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ORIGINAL ARTICLE

Development of the ITHACA Toolkit for monitoring human rights and general health care in psychiatric and social care institutions

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Background. Human rights violations are commonly experienced by people in psychiatric and social care institutions. States and private organizations providing such health and social services must comply with international human rights law. Monitoring of such compliance is increasingly recognized as a vital component in ensuring that rights are respected and violations are brought out in the open, remedied and prevented.

Aims. The Institutional Treatment, Human Rights and Care Assessment (ITHACA) project produced a method to document violations and good practice with the aim of preventing human rights violations and improving general health care practice in psychiatric and social care institutions (www.ithacastudy.eu).

Methods. A methodological and implementation study conducted across 15 European countries developed and assessed the ITHACA Toolkit in monitoring visits to 87 mental health organizations.

Results. The toolkit is available in 13 European languages and has demonstrated applicability in a range of contexts and conditions. The information gathered through monitoring visits can document both good practice and areas for improvement.

Conclusions. The ITHACA Toolkit is an acceptable and feasible method for the systematic monitoring of human rights and general health care in psychiatric and social care institutions that explicitly calls for the participation of service users in the monitoring of human rights violations and general health care practice.

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Introduction

Worldwide many people with mental illness related disability have little or no access to supportive systems that provide talking therapies, pharmacological and/or social assistance (World Health Organisation, 2005).

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Although such disabilities are difficult to define, many such people live in conditions outside the purview of the local, national or international communities. In many countries, laws facilitate exclusion and stigmatization against people with disabilities. In 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). This Convention represents a paradigm shift in the perspective on human rights for people with disabilities, and it uses a social model of disability, one that sees disability as not something which a person embodies but rather as one variation on the spectrum of human experiences. The Convention is based on the view that people are not disabled, but it is society that fails to enable them. As such, individuals are seen not as recipients of charity but as subjects of human rights who are entitled to assert their rights autonomously and where needed, with reasonable accommodation or support by others. The Convention also makes clear that its provisions extend to people with mental health problems as well as people with intellectual disabilities (Article 1 CRPD). Although the CRPD does not include any new rights, it does explicitly define the protections and entitlements for the estimated 800 million people with disabilities worldwide (Mont, 2007). The CRPD served as the normative framework for the development of the Institutional Treatment, Human Rights and Care Assessment (ITHACA) Toolkit. This toolkit is developed at a time when a series of initiatives have produced related assessment methods including DEMoBINC (Killaspy, 2009), QuIRC (Killaspy, 2011) and QualityRights (World Health Organization, 2012).

The regulatory bodies within each European country vary widely and are beyond the scope of this paper. However, various mechanisms exist within Europe to monitor and document the human rights of people in psychiatric and social care institutions, including the right to health (Bartlett *et al.* 2006; Council of Europe, 2009). The Committee for the Prevention of Torture (CPT) and Inhuman or Degrading Treatment or Punishment is a body of the 47-member organization, the Council of Europe. The CPT visits the States each year and carries out a mission during which it monitors several places of detention including prisons, police stations and psychiatric and social care institutions. Its mandate is to prevent torture and other forms of ill-treatment. After each visit, it writes a report to the relevant government on its findings. The government may authorize publication of the report, and if this happens the report is uploaded to the CPT's website (see http://www.cpt.coe.int/en/). Governments may issue a response. Some European countries have ratified the optional protocol to the UN Convention against Torture, which obliges the States to establish a national preventive mechanism independent of the government to carry out visits to places of detention. Little information is available on the coverage, in terms of psychiatric and social care institutions and the effectiveness of these mechanisms (Niveau, 2004). The European Court of Human Rights has ruled on several seminal cases involving human rights violations in psychiatric facilities. Most notably are Shtukaturov *v.* Russia 2008 and Kucheruk *v.* Ukraine 2007. In order for the cases to be heard at this level, all local and national legal avenues must be exhausted. This makes litigation and advocacy through these mechanisms a lengthy and arduous process. More localized and immediate mechanisms are needed to introduce real change in a system that can oftentimes be rife with violations and poor practice.

