

# Fighting for their rights

Restraint, deprivation and physical abuse may be things of the past in UK mental health services, but are still commonplace in some other countries. The World Health Organization is trying to change this. Mary O'Hara reports

“I was now a resident, or rather an inmate, of the hospital,” says a mental health service user, of their experience in an institution. “I saw no one except the other people on the floor, who wore identical striped hospital robes and plastic bracelets with identifying names. The mental health workers were the only ones who could open the locked door. I left my hope on the other side of the locked door.”

This may seem like a throwback to the experiences people had on mental health wards in decades past but according to the World Health Organization (WHO) not only is this particular person's encounter with services recent, it is also commonplace in many parts of the world.

In fact, the WHO says this example is far from being among the most distressing of the breaches of human rights regularly inflicted upon people with mental health problems. From people being physically abused or kept chained to walls, to being locked up in dirty 'cell-like' rooms with little or no amenities, the litany of mistreatment and neglect is extensive. It is also under-reported.

## Quality Rights

It is because of the widespread and systematic nature of the human rights abuses it has documented that the WHO launched the Quality Rights programme, a worldwide initiative that aims to shed light into the darkest corners of mental health treatment but also offers to help countries improve their provision.

Part campaign, part practical assistance, when it launched formally WHO executives pulled no punches, declaring that Quality Rights was an urgent and necessary response to a “hidden human rights emergency”. It made clear that the programme was intended to expose the degree to which service users are being mentally, physically and emotionally abused in hospitals, and to place such abuse firmly in a human rights – not just health – context.

It also made clear that the project would focus on experiences outside of institutions because, it concluded, people with mental health problems are frequently “denied basic rights” such as fair access to education, employment and even homes.

Crucially, according to Michelle Funk, the WHO coordinator spearheading the project, it targets not only poorer countries with the least resources but also wealthy nations because they too “are not exempt” from poor care, or discrimination and stigma within wider society.

“Quality Rights is aimed at low, middle and high income countries,” Funk explains. “The human rights

issues around mental health have been so neglected for too long. The problems are different depending on the country but the aim is to reform policy and to work with local agencies, families and service users to advocate for the rights of people with mental illness in each country.”

After consulting with mental health experts and service users internationally, the WHO began establishing contacts with politicians, health professionals and community groups open to being helped. A prerequisite for involvement with Quality Rights was that service users would be directly involved in determining what improvements to services were needed. Countries as divergent as Spain, Palestine and Somaliland were among the earliest recruits with Greece, Portugal and Panama now in the early stages of collaboration.

The programme is ambitious. Funk says there is “no doubt” that attempting to transform mental health services on a global scale to guarantee basic human rights will be an uphill struggle but insists that significant change can be brought about in the long-term with a “participatory” approach.

The first stage of this approach involves committees comprising professionals, legal experts and people with mental health problems forging relationships with local agencies and advocates who understand the country's existing mental health system, its culture and politics. The degree of involvement varies depending on a country's needs but committee members help assess the quality of facilities in partnership with people working in and using the services. Where necessary, an improvement programme is drafted that includes specific goals and step-by-step guidance for how changes can be made. Again, depending on the country, initial improvements might be as rudimentary as taking people out of chains and providing clean bed linen.

## Tool kit

A Quality Rights ‘Tool Kit’ is also distributed to local agencies and service users. Using the UN Convention on the Rights of Persons with Disabilities as its starting point, the tool kit provides an index of human rights standards that need to be complied with to guarantee acceptable levels of care. It incorporates straightforward guidance for professionals and service users on how to assess the standards of care, introduce improvements, and how to evaluate them. It is designed to apply to all care settings.

In tandem, service users are coached to set up self-advocacy groups where there are none and to lobby for further reform of legislation and service delivery. “The idea is, of course, to improve services but it is also to

Mary O'Hara  
is a freelance  
journalist



## Quality Rights in action

When Julie Currie-Taylor first arrived at Hargesia Group Hospital in Somaliland in February 2011 she was working with a small Italian voluntary organisation, Gruppo per le Relazioni Transculturali (GRT), on a project to develop mental health and human rights legislation in the country. Hargesia was one of two hospitals she was scheduled to work with to try to improve mental health treatment. What she found on arrival shocked her.

“When I arrived the ward was being used as a dumping ground. There were people who seemed to be living there; people society had rejected. Homeless people. There were between 110 and 120 patients. They were sleeping on the ground. They were locked in. Some were chained to walls. The staff didn’t even know most people’s names and the older staff would stand away from the patients and throw their pills at them. There were no case histories. Nothing. It was in a bad way.”

Currie-Taylor says the process of transforming the ward into a functioning mental health facility was slow but made possible by support from WHO’s Quality Rights project, specifically its tool kit for guiding workers and service users on how to introduce basic human rights standards. She used the tool kit to: set down objectives for her work, conduct an assessment of the facility, recruit and train qualified staff, and measure progress. It also encouraged her to consult with the people on the ward and their families to ascertain what they needed. “It helped me get started from scratch. It gave me a systematic framework to work from. It helped me put structure on a very difficult task. I was overwhelmed at first but the tool kit changed that.”

Less than two years later the hospital has a more professional staff. It is clean. No one is chained up. Many of the patients have been released and some have found jobs. “Even now the ward is a difficult place,” Currie Taylor concedes. “But it’s a very different place. The community is beginning to open its eyes too and realise that people [with mental illnesses] have rights and deserve respect.”



ensure a legacy that means service users are confident to promote autonomy,” Funk explains. “It is about working with facilities, service users and policymakers to promote positive change in a collaborative way. This is not about telling people what to do but giving them the tools to shape their own services.”

It is early days for the project but there is evidence that where local champions are found, services can be transformed. Dr Ramon Quiros, who as Minister of Health in the Spanish region of Asturias in 2009 adapted an early version of the tool kit to conduct a review of all mental health services in the area, says the exercise was invaluable. “We had never done a 360-degree review before, yet we used an adapted version of the tool kit to conduct a thorough evaluation. We were able to implement many improvements suggested by [service users].”

Dr Quiros says that while in the beginning there was some hostility from medical professionals about involving service users, this abated as they worked more closely. “We found easy solutions to old problems. Most did not cost a lot to put in place.”

### British interest

Even if not quite in need of as much hand-holding as

other countries, there is burgeoning interest in Britain in the Quality Rights programme. Neil Quinn, a senior lecture in the School of Applied Sciences at the University of Strathclyde, and his colleague, Lee Knifton, who are working to see how it might be applied in the UK, say the focus the programme puts on human rights is applicable anywhere.

“Existing campaigns don’t really put the emphasis on human rights,” Quinn suggests. “This could be key to helping change behaviour rather than just attitudes toward mental illness.”

According to Knifton, no matter how advanced we think we might be in Britain: “We can’t afford to be complacent. You only have to look at levels of stigma.”

If Quality Rights is ambitious in scale it is all the more so because there aren’t huge sums of money available to implement it. In some cases, such as in Spain and Somaliland, funding from government and NGOs has been essential. Funk admits that this is one of the biggest challenges, especially when it comes to bringing about change in poorer countries. “There is not a lot of money around. But what we have seen already is that you can do a lot with limited funding. Step by step we hope to empower service users where we can. I think it can be done.” ■