

Creating a Wave of Change in the Mental Health Act

Conference Winning Paper



Three organisations have been working together to stimulate a wave of change in the Mental Health Act. Rachel Medcalf and Seb Newton (Adelphi Research), together with Will Johnstone (Rethink Mental Illness) and Giles Davey (Janssen) were delighted to receive the Keith Munroe award for Best Conference Paper for their work at the BHBA 2018 Annual Conference. Here's their story...

Rethink Mental Illness is a charity with a mission of leading the way to a better quality of life for everyone severely affected by mental illness, including their loved ones. One of their main areas of interest is reform of legislation and practice for people who have been detained under the Mental Health Act. The Mental Health Act was introduced in 1983, and while attitudes to mental health, and the principles of involving people in their care have evolved significantly over the past 35 years, the Mental Health Act has not.

In 2017, Rethink Mental Illness conducted a survey on behalf of the Mental Health Alliance on the principles behind the Act. The research found that 80% of detainees felt unequally treated compared to physical illness.

Rethink Mental Illness identified the need to build on the findings from the Mental Health Alliance report through in-depth qualitative research. With a strategic partnership already in place between Rethink Mental Illness and Janssen, this was an ideal opportunity to move the research forward.

Good things come in threes

There was an initial assumption that a couple of focus groups was all that was required. However, it was immediately clear to Janssen that a robust, multicentred project was needed to make it meaningful.

Adelphi Research was one of the healthcare research agencies that was approached for advice. After explaining the objectives, Giles dropped the bombshell that there was no budget for this project. However it soon became clear that this project presented a chance to make a real difference to patients' lives in

mental health, an area close to Adelphi's personal values. Rachel therefore agreed Adelphi would work together on this with Janssen and Rethink without fees.

Three parties, one goal



At about the same time, Theresa May appointed Sir Simon Wessely to conduct a full review of the Mental Health Act. Rethink Mental Illness were working with the Independent Review Team, so they suggested the insights from the project should also be shared with the review team leaders. The importance of this research had suddenly ramped up tenfold. The pressure was on!

A bold approach

Adelphi devised a methodology with two main stages, firstly unpicking the problem and secondly co-creating the solution for legislative reform. The methodology involved a co-creation day, mobile research capturing personal video clips and individual telephone interviews.

The participants included service users that had been previously sectioned under the mental health act, their friends and family and a range of healthcare professionals such as psychiatrists, social workers and mental health nurses.

Alarm bells ring

It was a brave approach and one that was beset with multiple challenges from the outset. One of the main challenges was ethical considerations around recruiting and interviewing highly vulnerable people in this very sensitive area. As personal data including video clips were being collected and processed, there were also many important General Data Protection Regulation (GDPR) considerations that needed to be addressed.

In this pro-bono relationship, the classic roles of client, agency and sponsor went out of the window a bit at times and everyone mucked in. Giles (Janssen) acted more as an agency colleague to Adelphi rather than the client and helped out with the moderating, workshop facilitation and the analysis. As Rethink Mental Illness was sourcing some of the participants from their membership, they had to learn the ropes of market research recruitment and compliance with GDPR.

Recommendations

The research highlighted a number of key areas to ensure that the rights of people detained under the Mental Health Act are protected and overall care is improved. These suggestions include:

- Greater overall involvement of service users in their care via mandatory access to Independent Mental Health Advocate (IMHA) within 48 hours of admission (currently, service users have a right to access advocacy, but not within set timeframes)
- The standardisation of information provided to include more information on rights to tribunals and appeals, along with details of medicines and potential side effects
- A change to legislation on the appointment of the nearest relative, to give service users the right to choose their own representative
- Inclusion of advance decisions as a routine component within the care pathway and legislative changes that give legal weight to advance decisions.

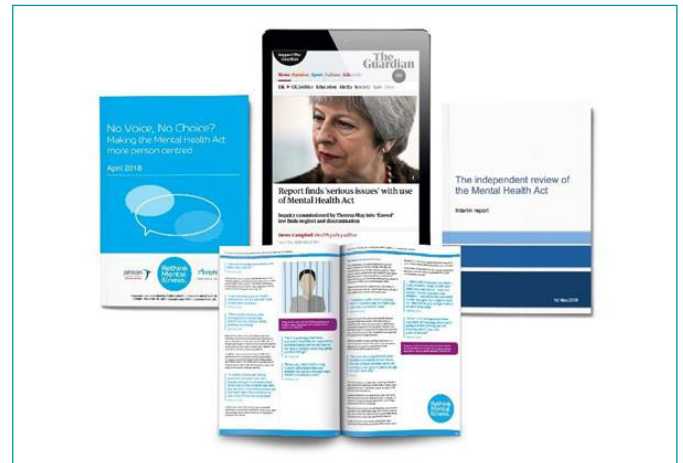
Throughout the research, patients also referred to the culture and setting of their detention as if it were a prison. It was found that patients were regularly stripped of their rights and often had to earn back basic amenities, such as their shoes or a toothbrush.

Lobbying government for change

Initially Adelphi presented their findings to Rethink Mental Illness and Janssen. The findings were then presented to Sir Simon Wessely and other key decision makers from the government appointed independent review team. There were also representatives from the CQC, NHS England and a range of mental health charities including MIND and the Centre for Mental Health Research.

Adelphi and Rethink Mental Illness published the findings in their report 'No Voice No Choice – making the mental health act more person centred' on 1st May 2018. This was specifically timed to be released just ahead of the interim report from Theresa May's independent review team.

Creating ripples in high places



What next?

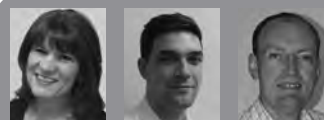
Rethink Mental Illness is working with the Mental Health Review team to ensure that the issues raised about the law make their way into reform of the Act. An Early Day Motion (EDM) has been submitted to Parliament and so far, the petition is going well – at the time of publication, 45 MPs had signed-up.

Rethink Mental Illness is running a public awareness campaign across multiple channels. Their work also continues with Janssen to develop tools and materials to support service users to take action and improve the extent to which they're involved in their care.

Key learnings

This piece of research has demonstrated that important work can happen with the pro-bono support of agencies and partnerships with pharma. Pro-bono work is a hugely rewarding experience and although not something that can be commercially viable across all projects, with the right partner on the right projects it's worth serious consideration.

Working with risks can be a bit daunting. However, with careful preparation and planning, even in this highly compliance driven environment, great things can be done to make a real difference in an area ripe for change.



Rachel Medcalf, Seb Newton – Adelphi Research
Giles Davey – Janssen