



# Mental health, human rights and standards of care

Assessment of the quality of institutional care for adults with psychosocial and intellectual disabilities in the WHO European Region



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adults with psychosocial and intellectual disabilities  
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The project and this report were implemented and overseen by  
the WHO Regional Office for Europe, with support from Picker  
Institute Europe in data analysis and reporting.

# Abstract

The WHO project on adults with psychosocial and intellectual disabilities living in institutions in the WHO European Region targets a highly marginalized, vulnerable group whose quality of life, human rights and reinclusion in society are seriously compromised by outdated, often inhumane institutional practices.

The specific objectives of the project were to address gaps in knowledge about the number and characteristics of such long-term institutions and to identify deficiencies in current care standards through the lens of the United Nations Convention on the Rights of Persons with Disabilities.

## Keywords

MENTAL HEALTH  
MENTAL HEALTH SERVICE  
MENTAL DISORDER  
INTELLECTUAL DISABILITY  
HUMAN RIGHTS  
DELIVERY OF HEALTH CARE  
EUROPE

ISBN: 978 928 905 3204

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Publications  
WHO Regional Office for Europe  
UN City, Marmorvej 51  
DK-2100 Copenhagen Ø, Denmark

Alternatively, complete an online request form for documentation, health information, or for permission to quote or translate, on the Regional Office website (<http://www.euro.who.int/pubrequest>).

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# Acknowledgements

## **World Health Organization**

The project was managed by the Mental Health Programme in the WHO Regional Office for Europe (Melita Murko, Technical Officer; Dan Chisholm, Programme Manager) under the direction of Gauden Galea (Director of Noncommunicable Diseases and Promoting Health through the Life-Course), with the support of Zsuzsanna Jakab, WHO Regional Director for Europe. The project was instigated and initially led by Matt Muijen, former Programme Manager for Mental Health, with support from Elena Shevkun. The administrative support of Nathalie Germain-Juskov and Jesus Onn Toi Chew Ambrosio is warmly acknowledged.

The project team would like to thank Michelle Funk and Nathalie Drew from the Department of Mental Health and Substance Abuse, WHO headquarters, who provided training in the use and application of the WHO QualityRights toolkit, and advice and support to the project team throughout phase 2 of the project, including a detailed review of the draft regional report.

Project support was generously provided by the following heads of country offices and their teams:

Albania: Nazira Poolatovna Artykova

Armenia: Egor Zaitsev

Azerbaijan: Kamran Garakhanov

Bosnia and Herzegovina: Victor Olsavszky

Bulgaria: Skender Syla

Croatia: Antoinette Kaić-Rak

Czech Republic: Alena Šteflová and Paulina Karwowska

Estonia: Marge Reinap

Georgia: Marijan Ivanuša

Hungary: Ledia Lazeri

Kazakhstan: Tatiana Kolpakova and Oleg Chestnov

Kyrgyzstan: Jarno Habicht

Latvia: Aiga Rūrāne

Lithuania: Ingrida Zyrlyte

Poland: Paulina Karwowska

Republic of Moldova: Haris Hajrulahović

Romania: Miljana Grbić

Serbia: Zsófia Pusztai

Slovakia: Darina Sedláková and Tatul Hakobyan

Slovenia: Marijan Ivanuša and Darina Sedláková

The former Yugoslav Republic of Macedonia: Margarita Spasenovska and Jihane Tawilah

Turkmenistan: Bahtygul Karriyeva

Ukraine: Marthe Everard

Project support for Kosovo (in accordance with United Nations Security Council resolution 1244 (1999)) was provided by Ardita Tahirukaj.

## **Picker Institute Europe**

The WHO project team wishes to thank Helen Bohan, Bridget Hopwood, Susanne Käsbaauer, Andrew McCulloch, Alan J. Poots, Anna Perris and Amy Tallett at Picker Institute Europe for their extensive support in data analysis and reporting.

## **External advisor**

The WHO project team extends special thanks to Roger Banks, President of the European Association for Mental Health in Intellectual Disability, for his expert advice and assistance throughout phase 2 of the project.

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Belgium: Daniel Reynders

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Cyprus: Georgia Antoniou, Andreas Elia, Tasos Ioannou, Irene Pantela-Hadjilyra, Anna Stefanidou

Czech Republic: Dana Chrtková, Dana Lupačová, Dita Protopopová, Lucie Rybová, Petr Šturma, Petr Winkler

Denmark: Jens Bjerg Johansen

Estonia: Maiu Kauber, Katre Koit, Ingrid Ots-Vaik, Helen Tähtvere, Katrin Tsuiman

Finland: Helena Vorma

Georgia: Madona Asatiani, Manana Eliashvili, Ketevan Goginashvili, Lali Tsuleiskiri, Nana Zavrardashvili

Germany: Chariklia Balas

Hungary: Zsuzsanna Csató, Szilárd Hamvas, Gábor Kapócs, János Réthelyi, Réka Zsigmond

Kazakhstan: Kuanysh Altynbekov, Elmira Auezova, Anastassiya Sadovskaya, Elmira Zhussupova

Kyrgyzstan: Elmira Mukashnovna Asanbaeva, Sabira Sultanovna Musabaeva, Zarina Timurovna Fayzulina, Kirill Pavlovich Filippov, Tynchtykbek Tolonbaevich Koychumanov

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Lithuania: Ona Davidonienė, Nijolė Goštautaitė Midttun, Ugnė Grigaitė, Dovilė Juodkaitė, Rasa Laiconienė, Karilė Levickaitė, Darius Pauliukonis, Romualdas Žekas

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Serbia: Nikolina Arbutina, Aleksandar Damjanović, Nataša Đurašinović, Jelena Janković, Milka Kalaba, Maja Milosavljević, Marta Sjeničić, Jasmina Stojković Pavlović

Slovakia: Miroslav Cangár, Marian Horanič, Ľubomíra Izáková, Veronika Mészárosová

Slovenia: Nadja Čobal, Mojca Zvezdana Dernovšek, Marjetka Gombač, Klara Nahtigal, Nataša Udovič

Switzerland: Andreas Rieder

The former Yugoslav Republic of Macedonia: Stojan Andonov, Jovanka Kostovska, Suzana Manevska, Antoni Novotni, Pavlina Vaskova

Turkmenistan: Yusup Veliyev

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<sup>1</sup>In accordance with Security Council resolution 1244 (1999)

# Abbreviations

|      |   |
|------|---|
| CIS  | Commonwealth of Independent States (including Georgia, a former member, and Turkmenistan and Ukraine, associate states) |
| CRPD | Convention on the Rights of Persons with Disabilities   |
| SEE  | South-eastern Europe  |

## A note on terminology

This report provides results for adults with psychosocial and intellectual disabilities living in long-term institutional settings. The term “people with psychosocial disability” includes those who have received a diagnosis related to their mental health or who self-identify with the term. The term “intellectual disability” is considered to cover people who have received a diagnosis specifically related to their intellectual functioning. Individuals with cognitive disability, including dementia, live in some of these institutions; however, they were not the focus of this assessment project.

In this report, the terms “service users” and “residents” are used interchangeably to refer to adults living in institutions.

# Foreword

*Ensuring access to safe, effective, high-quality care is a central objective of national mental health policies and programmes throughout the WHO European Region and is a vital element of regional policy frameworks, including Health 2020 and the European Mental Health Action Plan 2013–2020. Many Member States, however, have reported that fulfilling such principles is a major challenge because of the low priority of and investment in mental health systems and their reform. One consequence is that many of society's most vulnerable, already marginalized individuals – those with intellectual and psychosocial disabilities – are caught between the stated policy goal of moving away from institutional care and a lack of effective means to bring about that change. The result is that many such institutions are run down, poorly maintained and too often the setting for practices that are inhumane or antithetical to safe, effective, high-quality care.*

*At the request of Member States, the WHO Regional Office for Europe undertook an assessment of current practices and shortcomings in such institutions. An earlier assessment, targeted to children and young people, led to endorsement in 2011 of the European Declaration and Action Plan on the Health of Children and Young People with Intellectual Disabilities and their Families. In the current phase of work, which is the subject of this report, the focus is on adults.*

*In this phase of the project, the quality of care and protection of human rights in selected institutions in over 20 countries in the WHO European Region were rated with the WHO QualityRights toolkit. The results are cause for great concern because of the regularity with which personal liberty, legal capacity and freedom from abuse were considered by national assessment teams to be violated. Importantly, however, the findings point to clear actions that can be taken by governments and stakeholders to address deficiencies and bring the services into line with the principles and standards to which governments have committed themselves at national, regional and global levels. The United Nations Sustainable Development Goals provide an opportunity to intercede more strongly for mental health and human rights, because mental health and well-being are specified targets of the health goal and because of the close links between mental health and other goals, including equality, inclusion and justice.*