There is now a clear impetus to build the effectiveness of independent human rights monitoring. Paul Hunt, the former UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, has pointed out, '[a] lack of monitoring of psychiatric institutions and weak or non-existent accountability structures allow these human rights abuses to flourish away from the public eye' (Hunt, 2005; Hunt & Mesquita, 2006).

Methods

This project, co-funded by the European Agency for Health and Consumers of the European Commission, was implemented by a consortium including 15 countries (Austria, Belgium, Bulgaria, Czech Republic, Finland, Germany, Hungary, Greece, Italy, Lithuania, The Netherlands, Romania, Slovakia, Turkey and UK). The project began in May 2007 and was completed in April 2010. All the collaborators provided feedback on the toolkit structure, methods and content. Each country conducted monitoring visits to collect information on the human rights and general health care conditions in Europe to test the feasibility of the toolkit.

Toolkit development

The toolkit is available for download from the project website (www.ithacastudy.eu), and it was developed directly with relation to the CRPD framework and is also informed by the Right to Health Framework as set out in Article 12 'The right to the highest attainable standard of health' of the International Covenant on Economic, Social and Cultural Rights (Office of the

United Nations High Commissioner for Human Rights, 1966). This framework refers to the following key criteria to monitor the extent to which rights are being protected, respected and fulfilled. *Availability* explores whether the programme or service is available or open to the entire population. *Accessibility* explores whether it is geographically convenient and easily accessible, economically feasible for the average consumer or client. It further determines whether the information regarding the service or programme is freely available and accessible without discrimination. *Acceptability* further investigates whether these services or programmes are appropriate, culturally congenial and acceptable to people regardless of ethnicity, race, religion, sex, sexuality or other prohibited grounds of discrimination. The final aspect explores whether these programmes are of *good quality* and how that is measured, monitored and evaluated over time.

Consultation with service users

From March to July 2008, 15 focus groups were organized in 15 countries, gaining the perspectives of 116 individuals with a range of experiences in psychiatric care. They were invited on the basis of their expertise through experience to discuss what they felt were the necessary issues to cover with regard to human rights and health care as well as to feedback on the first draft of the toolkit. The topics discussed included perspectives on human rights, perspectives on general health care, feedback on the ITHACA tool and advice for conducting monitoring visits. The focus groups with service users provided rich insights into the varied experience of human rights and general health care across Europe. Some of the issues raised and direct quotes are listed in the results below.

The outcome of these discussions provided an important and enlightening perspective to the development of the toolkit. A social science researcher with a personal experience of receiving institutional psychiatric treatment (Russo) was in charge of developing the topic guide, facilitating three focus groups, performing the qualitative analysis and issuing the report on the outcomes. The remaining focus groups were facilitated by local researchers employed on the ITHACA project. This participatory approach was purposely chosen to ensure the input of those best informed on the most salient issues for their particular local context. The analysis was conducted using English translation of the transcripts with the help of NVivo software (Version 2). Beyond its task to inform the ITHACA project, the report of the focus groups' outcomes offers a valuable source for any empirical research on human rights in psychiatric care. The participants in these focus groups ranged across the 15 sites. Some were recruited through psychiatric facilities, while others were recruited through user groups or local support networks. Exclusion and inclusion criteria, as such, were not explicitly outlined because of the variable contexts across Europe. The intention of the focus groups was to capture the range of experiences and opinions across the 15 countries represented. As such, these focus groups were recruited through mechanisms most appropriate for the given site.

