their services, meaning that targeting professional education (and professional empathy) is a priority.³ Third, it was troubling to learn that ethnic minority rates of stigma remain high and that much of the stigma and discrimination experienced by people using mental health services emanates from their friends and family members.³ Stigma strikes close to home.

Overall, I find the results of the TTC programme simultaneously encouraging and sobering. Any social change - in this case, reducing the stigmatisation of and discrimination against mental illness will require action at multiple levels, including 'top down' (e.g. an end to discriminatory policies and practices in the workplace and in healthcare), 'bottom up' (e.g. changes in human hearts, as a function of meaningful social contact with individuals in the outgroup) and 'middle out' approaches (e.g. changed media portrayals, fostering humanisation of individuals with mental illness).¹² Without sustained, multi-pronged efforts and without realistic objectives rather than overzealous promises (which, when they are not delivered as promised, promote demoralisation and backsliding), momentum will be lost and additional decades of stigma and discrimination are likely to mount. All of us - family members, citizens, investigators and clinicians - must be aware of the multiple, sustained levels of effort required to effect fundamental, lasting social change. Time to Change is a landmark effort, and it will require considerable investment and diligence to learn from its lessons as additional anti-stigma and antidiscrimination programmes are proposed and implemented. The hope for recovery in loved ones and family members burns deep, and overcoming stigma is essential in this regard.

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