*For many countries, the subject of this work is seen to be important but also sensitive. I am therefore particularly pleased to see that so many Member States have participated in the assessment and very grateful to them for their openness in collaborating and collectively learning from this initiative. WHO stands ready and committed to continue its support to Member States to improve the quality of care in existing long-stay institutions and to promote and facilitate the move away from them towards more independent, community housing, care and rehabilitation.*

Zsusanna Jakab

WHO Regional Director for Europe





# Executive summary

## Purpose

The WHO project on adults with psychosocial and intellectual disabilities living in institutions in the European Region addresses a highly marginalized, vulnerable group whose quality of life, human rights and reinclusion in society are compromised by outdated, often inhumane institutional practices. The goal of the initiative is to promote and facilitate deinstitutionalization. A first step is better understanding of the scale and quality of long-term care arrangements in the WHO European Region. The specific objectives were to address gaps in knowledge about the number and characteristics of long-term institutions and to identify deficiencies in current care standards from the perspective of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

## Implementation

In phase 1, all Member States in the European Region were invited by the Regional Director to complete a survey of institutions that provide long-term care for adults with psychosocial and intellectual disabilities. The survey was administered in the 31 participating countries and Kosovo (in accordance with United Nations Security Council resolution 1244 (1999)). The findings were used to construct a regional profile of the current ownership, management and inspection of institutions and the demographic, clinical and other characteristics of the resident populations. Not all the countries answered all the questions, and there were few standardized data collection policies and procedures within or between countries.

In phase 2, the quality of care and observance of human rights were assessed in a sample of institutions. The WHO QualityRights toolkit was the main instrument used for data collection on 25 standards within five interrelated themes:

- Theme 1. The right to an adequate standard of living (Article 28 of the CRPD);
- Theme 2. The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the CRPD);
- Theme 3. The right to exercise legal capacity and the right to personal liberty and the security of person (Articles 12 and 14 of the CRPD);
- Theme 4. Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 and 16 of the CRPD);
- Theme 5. The right to live independently and be included in the community (Article 19 of the CRPD).

In 2017, QualityRights assessments were conducted in 75 facilities across 24 WHO Member States and also Kosovo (in accordance with United Nations Security Council resolution 1244 (1999)). The institutions for assessment were selected by government-nominated national assessment teams. Overall, the facilities differed appreciably in terms of size, staff composition, sectoral accountability, type of ownership, living conditions and service culture. Their identity has been kept confidential in line with what was agreed with national partners.

## Main findings

The findings reveal and confirm that long-term institutional care for people with psychosocial and intellectual disabilities in many European countries is far below the standard. A significant proportion of the assessed institutions were violating the fundamental rights of people with psychosocial and intellectual disabilities, including their legal capacity, autonomy, dignity, liberty and security of person, physical and mental integrity and freedom from torture and ill treatment and from exploitation, violence and abuse. Some of the most egregious violations reported were: use of mechanical and pharmacological restraints to manage difficult behaviour, a culture of impunity with regard to reported cases of sexual abuse, numerous irregularities concerning informed consent, discrimination and barriers to access to high-quality care for general and reproductive health, lack of alternative or complementary mental health treatment options and a general lack of opportunities for meaningful daily activities within or outside the institutions.

Fewer than a third (28%) of the 2450 ratings of standards made by the 25 assessment teams were “achieved in full”, indicating enormous scope for improvement throughout the European Region. This indicates that CRPD signatories are at risk or culpable of substantial breaches of the treaty.

A number of the assessed care standards could be improved with targeted interventions in facilities, such as reducing the number of beds in wards and introducing personalized recovery planning, whereas other care standards will require more systemic changes, such as in legislation to allow supported decision-making, e.g. advance directives.

Although there was appreciable variation within and across participating countries with respect to quality and human rights standards, a number of common deficiencies require urgent attention and action.

- A lack of knowledge or awareness about mental health and the protection of human rights: There was a particular “blind spot” concerning the legal mechanisms that ensure that people with psychosocial disabilities can exercise their legal rights and capacity (for example, through complaints procedures).
- A lack of a personalized approach to care: For example, there was a virtual absence of meaningful recovery plans to promote and enable an individual’s integration into community life.
- A lack of rehabilitative or even recreational activities: This was observed in most of the institutions assessed. Residents often had literally nothing to do and were not given opportunities for learning or training in skills that might provide them with an occupation.
- A lack of legal provisions or legal representation: Not only was legal advice lacking, but there was a virtual absence of supported decision-making.
- A lack of community alternatives: Alternatives such as independent housing were lacking, thus perpetuating the stay in the institution and removing opportunities to live an independent life. In many reports, a simple message was reiterated: The majority of residents would like to leave the institution but have nowhere to go.

## Next steps

The results of this work indicate the next steps or priorities required to continue progress towards deinstitutionalization and to ensure that the human rights of people with psychosocial and intellectual disabilities are respected, protected and fulfilled by all providers of mental health and related services:

- revision, as necessary, of policies and legislation to ensure their alignment with the CRPD;
- staff training in human rights in the context of mental health services and other special modules, such as personalized recovery planning; strategies to avoid and defuse difficult situations and reduce and ultimately end coercive practices, including seclusion and restraint; and supported decision-making and advance planning;
- evidence-based, independent monitoring of progress to inform and improve services; and
- knowledge exchange nationally and internationally through joint initiatives, twinning projects, conferences and continuous policy dialogue.

With the important insights from the assessment reports and a newly available set of WHO QualityRights capacity-building and guidance tools, this project now moves beyond assessment of quality to the next phase: the improvement of facilities.

### **Personal reflections from national assessment team leaders**

“The project results create a basis for discussions among countries with the same background and also for networking on solutions and future projects. The country team members are inspired to continue this project, as it was very informative, even at a personal level. It gave us a new perspective on our work and on possible implementation of our new knowledge. I now feel better informed when advising my Government on what is needed for mental health reform in Armenia.”

*Armenia*

“The WHO QualityRights Toolkit allowed us to hear the voices of residents in long-term facilities in Croatia, to capture what it is like to live in those institutions and to empathize with the residents’ deep longing to leave their confinement and live and work like other people, for the institutional setting itself lies at the heart of human rights violations.”

*Croatia*

“Implementation of the WHO project was auspiciously timed to coincide with a reform of psychiatric care currently under way in the Czech Republic. We consider the QualityRights toolkit ideal for assessing and subsequently bringing about changes in the quality of care in our psychiatric institutions, and a decision has been made to use the instrument in all institutions in our country.”

*Czech Republic*

“Thanks to the WHO QualityRights assessments, we were able to gather more knowledge and deeper insight into the status of mental health service provision in Estonia and also to empathize with the residents. During one interview, a man told us that his favourite things were his “radio and his sweatshirt”, yet he was forbidden access to them, for reasons that were not explained either to him or to us.”

*Estonia*

“Almost 20 years ago, as a medical student, I wrote a paper on psychiatric ethics and the situation of chronic mental institutions in Hungary. My interest in ethics and human rights has accompanied me ever since, although, as a clinician, I do not have much time for these difficult questions. Therefore, it was a great experience to be exposed to social and institutional ethics issues once again in the framework of the WHO project. Over the years, we have struggled to organize the treatment of patients with severe chronic conditions without family support in long-term institutions, but I never visited the places. In this project, I had the chance to organize a great team of experts and to visit some of the institutions in Hungary. We saw both good practices that could be shared with other institutions as well as systemic problems that should urgently be dealt with.”

*Hungary*

“The implementation of reforms in institutions differs, depending mainly on the attitude of leaders to the reforms. While there is generally a will to reform mental health services, specialists often do not fully understand the reform process and its indivisibility with human rights. In this regard, we need educational programmes to help specialists make efforts in the right direction.”

*Kyrgyzstan*

“My strongest impression was seeing the happiness of the residents that came from being a part of a rare social event (in this case, our visit). In one institution, a participant who was in the hairdressing salon at the time saw that the interviews were about to start and hurried to finish her appointment in order to join us and the group we were talking to. Her need and the need of many residents to be included and feel part of the group was very touching.”

*Serbia*

# Introduction

## Context

Long-term care of people with psychosocial and intellectual disabilities is complex, with major challenges, including the multisectoral nature of its organization, with many professional disciplines involved in planning and provision, competing interests and viewpoints on the ways in which it should be reformed, and the low priority typically accorded to this area of health and social care.