Human rights monitoring training

In 2008, a training meeting was held in Budapest led by the Mental Disability Advocacy Centre (MDAC) and the Institute of Psychiatry. A leading human rights expert, psychiatrist and Member of the European CPT was one of the trainers. The training focused on the

Table 1. *Topics covered in the ITHACA Toolkit prompt questions*

1. Monitoring visit details
2. Institution details
3. Living standards and conditions
4. Involuntary commitment and review procedures
5. Living independently and being included in the community after discharge
6. Participation in cultural life, recreation, leisure and sport
7. Participation in political and public life
8. Education, training, work and employment
9. Freedom of religion
10. Correspondence and visitors
11. Family and privacy rights
12. Freedom of expression and opinion and access to information
13. Freedom from torture, ill-treatment, abuse and neglect
14. Restraint and seclusion
15. Habilitation and rehabilitation
16. Consent to treatment
17. Access to physical health care
18. Access to mental health services
19. Access to general practitioners/family physicians
20. Access to nurses and care staff
21. Access to therapy
22. Health records
23. Physical health promotion and physical illness prevention
24. Medication for mental and physical conditions
25. Physical health assessment on admission
26. Diagnosis (physical and mental)
27. Electro-convulsive therapy (ECT)
28. Alcohol, cigarettes and illegal drugs
29. Involvement in care plans
30. Consent to participate in research

principles and methods involved in the monitoring of psychiatric and social care institutions. The training prepared participants to monitor institutions with the (at that time first draft of the) ITHACA Toolkit; introduced and allowed participants to practice interviewing, observational and document-review skills necessary to carry out effective human rights monitoring; fostered a deeper insight into the complex nature of human rights; encouraged a network of support and exchange between local and international collaborators; taught the necessary background material to carry out monitoring visits and engaged participants in discussions with people from different perspectives and backgrounds.

Using the Toolkit

The toolkit is divided into nine sections referring to: aims, what are human rights, what is general health care, why conduct human rights monitoring, principles of human rights monitoring, methods of human rights monitoring, steps in conducting human rights monitoring, a guide to the ITHACA Toolkit prompt questions and the prompt questions for monitoring visits. These prompt (aide memoire) questions cover 30 topics as specified in Table 1 below, where these topic headings are directly grounded in the sections of the Convention on the Rights of Persons with Disabilities (CPRD). The toolkit is written for human rights monitoring teams, which should include a service user, a health care practitioner and a person with a human rights background. The toolkit also states that human rights monitoring requires familiarity with the international human rights standards, the various topics to be addressed, the methods of gaining information in an institutional setting and the principles of human rights monitoring – including regular monitoring, demonstrating independence from the service being visited, not doing harm and collecting credible data. Applying rapid ethnographic assessment techniques (Trotter *et al.* 2001), the toolkit requires the monitors to enter an institution and rapidly but effectively uncover how the institution works, who has power and who does not, and to bring together the experiences of the staff (clinical and support) with those of the clients or service users. For example, if discussing the issue of food, what do the clinical staff say, what do support staff say and what do the service users and family members say and where are they in agreement or disagreement? Indeed, if families are estranged, their whereabouts unknown, or not consulted then these may also be human rights issues.

The overall procedures is set according to the following 10 steps: (1) set objectives for monitoring; (2) build the monitoring team; (3) train the monitors; (4) gather background information; (5) plan the visits; (6) carry out the visits; (7) write the report; (8) disseminate the report; (9) evaluate the process and (10) plan future visits. The method of conducting monitoring, therefore integrates three types of data (i) interviews with staff and with residents (separately); (ii) observation of the institutional setting and (iii) review of relevant documentation.

To conduct the monitoring visit each team must meet before the visit and roughly divide the tasks for the day of the visit. All monitors should be familiar with the institution to be monitored and should have conducted as much background research as possible on the institution. Arguably, the gold standard for human rights monitoring is to conduct a several day visit that is unannounced, appreciating that this may not always be possible and that important information can be collected in announced visits as well.

During the visit, the monitoring team should try to cover all topics covered in the toolkit but should have a degree of flexibility to follow the topics that are most important to the residents and/or staff who work there as well as any gross negligence, violations or good practice. The questions outlined in the toolkit are to be used as prompts for inquiry and not as specific questions all of which need to be asked. Rather they are aide memories to ensure that all the key areas of enquiry are considered by members of the monitoring team. The monitors should use all their senses when conducting monitoring: combined, they need to see, hear, smell, touch and taste. They need to triangulate information to gain the perspective of patients/residents, management, clinical and support staff and families or their proxies.

