

Announcing the new European Toolkit to monitor Human Rights and General Health Care in Mental Health Facilities

What is the ITHACA Toolkit?

The Institutional Treatment, Human Rights and Care Assessment (ITHACA) Toolkit has recently been developed by a consortium from across 15 EU countries, funded by the EC. The ITHACA Toolkit provides a clear and practical way to monitor human rights and general health care in mental health facilities. The Toolkit was designed by service users, human rights experts, psychiatrists, psychologists and social scientists. It has been successfully field tested in 87 sites across 15 countries, covering a wide range of mental health care settings and can identify both human rights violations and examples of good practice in protecting, respecting and fulfilling the rights of persons with mental disabilities.

Strong service user participation

In developing the ITHACA Toolkit service users were consulted and employed at all stages. At the first stage, over 100 service users participated in the focus groups which took place in each country. All participants in the focus groups had experience of living in the kinds of mental health facilities monitored by ITHACA. Most of the focus groups were facilitated by service users who also had this experience and the focus group project was overseen and analyzed by a service user. Her report fed directly into the development of the ITHACA Toolkit.

Secondly, at each site visit there was a service user monitor. These monitors came to Budapest for two days training before beginning their work and much of the training was done by a service user. This was considered very important as it is naive to suppose that service users can carry out such a task without careful preparation. During the visits, the service user monitors played a full part but focused particularly on what they knew, from their own experience, were the key issues in human rights and general health care from the point of view of residents. In most cases, they were responsible for gathering residents' views. In Finland, for example, eight service users were involved in conducting monitoring visits and testing the usefulness of the toolkit. As one of the service user researchers from Finland says *"The experience has been very rewarding and we have learned a lot. The starting point was to combine human rights monitoring with trying to have an effect on developing the services as well...I am even more convinced that it is really necessary to have users monitoring, evaluating and researching"*. Finally, as the ITHACA toolkit was nearing its final version, members of the European Network of (ex) Users and Survivors of Psychiatry (ENUSP) made some further refinements to it.

The need for the ITHACA Toolkit in Europe and the role of service user monitors

People in mental health institutions across Europe too often remain out of sight, with poor monitoring to assess the human rights and general health care of their residents. Such people are an extremely vulnerable population to neglect or abuse in relation to their basic necessities of life as well as their civil and political rights. The international community took an important step forward in securing and protecting these rights in passing the United Nation's Convention on the Rights of Persons with Disabilities (CRPD) in 2006, which places the responsibility for meeting the needs of all people with disabilities (including those with mental disabilities) on society. Persons with disabilities are not *objects* of charity or welfare but *actors* with rights. The ITHACA Toolkit can help bring about change if used in the right way. User monitors or researchers are key to this as they have the first hand experience of what it is like to live in facilities where their rights may be violated or general health care may not be up to standard. We therefore recommend that any monitoring visit using the ITHACA Toolkit always includes a user monitor/ researcher, but remembering that this person must be trained in the same way as any other monitor.

Language versions available

The ITHACA Toolkit is now available in the following languages: Bulgarian, Czech, Dutch, English, Finnish, German, Greek, Hungarian, Italian, Lithuanian, Romanian, Slovak, and Turkish.

Contact details and additional resources

For full details of the ITHACA Toolkit please go to our website at <http://www.ithaca-study.eu/>, or contact Graham Thornicroft at King's College London graham.thornicroft@kcl.ac.uk. For more detailed background go to:

1. Convention on the Rights of Persons with Disabilities (<http://www.un.org/disabilities/>)
2. Mental Disability Advocacy Centre (<http://www.mdac.info/>)
3. European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) (<http://www.enusp.org/>).