Large long-stay institutions are still the main form of care in many countries in the WHO European Region, a geographical area encompassing western, southern and eastern Europe as well as central Asia and the Caucasus. Such institutions are still perceived by many professionals and the public as an appropriate or acceptable setting for the care of people with psychosocial and intellectual disabilities; however, there is ample evidence that they are inappropriate, with poor-quality standards of care and violation of human rights. Many informed voices among professionals and the public are calling for transformation or elimination of such service arrangements.<sup>2</sup>

Marginalization and neglect of people deemed to require long-term support is widespread in the European Region, with people being placed in social care homes irrespective of their needs or diagnosis. For many institutions, there are no specific diagnostic criteria for entry, so that people with a wide range of disabilities and disorders (including autism, Down syndrome, schizophrenia and dementia) receive treatment in the same place.<sup>3</sup> Residents often receive little health care, individual support or rehabilitation. Such “homes” are often isolated geographically and inadequately staffed by people who receive insufficient training, little supervision, low pay and little respect. These institutions are often brought to the attention of the public or policy-makers only when another incident of abuse or malpractice is considered to be newsworthy.

Accounts of gross human rights violations of children and young people with intellectual disabilities living in institutions across Europe, of which some clearly amount to ill-treatment or even torture, were brought to the renewed attention of the WHO Regional Office for Europe in 2008. WHO’s response was to initiate a project “to bring the countries in the Region together behind a common vision of how to ensure the right to health of these particularly vulnerable children so that they may be cherished and supported in every opportunity to live their lives to the full as equal, participating and accepted members of society.”<sup>4</sup> This initiative produced the European Declaration and Action Plan on the Health of Children and Young People with Intellectual Disabilities and their Families, endorsed in 2011 by the Regional Committee for Europe in resolution EUR/RC61/R5.

The Regional Office resumed work in this area in 2015, again in response to serious concerns raised by a number of Member States, this time about the status of institutional care for adults. In her letter to Member States to announce the new project, WHO Regional Director for Europe, Dr Zsuzsanna Jakab, recalled that one of the Declaration’s priorities was to “collect essential information about needs and services and assure service quality”<sup>5</sup>, while information was lacking in particular about adults with psychosocial and intellectual disabilities, perhaps the most neglected and stigmatized group in the European Region addressed by the Convention on the Rights of Persons with Disabilities (CRPD).

The CRPD, which was ratified in 2006, is the culmination of a general movement towards a rights-based model of disability. It calls for the elimination of barriers to social, political, economic and legal integration into society and the rights of people with physical, psychosocial, intellectual and cognitive disabilities. Its uptake and operationalization have been and continue to be hampered by a number of difficulties. Moves towards deinstitutionalization, in particular, often meet barriers such as lack of enabling political frameworks, poor coordination among government sectors, insufficient funding, slow legal processes and resistance to change. It has been noted that the CRPD is not just a new treaty but a new paradigm.<sup>6</sup> Its realization implies uptake of the paradigm, not only by people with disabilities but by the rest of the population, an ideological shift that “cannot be introduced by administrative fiat... [and] is primarily a political process rather than a legal one.”<sup>6</sup> The political process relies on cooperation among many stakeholders, including the general population.

Caught between the old and the new world view of disability, people who currently live in these types of institutions are doubly disadvantaged: they endure uncertainty about whether or when they can expect to be discharged, and they endure ever-

<sup>2</sup> Forgotten Europeans, forgotten rights: The human rights of persons placed in institutions. Geneva: United Nations Human Rights Office of the High Commissioner; 2011.

<sup>3</sup> Muijen M. Quality of European mental health services – the special situation in eastern Europe. *Eur Psychiatry*. 2015;30:33.

<sup>4</sup> The case for change: a background paper for the WHO conference Better health, better lives: children and young people with intellectual disabilities and their families, Bucharest, 26–27 November 2010. Copenhagen: WHO Regional Office for Europe; 2011.

<sup>5</sup> Better health, better lives: children and young people with intellectual disabilities and their families. Copenhagen: WHO Regional Office for Europe; 2011 (EUR/51298/17/6).

<sup>6</sup> Bartlett P. Implementing a paradigm shift; implementing the CRPD in the context of mental disability law. In: Torture in healthcare settings: reflections on the Special Rapporteur on Torture’s 2013 thematic report. Washington DC: Centre for Human Rights and Humanitarian Law, American University; 2014.

degrading living conditions, because the dilemma of combining deinstitutionalization and improving the standard of living and observance of human rights in existing institutions has essentially not been resolved. The challenge has been taken into account in a number of reports, which recognize the need for short- to medium-term safeguards for the rights of people in institutions during deinstitutionalization. A report by the Office of the United Nations Commissioner for Human Rights in 2011, for instance, stated: “While governments need to develop and implement strategies for the shift from institutional care to community-based services, they must also protect the rights of individuals who remain in institutional care during this transition process.”<sup>7</sup> Thus, protection of the rights of people with psychosocial and intellectual disabilities must include longer-term priorities, with continued improvement in the human rights and quality of life of those who remain in institutional care.

The purpose of the WHO project is to ensure such protection, guided by the WHO Health 2020 policy framework, the WHO European Mental Health Action Plan, the CRPD and the Sustainable Development Goals. Health 2020 promotes three approaches considered to be important for transforming the care for people with psychosocial and intellectual disabilities in the spirit of the CRPD. The first is the whole-of-government approach, which “stresses the need for better coordination and integration, centred on the overall societal goals for which the government stands”. The second is the health-in-all-policies approach, “designed to make governance for health and well-being a priority for more than the health sector”. The whole-of-society approach “goes beyond institutions: it influences and mobilizes local and global culture and media, rural and urban communities and all relevant policy sectors”. Better inter-sectoral collaboration is clearly necessary, as is engagement with local communities in completing deinstitutionalization and creating genuine acceptance and inclusion.

Standards of care and protection of human rights in institutional care are being addressed in other studies, as reported in *Dementia in Europe Yearbook 2017: Standards for residential care facilities in Europe*, published by Alzheimer Europe,<sup>8</sup> and *Mapping and understanding exclusion in Europe*, published by Mental Health Europe<sup>9</sup> and the University of Kent in December 2017. The latter includes testimonials from service users about the quality of care, from admission to discharge, and concludes with a call to governments and the European Union for additional steps and continuing support for deinstitutionalization. These related but distinct sources of data and information reveal common deficiencies in the provision of care and support for people with intellectual, cognitive and psychosocial disabilities living in long-term institutions across the European Region. Tackling the deficiencies in such institutions is primarily the responsibility of governments and national partners; their task is to improve quality standards within existing institutions and at the same time systematically shift the focus of care away from institutions.

## Aims and objectives

The WHO Regional Office for Europe initiated a multiyear, intercountry project to determine the numbers of adults with psychosocial and intellectual disabilities who are living in residential care institutions in the WHO European Region and the quality of treatment and care they receive.

The project was implemented in two phases:

- phase 1, to collect data on the types and numbers of institutions in countries, including the workforce and regulations; and
- phase 2, to evaluate the quality of care and respect for human rights in a sample of institutions in participating countries, mainly with the WHO QualityRights toolkit (Box 1).

The data collected during the two phases should provide a general picture of the nature and quality of the long-term services available for adults with psychosocial and intellectual disabilities in the Region and provide a basis for improvement and for revision of national assessment frameworks and instruments, so that the legally binding articles of the CRPD are fully reflected in the work of national inspection or audit teams.

<sup>7</sup> *Forgotten Europeans, forgotten rights: the human rights of persons placed in institutions*. Geneva: Office of the United Nations High Commissioner for Human Rights; 2011.

<sup>8</sup> *Dementia in Europe Yearbook 2017. Care standards for residential care facilities in Europe*. Luxembourg: Alzheimer Europe; 2018.

<sup>9</sup> *Mapping and understanding exclusion in Europe*. Brussels: Mental Health Europe; 2017 (<https://mhe-sme.org/mapping-exclusion/>, accessed 30 March 2018).

### **Box I. QualityRights: transforming services, promoting rights**

QualityRights is WHO's global initiative to improve the quality of care provided by mental health services and to promote the human rights of people with psychosocial, intellectual and cognitive disabilities. It offers a new, rights-based, recovery-oriented approach to mental health care. Through QualityRights, WHO is supporting countries in putting into place policies, strategies, laws and services that are in line with international human rights standards, including the CRPD.

The objectives of QualityRights are to:

- build capacity to understand and promote human rights and recovery;
- improve the quality of care and respect for human rights in mental health and related services;
- create community based and recovery oriented services that respect and promote human rights;
- develop a civil society movement to conduct advocacy and influence policy-making;
- reform national policies and legislation in line with the CRPD and other international human rights standards.

For more information about QualityRights, visit [http://www.who.int/mental\\_health/policy/quality\\_rights/en/](http://www.who.int/mental_health/policy/quality_rights/en/).