The monitors should ask questions, listen, follow up with more probing questions, ask to see documentation, make observations and absorb the circumstances they are witnessing. Directly following the visit, each monitor should write and reflect on their findings and prepare the notes in as much detail as possible. The team should then meet and discuss their findings and reflections. The process of identifying the key issues with respect to both human rights observation (good practice) and human rights violations (poor practice) is carried out by the monitoring team. This is based on the data gathered from all sources, examines the extent to which any concerns identified can be verified and uses the different perspectives, expertise and experience of the members of the review team to form judgements on where the concerns need to be identified, and the specific evidence available to justify each issue raised as any such point may be challenged by the organization concerned. Specifically, during the staff interviews, staff

Table 2. *Summary of main findings from monitoring visits conducted using the ITHACA Toolkit*

Country	Type of institutions (number of beds indicated where available)	Most salient topics from Toolkit	Recommendations	Good practice
Austria[*]	1. Intellectual disability institute (314 beds) 2. Two psychiatric departments of general hospital (60 beds/ 50 beds) 3. Social care home (16 beds) 4. Neuro-Psychiatric hospital with psychiatric, neurological and neurosurgical beds 5. Psychiatric rehabilitation centre (120 beds)	1. Access to medical records and care plans 2. Complaint management 3. Correspondence and visitors 4. Access to nurses 5. Discharge management	1. Increase the involvement of the residents in setting up their care plan and increase transparency 2. Residents should be provided with clear information in a manner that is transparent and clear 3. Provide information in all languages found among minorities 4. Reduce barriers between outpatient and inpatient services by merging the financial systems between these two sectors	1. Discharge management: an established link between the hospital and regional psychosocial services provides for a better transition to independent living 2. Public relations: a public relations department works with local newspapers to discuss and inform the public on mental health issues and topics 3. Sign language communication was implemented to improve communication between residents and staff.
Bulgaria[†]	1. Psychiatric department of general hospital (17 beds) 2. Psychiatric dispensary (65 beds) 3. Day centre for adults with ID (60 beds) 4. Sheltered home for adults with ID (8 beds) 5. Social care home for adults (96 beds) 6. State psychiatric hospital (250 beds)	1. Knowledge of diagnosis 2. Use of Electroconvulsive Therapy (ECT) 3. Involvement in care plan 4. Assessment of general health condition on admission 5. Information on side effects of medicine 6. Poor prevention programmes 7. Residents have no access to records or files 8. Habilitation and rehabilitation 8. Access to hygiene facilities 10. Complaint mechanism	1. Continue monitoring of human rights and general health 2. Establish a board of trustees for each institution. The board should include former residents 3. Hire better qualified staff 4. Increase access to care and treatment plans	1. Director invests a lot of energy and time to seek additional resources and/or donations 2. Two residents participated in the Olympic Games for people with disabilities

Continued

Table 2. *Continued*

Country	Type of institutions (number of beds indicated where available)	Most salient topics from Toolkit	Recommendations	Good practice
Czech Republic[†]	1. Psychiatric department of general hospital (40 beds) 2. Social care home for adults (132 beds) 3. Psychiatric clinic (51 beds)	1. Privacy 2. Room access during the day 3. Clothes appropriate for weather and condition 4. Staff education and supervision 5. Access to psychotherapy 6. Outdoor activities 7. Lockable boxes/wardrobes 8. Therapeutic plans 9. Complaints procedures	1. Make bedrooms accessible throughout the day 2. Residents should wear their own clothes 3. Increase level of privacy for showers and toilets 4. Reconsider the placement and use of security cameras, some feel is a breach of privacy 5. Greater involvement in care plans 6. Better regulation and understanding of complaint mechanism	1. Sheltered housing allows married couples to live together and receive support 2. 'half open' ward on a psychiatric hospital allows residents to come and go as they wish 3. Health education programme for nutrition and physical activity
England*	1. Two residential care homes (10 beds/ 6 beds) 2. Acute psychiatric ward (27 beds) 3. Mental health unit for elderly (12 beds) 4. Recovery unit (15 beds) 5. Community based specialty unit for women (6 beds)	1. Involvement in care plans 2. Physical health 3. Medication 4. Habilitation and rehabilitation	1. Support more residents to receive training and work 2. Institute more staff on some wards 3. Revise the complaint mechanism	1. A physical health toolkit was applied to assess residents physical health 2. Patients council: made up of service users and former patients the council meets and discusses issues on the wards and provide feedback to the wards 3. 'Life story books': the books contain photos and stories from users' lives 4. Recovery programme: an 11 week course to help residents recover through life skills, coping, living skills, etc.