## Methods

### Phase I

The first phase of the project involved adaptation of an existing questionnaire to determine the type and number of institutions providing care for people with psychosocial and intellectual disabilities (Annex 1). The instrument was divided into two sections, one for the national context and one for individual institutions, and was administered by national focal points nominated by the relevant ministries. Data were collected on:

- ownership of institutions
- accountability for institutions
- responsibility for inspection
- independent complaint mechanisms
- number of complaints
- deinstitutionalization plan
- funding committed to deinstitutionalization
- implementation of deinstitutionalization if applicable
- number of institutions
- total number of residents in institutions
- gender
- age groups
- length of stay
- diagnosis,
- co-morbid conditions
- staffing

Data collection started in October 2015 and finished in September 2016. Additional clarifications were requested by the WHO coordinating team after the submissions. All data received by 11 November 2017 were included in the analyses presented in this report. Submissions were received from 31 of the 53 countries in the WHO European Region and Kosovo (in accordance with Security Council resolution 1244 (1999)).

## Phase 2

Phase 2 started in January 2017 and concluded in December 2017. All data received by 20 December 2017 were used in the analyses for this report.

Quality was assessed by 25 teams in a sample of institutions in their respective countries. The WHO QualityRights toolkit was the main instrument used to assess and rate the quality of care and respect for human rights, to document the findings and to make recommendations for changes and improvement of services. The toolkit provides a standardized approach to data preparation, collection and reporting in relation to standards of care. Facilities are rated according to five themes, 25 standards and 116 criteria. The five interrelated themes, each addressing an issue with regard to human rights and quality in articles of the CRPD, are:

- Theme 1. The right to an adequate standard of living (Article 28 of the CRPD);
- Theme 2. The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the CRPD);
- Theme 3. The right to exercise legal capacity and the right to personal liberty and the security of person (Articles 12 and 14 of the CRPD);
- Theme 4. Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 and 16 of the CRPD);
- Theme 5. The right to live independently and be included in the community (Article 19 of the CRPD).

The toolkit allows assessment of each theme overall and of the standards under each theme according to criteria for each standard.

The project team in the Mental Health Programme managed and coordinated training and data collection in phase 2, and ministries of health nominated focal points to coordinate activities locally, with support from the WHO country office. In consultation with the relevant ministry, the focal point proposed assessment team members and sought their formal nomination. Once the national team had been formed, two to five facilities were selected for assessment. A number of departments in each facility could be selected for assessment. If the departments differed substantially such that their scores could not be combined, they were assessed as independent facilities.

### *Institutional assessments*

Each assessment team as a group received standard training in conducting the assessment with the QualityRights toolkit by distance learning provided by the WHO Regional Office for Europe.<sup>10</sup> Each of 25 training courses was delivered in two sessions, for a total of five hours on average. The training covered:

- a discussion of the protocol, including all relevant procedures;
- presentation of the WHO QualityRights toolkit;
- presentation of the assessment tools (interview tool, documents and observation tool) and practical exercises; and
- presentation and discussion of the reporting template, adapted for the purposes of the project.

During assessment visits, the team observed all aspects of the facilities, including male and female wards. The observations included physical conditions and interpersonal interactions between staff and residents and among residents. The facility documents reviewed included:

- facility policies, guidelines, standards and other official directives;
- administrative records, such as number and categories of staff; number, age and gender of service users; admission and discharge records;
- records of events such as complaints, appeals against involuntary admission and treatment, incidents of theft, abuse or death; and
- personal records or files of service users.

Assessment visits were announced in advance to the facilities by the relevant ministry and the assessment team members. No unannounced visits were made.

<sup>10</sup> WHO QualityRights tool kit. Geneva: World Health Organization; 2012 ([http://www.who.int/mental\\_health/publications/QualityRights\\_toolkit/en/](http://www.who.int/mental_health/publications/QualityRights_toolkit/en/), accessed 30 March 2018).



## Interviews

Semi-structured interviews were conducted with service users, their family members, friends or carers and staff after informed consent.<sup>11</sup> The teams completed as many interviews as possible in the short time available for each visit and until saturation within responses, i.e. until they had collected sufficient information to assign scores to the criteria, standards and overall themes.

## Scoring

After data collection, the teams discussed and reached a consensus on the final scores for each facility (Table 1). If consensus could not be reached, the lowest assigned score was used. The ratings for standards provide a balance between high resolution, actionable findings and manageable volume of output.

**Table 1. The scoring categories assigned by assessment teams**

| Level of achievement  | Description   |
|-----------------------|---|
| Achieved in full      | There is evidence that the criterion, standard or theme has been fully realized.  |
| Achieved partially    | There is evidence that the criterion, standard or theme has been realized, but improvement is necessary.  |
| Achievement initiated | There is evidence that steps are being taken to fulfil the criterion, standard or theme, but significant improvement is necessary.              |
| Not initiated         | There is no evidence of attempts or steps to fulfil the criterion, standard or theme.   |
| Not applicable        | The criterion, standard or theme does not apply to the facility in question (e.g. sleeping quarters in outpatient or day treatment facilities). |

## Data cleaning

### Phase 1: survey data

Data from Phase 1 did not require cleaning before analysis, as they were provided in tabulated form.

### Phase 2: quantitative data

Facilities were rated according to the five themes, 25 standards and 116 criteria. If the rating of a theme or standard was not reported, the team was asked to provide a value, and, if the summary table rating in a report did not correspond to the component ratings, the WHO coordinating team proposed a revised score, which was confirmed with the assessment team.

### Phase 2: qualitative data

Qualitative data were reviewed, and the names of institutions, countries and regions were removed to ensure the anonymity of service users, staff and facilities. No further information was removed before analysis.

## Analyses

The analyses were concluded in January 2018 after the provision of all assessment data and clarifications.

### Phase 1

Descriptive statistics were used for totals, frequencies and percentages for the sample as a whole and then by “country group”, the blocks into which the WHO Europe Region is divided (Annex 2):

- Commonwealth of Independent States (CIS; including Georgia, a former member, and Turkmenistan and Ukraine, associate states);
- South-eastern Europe (SEE);
- European Union (post-2004) and
- European Union (pre-2004).

Any reported difficulties in data quality or availability were noted for each data item.

<sup>11</sup> Clearance from national ethical committees was optional, as (i) the participants were not randomized to different groups, (ii) the protocol did not require that the treatment or care plans of residents be changed, and (iii) the findings are specific to the institutions and are not generalizable. The project was thus considered to be a service evaluation and not research.

## **Phase 2: quantitative**

Data were analysed according to the ratings for standards. While aggregate figures can provide an attractive summary, caution was used because of differences in the number of standards per theme (median, 5; range, 4–7) and in the number of assessments per country. For instance, assessment of four facilities in a country provided four scoring opportunities for each assessed standard. The effect was reduced by comparing the percentages of facilities rated for each category. Similarly, for analyses and calculations within countries, the percentage of scoring opportunities rated as “achieved in full” was used, as it is easier to interpret.

The percentages of scoring opportunities for each standard rated as each category were analysed and grouped by theme to determine the standards most and least commonly assessed as “achieved in full” and the prevalence of the categories “not initiated” and “not applicable” in the assessments.

To account for different numbers of assessments in each country, the proportion of scoring opportunities rated as “achieved in full” (the “index” category) was calculated for each country and each country grouping. With the index as the outcome variable, univariate analyses were conducted for a range of categorical and continuous predictors to determine whether the index could be predicted by that variable. Country characteristics were taken from phase 1 data tables, from the WHO Global Health Expenditure Database<sup>12</sup> or from the World Bank Data Catalog.<sup>13</sup> Missing values were replaced with the series mean. The independent variables were:

- gross domestic product (in 2015 US\$)
- health expenditure per capita (in 2015 US\$)
- population size
- dummy-coded variables pertaining to ownership of facilities
- existence of a national deinstitutionalization plan
- funding available for deinstitutionalization
- number of institutions
- number of service users
- country group

Repeated testing of the same dependent variable incurs a risk for erroneous rejection of null hypotheses and a conclusion that any effects are a consequence of multiple testing. To mitigate this “family-wise error rate”, the Holm-Bonferroni correction<sup>14</sup> was applied, in which the alpha threshold for statistical significance (i.e. rejection of the null hypothesis, typically 0.05) is modified by the number of tests conducted. If initial tests show statistically significant differences among pairs of variables, a multivariable regression model is built by purposive selection of covariates to include those variables for which a univariate test shows significance at an arbitrary level (alpha = 0.25), to mitigate the failure to identify variables.<sup>15</sup> In the multivariable model, statistical significance is tested at alpha = 0.05.

The scores were not compared to a baseline or reference score, which were not available for countries. Moreover, no comparisons of results were made among countries. The results offer a starting-point for understanding the quality of care to provide a basis for initial improvements and future data collection and monitoring.