Finland*	1. Rehabilitation home (12 beds) 2. Substance abuse and rehabilitation centre (20 beds) 3. Psychiatric inpatient unit in public general hospital (16 beds) 4. Rehabilitation ward in public psychiatric hospital (20 beds) 5. Sheltered housing unit (12 beds) 6. Rehabilitation home for young service users (6 beds)	1. Education, training, work and employment as non-existent means for habilitation and rehabilitation. 2. Living independently and being included in the community. 3. Family and privacy rights 4. Freedom from ill-treatment, abuse and neglect.	1. Each resident should have their own room 2. Rehabilitation should start at the moment of admission, reduce boundaries between hospital and outpatient care 3. Staff should spend sufficient time with patients 4. Avoid ‘rules for all’, everyone should be involved in negotiating and discussing rules 5. Physical examination on admission	1. Peer visits and peer group activities for alcohol and drug rehabilitation 2. Close care on a psychiatric ward: when a resident becomes agitated a nurse calmly leads the resident to a quiet and calm place to settle 3. Supportive living of young people: the resident moves through progressively more independent living and is supported across all stages
Germany*	1. Department of psychiatry and psychotherapy in psychiatric hospital 2. Group home 3. University department of psychiatry and psychotherapy 4. Psychiatric department of general hospital 5. Psychiatric day hospital and community centre 6. Living houses for people with mental illness	1. Staff training 2. Complaints mechanism 3. Lifestyle 4. Participation in cultural life, 5. Education, training, work and employment 6. Habilitation and rehabilitation	1. No recommendations made	1. Therapeutic approach for borderline personality disorders 2. Reintegration in group home for people with severe mental illness 3. Highly integrated psychiatric hospital within the community 4. Small housing units with individual target planning and community integration

Continued

Table 2. *Continued*

Country	Type of institutions (number of beds indicated where available)	Most salient topics from Toolkit	Recommendations	Good practice
Greece[†]	1. Psychiatric unit of general hospital 2. Unit of a large psychiatric hospital 3. Group home 4. Two boarding homes 5. Day centre	1. Integration into the community 2. Financing 3. Staff training 4. Complaint mechanism 5. Living conditions 6. Rehabilitation services 7. Access to clinical staff 8. Residents' access to medical records 9. Ongoing monitoring systems	1. Restricted movement violates fundamental human rights and residents should have the right to leave the facilities 2. The ministry of health and social welfare should settle the financial constraints currently hindering the facilities 3. Establish continuing education programmes 4. Establish an independent complaint mechanism 5. Provide a better, more homely environment for the residents 6. Provide secure outdoor areas 7. Implement comprehensive rehabilitation activities 8. Establish regular meetings with psychiatrists 9. Instituting psychotherapeutic intervention 10. Provide access to medical records and involvement in care plan	1. The day centre employs two people with mental illness 2. Utilization of public sports facilities after agreement with the local authority
Italy*	1. Two community based hostels with 24 h support (12 beds/ 22 beds) 2. Two group apartments (6 beds/ 13 beds) 3. Residential facility (130 beds)	1. Privacy 2. Access to general health staff 3. Monitoring of physical health concerns	1. Raise awareness among all the staff of the physical and mental health and legal status of all residents 2. Improve the nutrition and physical activity levels of all residents 3. Increase specialist involvement 4. Provide better screening of general health issues and concerns	1. Day Centre: includes a range of activities to support residents in developing skills and being active, e.g. writing a newspaper, working with computers, participating in theatre groups 2. Work placement: learn social and working skills and then phased into work placement 3. Labour activities: gardening and other activities around the facility allow residents and staff to work together