## **Phase 2: qualitative**

The qualitative data provided by the assessment teams were analysed by analytical induction. All the “narratives” in facility reports were scanned for themes and categories to prepare a working scheme, which was refined continuously on the basis of subsequent data.<sup>16</sup> Negative instances or discrepancies that did not fit were used to expand the scheme. The final scheme was used as a coding framework to group the qualitative data by theme and category (Annex 3), to facilitate broad understanding of the experiences of service users and the assessment team. Explanations are provided in accordance with emerging themes. A qualitative approach to data analysis places the emphasis on a description of experiences rather than enumeration.

<sup>12</sup> Global health expenditure database. Geneva: World Health Organization; 2018 (<http://apps.who.int/nha/database/Select/Indicators/en>, accessed 30 March 2018).

<sup>13</sup> Countries and economies. Washington DC: The World Bank; 2018 (<https://data.worldbank.org/country>, accessed 30 March 2018).

<sup>14</sup> Holm S. A simple sequential rejective multiple test procedure. *Scand J Stat.* 1979;6:65–70.

<sup>15</sup> Bursac Z, Gauss CH, Williams DK, Hosmer DW. Purposeful selection of variables in logistic regression. *Source Code Biol Med.* 2008;3(1):17.

<sup>16</sup> Haley E. Exploring the construct of organization as source: Consumers’ understandings of organizational sponsorship of advocacy advertising. *J Advertising.* 1996;25(2):19–35.

# Results

## Phase I

The ratings and data tables for phases 1 and 2, which provide the numbers for the graphs and tables, are shown in Annex 4.

### Responses

Thirty-one countries and Kosovo (in accordance with United Nations Security Council resolution 1244 (1999)) returned responses; however, not all provided answers to all the questions. The question for which there were fewest answers was the age distribution of service users, for which there were only 10 responses. Questions on ownership of facilities and the existence of a deinstitutionalization plan were answered by all. Seven responses were returned from the CIS, nine from the European Union (post-2004), seven from the European Union (pre-2004) and nine from the SEE.

The participating countries were:

|                        |   |
|------------------------|---|
| Albania                | Kazakhstan                                |
| Armenia                | Kyrgyzstan                                |
| Austria (phase 1 only) | Latvia                                    |
| Azerbaijan             | Lithuania                                 |
| Belgium (phase 1 only) | Luxembourg (phase 1 only)                 |
| Bosnia and Herzegovina | Poland                                    |
| Bulgaria               | Portugal                                  |
| Croatia                | Republic of Moldova                       |
| Cyprus                 | Romania                                   |
| Czech Republic         | Serbia                                    |
| Denmark (phase 1 only) | Slovakia                                  |
| Estonia                | Slovenia                                  |
| Finland (phase 1 only) | Switzerland (phase 1 only)                |
| Georgia (phase 2 only) | The former Yugoslav Republic of Macedonia |
| Germany (phase 1 only) | Turkmenistan (phase 1 only)               |
| Hungary                | Ukraine                                   |

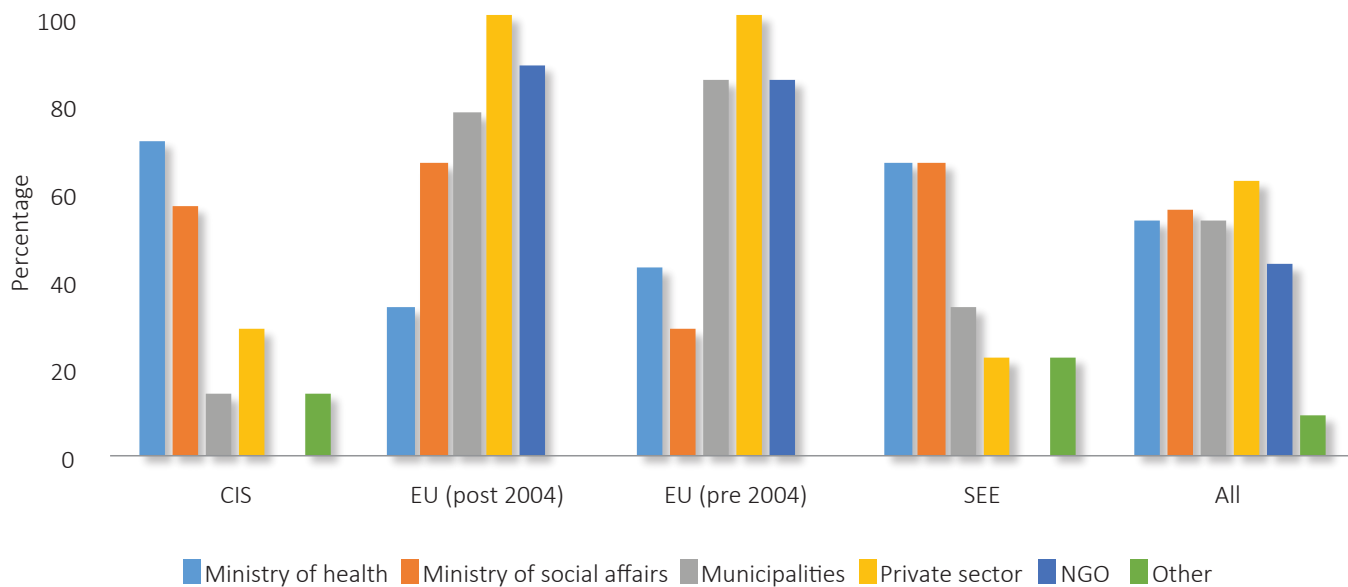
### Context of facilities

The distribution of ownership of facilities among sectors was fairly even, the private sector being the most frequently reported owner (Fig. 1). Larger percentages of countries in the CIS and SEE groups reported ownership of facilities by the ministry of health, while many of those in the European Union groups reported private sector ownership. The ownership models varied within groups.

Overall, there was some similarity among countries in the organization to which facilities were accountable, the ministry of social affairs being the most frequent (Fig.2). Larger percentages of countries in the CIS and SEE groups reported accountability to ministries of health and social affairs, while countries in the European Union (pre-2004) usually reported accountability to a state regulatory authority or municipalities. The model for accountability varied within each group and country.

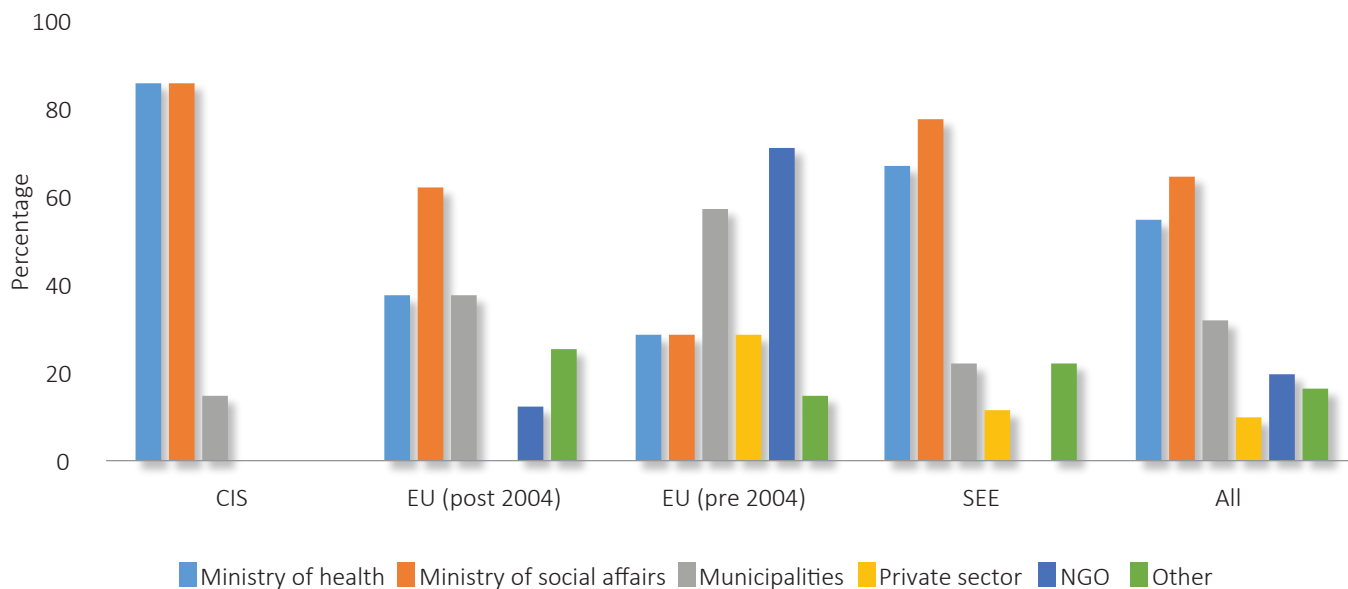
The body responsible for inspecting facilities varied (Fig. 3), with “other” as the commonest category. These included audit offices, financial offices, legal institutions and social insurance boards. Regional agencies and the ministry of health were selected by nine countries. One country did not return a response, and one reported that there were no regular inspections. A large percentage of countries in the European Union (pre-2004) reported that a regional agency was responsible for inspection, while a larger percentage of countries in the SEE stated that the ministry of health was responsible.