Lithuania*	1. Three social care homes 2. University hospital psychiatric clinic 3. Forensic psychiatric unit 4. Psychiatric hospital	1. Involuntary court and review procedures 2. Living independently and being included in the community 3. Visitors and correspondence 4. Restraint and seclusion 5. Right to privacy	1. Staff should follow appropriate and clear rules on use of restraint and seclusion 2. Improve private facilities so that residents can bathe, make phone calls and spend time alone 3. Improve habilitation and rehabilitation programmes 4. Improve general health care services and integrate better with mental health services	1. Long stay apartments allow residents to live more independently but still with the support of clinical staff 2. Seeing the client 'as customer' and allowing them to be more involved in the care plan and the organization of the institution 3. Allowing couples to live together in social care homes 4. Providing legal assistance to residents in social care homes, particularly to those under guardianship
Romania†	1. Psychiatric department of a general hospital 2. Psychiatric hospitals 3. Mental health day and community centre 4. High security psychiatric facility 5. Social care institution	1. Access to care plans 2. Staff training and qualifications 3. Number of staff 4. Complaint mechanisms 5. Information on medication	1. Improve the number of community psychiatric facilities 2. Institute therapeutic protocols 3. Improve collaboration between physical and mental health care professionals and institutions 4. Improve therapeutic and rehabilitative activities	1. One hospital included a work programme
Slovakia*	1. Psychiatric hospital (260 beds) 2. Two psychiatric wards of hospital 3. Two day care centres 4. Psychiatric wards in general hospital	1. ECT 2. Restraints and seclusion 3. Staff training and availability	1. Improve the number of qualified staff 2. Access to better information 3. Improve informed consent procedures 4. Better information on receiving treatment in the community 5. Adapt institutions for physical accessibility	1. Supported independent living provided by NGOs 2. Patient advocacy programme to promote freedom of expression and opinion and access to information 3. Accessibility for physically disabled

Continued

Table 2. *Continued*

Country	Type of institutions (number of beds indicated where available)	Most salient topics from Toolkit	Recommendations	Good practice
Turkey*	1. Three state mental hospitals 2. Psychiatry department of education and research hospital 3. Psychiatry department of university hospital 4. Psychiatry department of general hospital	1. Freedom of movement 2. Access to information 3. Lack of access to bedrooms 4. Insufficient number and quality of staff	1. Establish a mental health code at national level 2. Establish a monitoring mechanism 3. Inform patients of their rights and responsibilities 4. Improve working conditions and take staff requests into consideration 5. Include vocational training 6. Allow access to bedrooms throughout the day 7. Allow residents to leave throughout the day 8. Improve communication with outside and visitors 9. Improve and increase recreational and vocational activities	1. No dress code 2. Some institutions allow access to outside throughout the day and without restriction

*General health care and human rights assessment completed.

†General health care assessment only.

Data were not available for Hungary.

are asked to indicate why they consider their institutions to be examples of good practice (related to human rights) in their institution. The information is then compiled in a report that outlines the process of the monitoring visit, the findings for each of the topics and any recommendations or suggestions with relation to identified good or poor practice. The findings should be discussed in the final report that outlines the process of the visit as well as the outcomes and findings of the visit. These reports are then made public to draw attention to problem areas as well as better practice.

Results

Focus groups

The selection of the statements below illustrates the range of experiences and perspectives on this topic in Europe:

> 'If you're admitted to a hospital, you are not able to see your rights [. . .]*What rights are you thinking of?* The right to smoke, right to take a bath, receive visitors, the right to spiritual care and social work. And very important is the right to freedom. You must work hard to earn that back'. Netherlands
>
> 'What do I think of when I think of human rights? For me one of the key issues was forced medication. I don't know enough about human rights legislation really and I wonder how much the staff on acute wards or in any settings do. I wonder very much'. UK
>
> 'I think that it is very important that patients know rights, at least those indicated in the mental health laws, and see them implemented, i.e. how the staff follows them. For instance, there is a rule that it is forbidden to restrain someone longer than for 2 hours without the break. From my own experience, I can testify that this rule is not followed. I was kept in restraint for the whole night, and the whole day. So, the staff itself badly knows the rights'. Lithuania
>
> 'I was told, you know, unless you take this medication there's nothing we can do for you, you know, you'll just have to leave and [. . .] I just find the whole totally dehumanising really and it has only really hit me, you know I think I have been really affected by the system even more than actually my own traumas have affected me'. UK
>
> 'Briefly speaking, there is no way to describe what is happening in our psychiatric services otherwise than calling it genocide against personality'. Bulgaria

With relation to human rights, across all the focus groups the three main areas of concern were: treatment methods, interaction with the institution staff and access to information. Some treatment methods or interventions were perceived as violation of human rights (such as detention, forced pharmacological treatment, involuntary electro-convulsive therapy (ECT), physical restraint and seclusion). Of equal importance to service users was scarce communication with the staff or their attitude towards patients. Furthermore, the lack of information about diagnosis and treatment, about one's own rights as well as available complaint mechanisms was raised as a human rights issue. Although socio-economic differences among countries did define some of the issues addressed (such as the issues of privacy and amount of personal space and places to secure one's own belongings) most themes remained consistent regardless of the socio-economic context.

General health concerns

With regard to the composition of the monitoring teams, participants felt it was important for service users to be employed because of the unique perspective their experiences within the psychiatric services bring and this is particularly true when discussing general health care. The quotes below highlight some of the themes generated in the focus groups: availability, being taken seriously, staff competence, institutional rules and living conditions and smoking and weight gain.

> 'When I went to the hospital I was so healthy, when I left it, I was ill'. Hungary
>
> 'I came to the hospital with some let's say problems like mental, physical problems, health problems but I left with worse ones'. Slovakia
>
> 'Always used to be the saying – about the worst place to have a cold is in a psychiatric acute ward'. UK
>
> 'If, by any chance, you'll get cold there, get a kidney crisis or some other physical malady, which is not directly connected to the psychic one, you are at the death's door. For sure you are at the death's door'. Bulgaria
>
> 'I remember quite often being admitted and not ever having any physical check-up at all. And I think that may happen quite a lot particularly if people are coming in on section [. . .] and brought in by the police or whatever. I think it's quite, quite often that the initial physical check-up doesn't actually happen'. UK
>
> 'Psychiatry paves the way to excessive smoking. Enormously. Terrible. Because you only get. . . when you're in a closed regime, you have only two rooms to sit in: one regular room and one smoking room. And then you meet people and sometimes more people who smoke and then you sit together the whole time and you smoke more and more. And yes that's actually really bad. There's sometimes nothing else to do'. Belgium
>
> 'Within the framework of the one's whole therapy and due to medication one has many occasions where one has to sit for a long time. This is also a reason why many patients then

> tend to put on weight. I think this is not something inevitable. I find that one should look out for something like some sport or some physical activity. I also think that it is necessary for the therapy and putting on weight is harmful'. Germany

Monitoring visit results

Our 87 visits included monitoring of institutions from a six-bed hostel facility in Italy to a large psychiatric hospital in Austria with 670 beds, and the ITHACA Toolkit was therefore used with relation to residents in institutions with a wide range of conditions across Europe. The data collected through the monitoring visits demonstrate the need for further monitoring of these institutions not only to expose and prevent violations and inadequacies but also to identify and share in better practice. Table 2 provides a summary of the types of institutions visited, the salient issues in each context and the key findings for better practice across all sites. For reasons of local approval, the visits presented here include some countries that were only able to test the general health care component of the toolkit. Some collaborators were not able to gain access to institutions to monitor human rights due to their status or relationship with those organizations and institutions.