**Fig. 1. Ownership of facilities by type of organization**



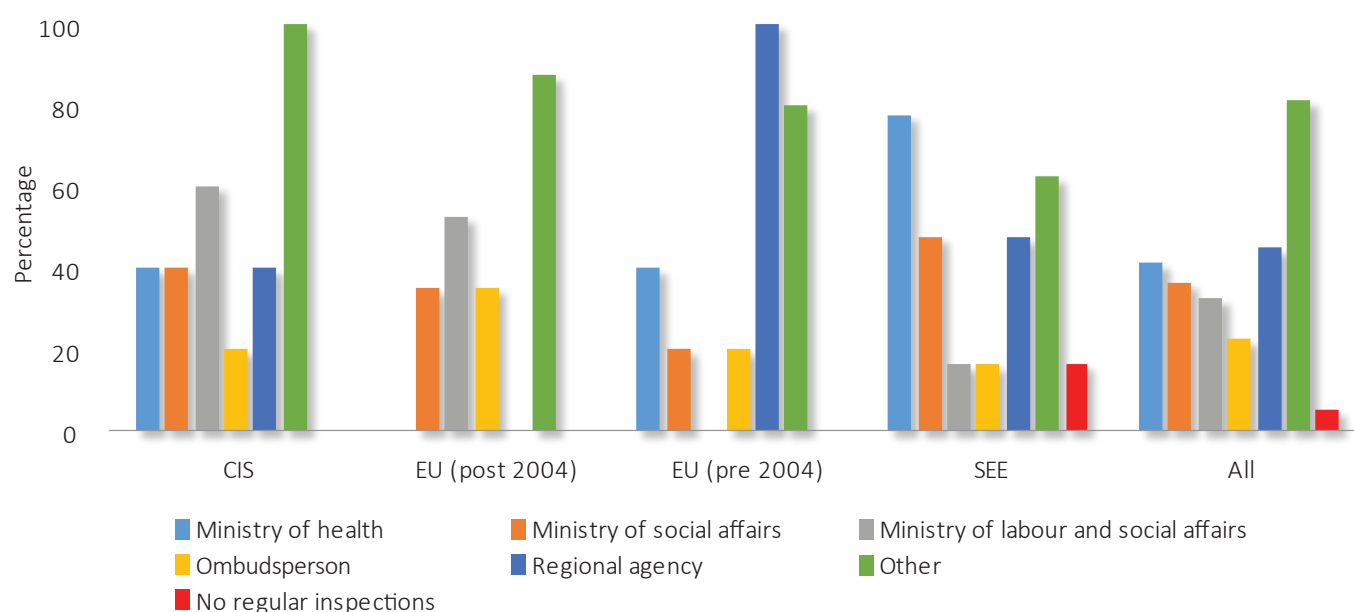
CIS, Commonwealth of Independent States; EU, European Union; NGO, nongovernmental organization; SEE, south-eastern Europe 32 responses. Multiple categories could be selected.

**Fig. 2. Organization to which facilities were accountable**



CIS, Commonwealth of Independent States; EU, European Union; NGO, nongovernmental organization; SEE, south-eastern Europe 31 responses. Multiple categories could be selected.

**Fig. 3. Authorities responsible for inspecting facilities**



CIS, Commonwealth of Independent States; EU, European Union; SEE, south-eastern Europe  
31 responses. Multiple categories could be selected.

An independent complaints mechanism was reported by 28 countries; one country did not respond. A total of 1630 complaints were recorded in 12 countries; however, they were made in different years and not from all the facilities in some countries. The other 20 countries did not report the number. One European Union (post-2004) and two SEE countries did not have an independent complaints mechanism.

All respondents completed the question about a national deinstitutionalization plan. Ten countries stated they did not have such a plan, but, of these, two had subnational plans. By country group, deinstitutionalization plans existed in two of seven CIS countries, six of eight SEE countries, all nine European Union (post-2004) countries and five of seven European Union (pre-2004) countries.

Sixteen countries stated that funding was available for deinstitutionalization, 12 stated that it was not, and four countries did not respond. Two of the countries without a national plan had funding from an outside agency, while five did not. The availability of national funding varied by country group; most European Union (post-2004) countries responded that funding was available (Table 2). Eighteen countries stated that deinstitutionalization was under way, four stated that it was “not applicable”, and seven stated that deinstitutionalization was not yet under way; three countries did not respond. Deinstitutionalization was in progress in most European Union (pre- and post-2004) and SEE countries, while two SEE and two CIS countries responded that the question was “not applicable” (Table 2).

**Table 2. National (or subnational) funding for deinstitutionalization and status of deinstitutionalization**

|                       |                  | CIS | EU (post-2004) | EU (pre-2004) | SEE | Total |
|-----------------------|------------------|-----|----------------|---------------|-----|-------|
| <b>Funding</b>        | Available        | 2   | 8              | 2             | 4   | 16    |
|                       | Not available    | 5   | 1              | 2             | 4   | 12    |
|                       | No response      | 0   | 0              | 3             | 1   | 4     |
|                       | No. of responses | 7   | 9              | 4             | 8   | 28    |
| <b>Implementation</b> | Under way        | 2   | 5              | 5             | 6   | 18    |
|                       | Not under way    | 1   | 4              | 1             | 1   | 7     |
|                       | Not applicable   | 2   | 0              | 0             | 2   | 4     |
|                       | No response      | 2   | 0              | 1             | 0   | 3     |
|                       | No. of responses | 5   | 9              | 6             | 9   | 29    |

CIS, Commonwealth of Independent States; EU, European Union; SEE, south-eastern Europe

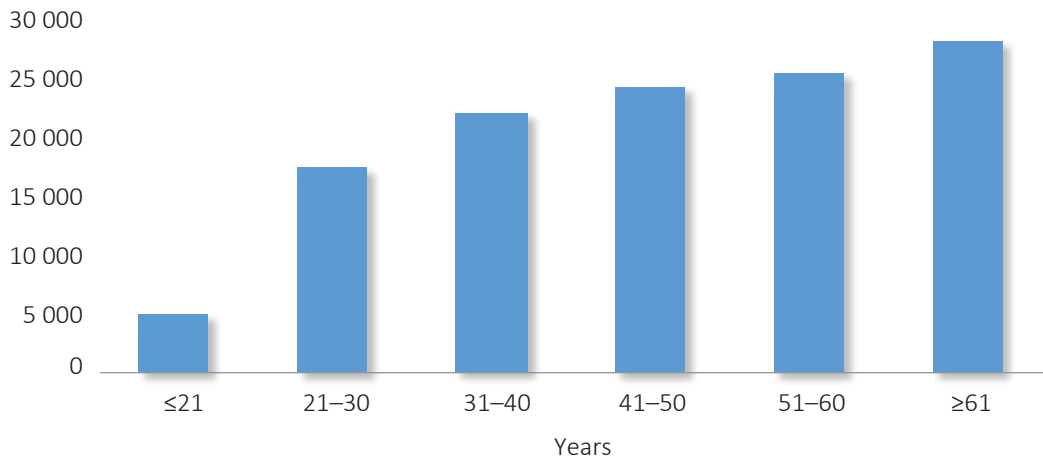
### Numbers of service users and institutions

Only a few countries provided comprehensive information on the numbers of service users and institutions, some reporting that the data were unavailable, and notes were made about the quality of the data. Therefore, an overview is provided, which should be considered only indicative. Analyses were not made by country group.

A total of 14 757<sup>17</sup> facilities were reported by 28 countries, and 27 countries reported a total of 408 352 service users (including some with dementia); however, notes on data quality were made by five and six countries for each figure, respectively. Twelve countries were unable to provide data on the gender of service users, and five countries reported limited data quality; 86 895 male and 74 484 female service users were reported, for a total of 161 739 users.

The age distribution of 121 295 service users in 13 countries was available, with notes on quality and availability by 6 of the countries. People aged ≥ 61 years were the most numerous (Fig. 4).