Discussion

The international, interdisciplinary project produced a comprehensive yet flexible toolkit to monitor human rights and general health care across a range of contexts. The toolkit draws on the skills and strengths of a range of disciplines. With relation to capacity building and service user involvement, throughout this project, service users actively engaged in the development, evaluation and utilization of this toolkit. Their involvement was imperative to the development of a toolkit that can assess the reality of those living in or being treated in psychiatric care systems. In this capacity and through structured activities including the focus groups, researcher training and monitoring visits, a new group of service user researchers have been engaged, trained and energized (Sayce & O'Brian, 2004). As one of the service user researchers from Finland states, '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'.

This project had several limitations. Of all the 15 sites, four were unable to test the human rights component of the Toolkit as this necessitated making the findings publicly available which they were not willing to do, as they were either employed or otherwise had a close relationship with the institution(s) which were to be monitored. In other countries, e.g. Finland, monitoring results were published and led to improvements in human rights of residents in the institutions monitored (Salo, 2010). The aim of the project was not to perform international comparisons, but to examine, document and comment on human rights, with relation to international standards and develop a participatory and service user led toolkit. Longitudinal monitoring with the ITHACA Toolkit in future will show whether human rights conditions and access to health care improves over time in Europe. The institutions in this project were not selected to be representative for all such institutions within or across countries, but to include a mixed selection of large and small health and social care facilities for the purpose of establishing the feasibility of the toolkit. Furthermore, the pragmatic nature of the project was reflected in the fact that not all sites followed the training and manual instructions precisely: one site simply used the toolkit prompt questions without referring to the manual. Another limitation of the development of the toolkit is that the training meeting provided human rights training only and not training on the general health care part of the toolkit, the content of which was finalized at a later point. It is also quite often the case that non-availability of data is a limiting factor, for example key staff who are not available for interview on the day of the monitoring visit, or poor or missing documentation. It could be considered a limitation that the identification of the human rights issues in each monitoring visit is the product of the judgements of the monitoring group members, working together, based upon their experience and the verifiable evidence for each concern.

Recommendations

Based on the experience of the ITHACA staff in data collection from all 87 monitoring visits, we recommend that European Union (EU) Member States: (1) align laws and policies to bring them into compliance with the CRPD; (2) ratify the CRPD; (3) ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities (see Article 16(3) of the CRPD); (4) ensure that persons with disabilities and their representative organizations are involved and fully participate in the monitoring process (see Article 33(3) of the

CRPD) (Mental Disability Advocacy Center, 2011 17046/id); (5) ensure that people with disabilities, and their representative organizations, are actively involved in the development and implementation of legislation and policies to implement the CRPD (see Article 4(3) CRPD); (6) ensure that resources are made available to fully implement the CRPD and to ensure good quality general health care, for example, by the progressive development of community-based services, consistent with Article 19 of the CRPD and the 2005 Helsinki Mental Health Declaration and Action Plan for Europe (World Health Organisation, 2005; Thornicroft & Rose, 2005).

For clinical and social care staff we recommend that, among other activities, they co-operate with independent human rights monitoring bodies to: (1) advocate that their national policy makers ratify and implement the CRPD; (2) develop, use and improve monitoring systems, for example, the ITHACA Toolkit with continuing input and development from service users (Sweeney *et al.*, 2009); (3) support local advocacy and support groups for service users; (4) support the development of mental health care that progressively develops community based services (Thornicroft *et al.*, 2010).

For service users and carers/family members we recommend that they: (1) speak out about observed and known human rights violations; (2) collaborate with non-governmental organizations, governments, international bodies and monitoring organizations to gain access to, and participate in monitoring institutions; (3) ensure that the results of the monitoring visits are disseminated to those who are in positions to enact improvement in policy and/or care provision; and (4) petition local, national and international bodies to protect, respect and fulfil human rights.

Finally, the development and initial implementation phases of the ITHACA Toolkit, as briefly described here, and in more detail in the full toolkit (www.ithacastudy.eu) have shown that the CPRD can be used as the framework for a practical method of data collection related to human rights of people with mental health problems, and that this method can be successfully applied in institutions to gather, collate and report upon specific good and poor practices that can be used as a guide for mental health service improvement.

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Declaration of Interest

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