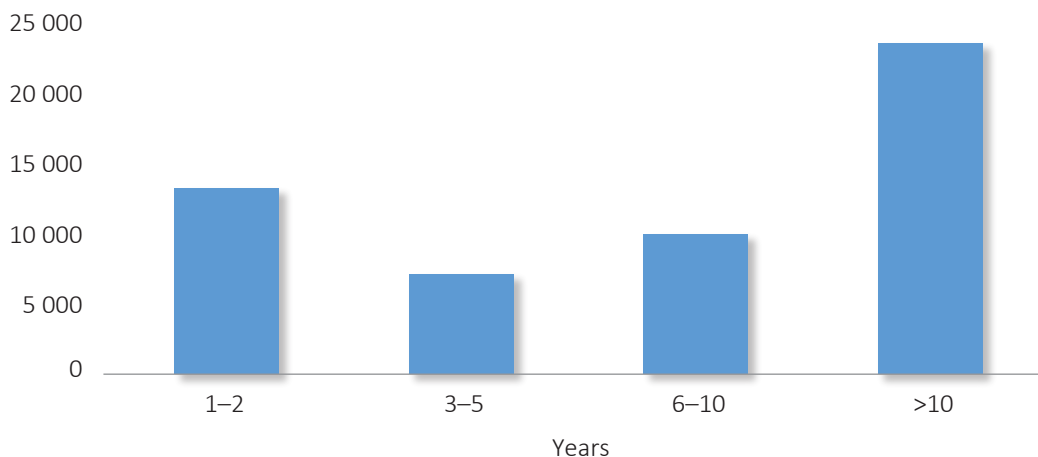
**Fig. 4. Age distribution of service users**



13 responses.

The length of stay of 53 510 service users was reported by 10 countries, with notes made on quality and availability by six of them. Most users had stayed for > 10 years (Fig. 5).

**Fig. 5. Length of stay of service users**



10 responses.

Diagnoses were provided for 88 538 service users, with four notes on data quality and availability, providing estimates of the distribution of psychiatric disorders (34 483; 15 countries), intellectual disability (35 493; 14 countries) or both (18 562; 12 countries). A physical co-morbid condition was recorded for 12 473 service users in 12 countries, and dementia was recorded for 8194 service users in 13 countries. In each case, the countries provided a figure for all service users (with notes on quality

<sup>17</sup> 12 745 facilities were reported by Germany alone.

and availability), allowing calculation of a breakdown of service users. The most commonly reported condition was intellectual disability (40%), and the least common was dementia (9%) (Table 3).

**Table 3. Reported diagnoses and co-morbid conditions of service users**

| Diagnosis               | No. of service users | Diagnosis or comorbid condition recorded | Estimated prevalence (%) | No. of countries |
|-------------------------|----------------------|--|--------------------------|------------------|
| Psychiatric disorder    | 92 400               | 34 483                                   | 37                       | 15               |
| Intellectual disability | 87 708               | 35 493                                   | 40                       | 14               |
| Both                    | 79 899               | 18 562                                   | 23                       | 12               |
| Physical disability     | 79 899               | 12 473                                   | 16                       | 12               |
| Dementia                | 89 566               | 8 194                                    | 9                        | 13               |

More countries were able to return figures on staffing levels, with 108 108 staff recorded (33% nonclinical); however, the number of countries that returned figures varied by staff type, and there were four notes on data quality and availability (Table 4).

**Table 4. Reported staffing levels**

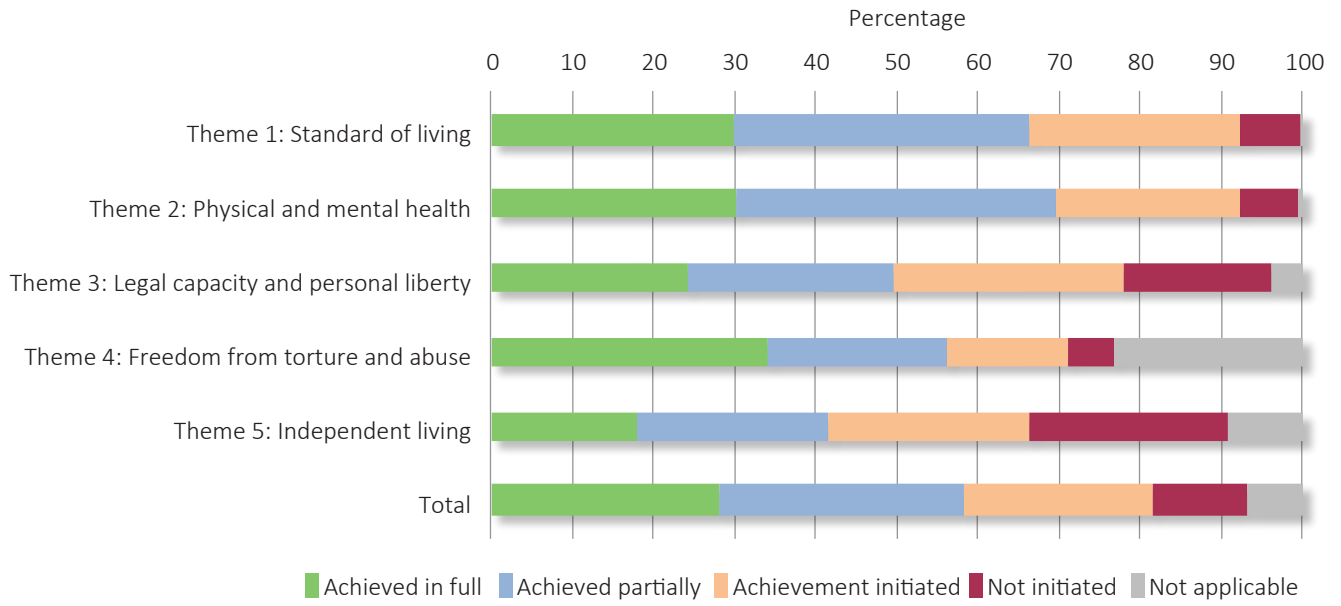
|                  | Psychiatrists | Other doctors | Nurses | Social workers | Other clinical staff | Nonclinical staff |
|------------------|---------------|---------------|--------|----------------|----------------------|-------------------|
| No. of staff     | 1 509         | 1 046         | 20 369 | 2 556          | 46 809               | 35 819            |
| No. of countries | 20            | 20            | 22     | 19             | 20                   | 22                |

## Phase 2

Assessment visits were made in 98 facilities or departments within a facility, with a median of three (range, 1–12) assessments per country. Quantitative summaries of the assessments of standards are given below, followed by qualitative results from the comments and discussions. The 25 standards per assessment provide a total of 2450 unique scoring opportunities to rate a standard at a particular facility or department (median per country, 75; range, 25–300).

Of the 2450 unique scoring opportunities, 686 (28%) were “achieved in full”, 745 (30%) were “achieved partially”, 570 (23%) were “achievement initiated”, 280 (11%) were “not initiated”, and 169 (7%) were considered “not applicable” (Annex 4). Theme 1 (seven standards) had the most scoring opportunities (686), while theme 4 (five standards) had the highest percentage of scoring opportunities that were rated as “achieved in full” (34% 167/490) and the highest percentage of “not applicable” (23%; 113/490; Figure 6). The assessment teams noted that the categories “achieved partially” and “achievement initiated” may be considered a continuum and are difficult to separate.

**Fig. 6. Scores for standards by theme and in total**





# Theme I.

## The right to an adequate standard of living

(Article 28 of the CRPD)

### Selected illustrative comments from the assessment reports

- The building is dilapidated; many windows are broken; floors are uneven and with holes; doors to toilets are not wide enough for wheelchair users.
- Bedbug infestation must be eliminated.
- Some residents sleep on the floor.
- Men and women have to share sleeping rooms, especially in rooms for people with severe disabilities.
- There is no privacy in bathrooms, no toilet paper, no towels, no toothpaste, and no sanitary products for women.
- Service users are not included in social activities and are totally isolated and excluded from community life and activities.
- The facility does not have a designated place for private communication, and there is a general problem of privacy in the facility.
- Residents live under supervision and control.
- Men and women have separate sleeping rooms; couples may share a room.
- Bathing and toilet facilities are adequate, modern and adapted to service users' needs. Privacy is guaranteed.
- Sleeping quarters are comfortable and clean. Service users have wardrobes and personal cabinets.
- Food and safe drinking-water are available in sufficient quantities, are of adequate quality and meet the national standards and health requirements.
- There are pleasant, spacious living rooms, dining rooms, communal rooms for socializing, a gym, a garden and a terrace.
- Residents can wear their own clothing.
- The institution has open gates and visitors can come in without restriction. Residents are free to leave the grounds of the facility.

**Theme 1. The right to an adequate standard of living (Article 28 of the CRPD)**

Standard 1.1. The building is in good physical condition.

Standard 1.2. The sleeping conditions of service users are comfortable and allow sufficient privacy.

Standard 1.3. The facility meets hygiene and sanitary requirements.

Standard 1.4. Service users are given food, safe drinking-water and clothing that meet their needs and preferences.

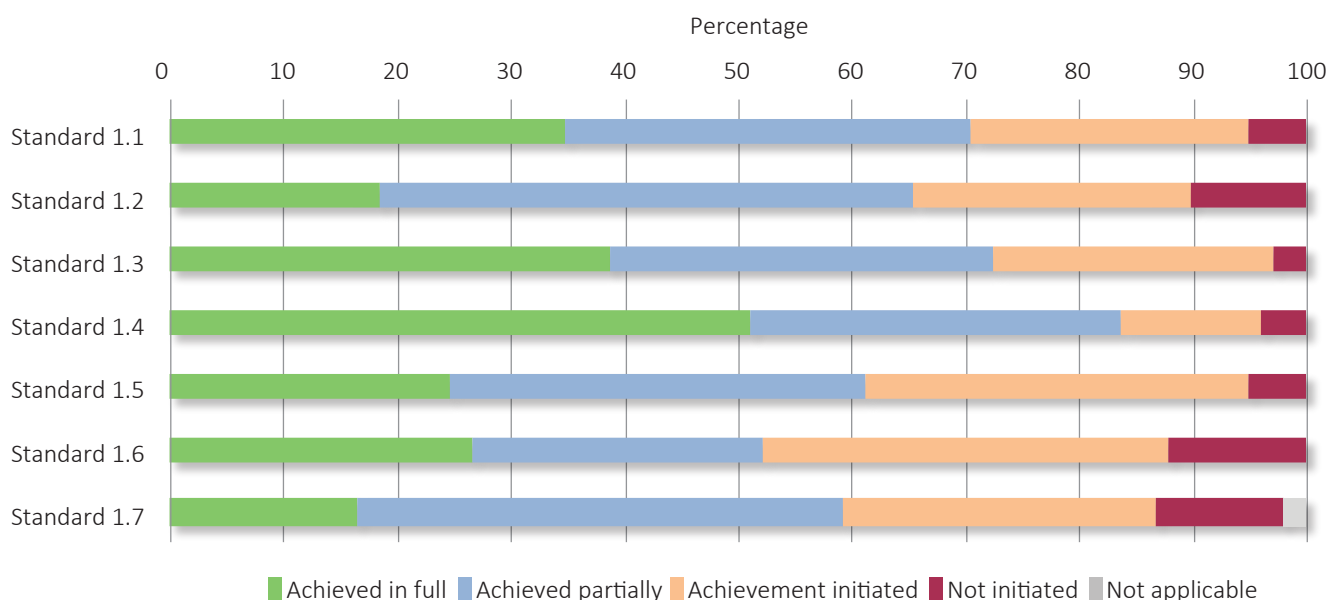
Standard 1.5. Service users can communicate freely, and their right to privacy is respected.

Standard 1.6. The facility provides a welcoming, comfortable, stimulating environment conducive to active participation and interaction.

Standard 1.7. Service users enjoy a fulfilling social and personal life and remain engaged in community life and activities.

Within theme 1, standard 1.4 was the most commonly assessed as “achieved in full” (51%; 50/98) and standard 1.7 the least commonly (16%, 16/98); in two facilities, it was scored as “not applicable” (Fig. 7); 7% (50/686) of scoring opportunities were assessed as “not initiated”, 33 of which were associated with standards 1.2, 1.6 and 1.7 combined.

**Fig. 7. Theme 1. Scoring opportunities for each standard rated per category type**



**Environment**

Environments and building quality varied widely among and within countries. While local building quality standards may have influenced the ratings of assessment team members, the areas of improvement noted were consistent. Some buildings were described as “purpose built”, with good-quality furnishings, sufficient communal space, therapy rooms and accessibility for wheelchairs and less mobile service users. Other buildings were old, overcrowded and in need of renovation; many had poor access to bathrooms and lacked privacy, communal space, activities, natural lighting, heating and ventilation.

Many teams reported that fire safety procedures and staff training in fire safety should be improved. Poor access to buildings jeopardized timely evacuation of service users in case of fire. Other suggested areas for improvements to buildings included removing mould and damp areas, eliminating bed bug infestation, providing a place to store personal belongings safely (e.g. locked night stands), changing overcrowded sleeping areas to provide sufficient space per person and providing clean mattresses and bedding.

**Personal hygiene**

Most assessment teams reported that service users appeared presentable or “clean and well-groomed”. Nevertheless, bathing and toileting were described as difficult for some service users, as not all those with limited mobility received the help they required from staff, and the bathing facilities were not all adapted. Service users had to request shampoo and soap from staff, and not all facilities had sufficient toiletries and personal hygiene products available.

Most facilities required service users to bathe or shower at a set time. As hot water was not continuously available in all institutions, most service users did not bathe or shower every day. At a minimum, service users had access to two baths per week.

The most pressing areas for improvement with regard to personal hygiene were privacy and cleanliness. Most facilities did not have doors on toilet stalls, and showers often did not have curtains or frosted glass panes. Mould in bathing and toilet facilities was mentioned by multiple assessment teams, which should be removed during building maintenance and with ventilation.

### **Communications**

Few facilities provided unrestricted access to telephone, e-mail and postal services, and service users could not always communicate with people outside the facilities. Furthermore, only a few institutions respected service users' right to privacy in communications. Most facilities restricted or sought to reduce incoming and outgoing communications.

Staff cited laws to protect service users and their conditions as reasons for limiting their communication with people outside the facilities. The extent to which communication by service users caused difficulties or additional work for staff could not be determined from most reports. In one case, staff reported that service users made "untrue" descriptions of their situation to family members, so that staff had to spend additional time convincing the family that their relative was being well looked after.

The communications of service users were limited by:

- allowing communications only on certain days of the week or times of day;
- allowing only incoming calls and prohibiting outgoing calls;
- not providing access to the necessary equipment or technology, e.g. telephones, mobile phones, computers or the Internet;
- restricting who could be called, e.g. only family; and
- requiring staff permission before making a telephone call (the basis for a staff decision or approval of calls was not described).

### **Interactions**

Assessment teams described service users' interactions with other service users, staff, family, other visitors and the local community. In some facilities, service users were helped to maintain positive relationships and interactions with visitors and the community, for example by access to a dedicated space for visitors that allowed for privacy. Some service users were accompanied to local community events or to activities such as shopping. Some facilities held events that were open to the community and encouraged participation and engagement.

In other facilities, staff behaviour and knowledge and the environment restricted meaningful interactions. The factors that limited interactions between service users and their relatives, staff or other service users included:

- lack of privacy for visitors;
- limited visiting hours;
- a daily regime that allowed little free time for interactions;
- prohibition of interactions between service users of the opposite sex and a perception that some service users would report such interactions;
- lack of resources, including staff time and funding for transport, preventing participation in community activities;
- lack of staff skill in language or sign language or lack of an interpreter; and
- lack of emotional warmth or support from staff.

### **Food and drink**

The food was described as "sufficient", "culturally appropriate" and of sufficient quantity in nearly all facilities. However, service users did not always have a choice of meals and did not always consider that their dietary requirements were taken into account. Sufficient drinking-water was available in most facilities, but there were not always enough glasses, and service users had to share them. With a few exceptions, the eating areas were described as clean and culturally appropriate. In some facilities, service users could cook and prepare drinks for themselves.

### **Clothing**

Some service users had their own clothing, but most was provided by local charities or humanitarian aid organizations. The clothes were generally described as of good quality, but they were not always seasonally appropriate and often did not fit the service users well.

Laundry facilities were provided, and some service users were responsible for washing their own clothes. Service users with severe disabilities were helped by staff to choose and to wash their clothing.

# Theme 2.

## The right to enjoyment of the highest attainable standard of physical and mental health

(Article 25 of the CRPD)

### Selected illustrative comments from the assessment reports

- Residents are poorly informed about their treatment and are not in a position to question it.
- Occasionally, there is a shortage of essential psychotropic medication in the facility.
- The number of mental health professionals is insufficient to meet the varied needs of residents.
- In some cases, the medical files of residents have not been updated for years.
- Almost all users in this institution have missing teeth.
- Residents face discrimination when accessing services at local hospitals.
- Staff have very limited knowledge about the CRPD and no training in human rights issues.
- In 2017, the facility began replacing the general treatment plan with more specific plans tailored to the needs of each service user.
- Service users can consult a psychiatrist or other mental health staff when they wish.
- All essential and newer psychotropic medication is available and prescribed by licensed staff.
- Individual recovery plans are used and reviewed regularly with the service users.
- There is regular screening (tuberculosis, dental health and gynaecology) and regular general health check-ups.

**Theme 2. The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the CRPD)**

Standard 2.1: Facilities are available to everyone who requires treatment and support.

Standard 2.2: The facility has skilled staff and provides good-quality mental health services.

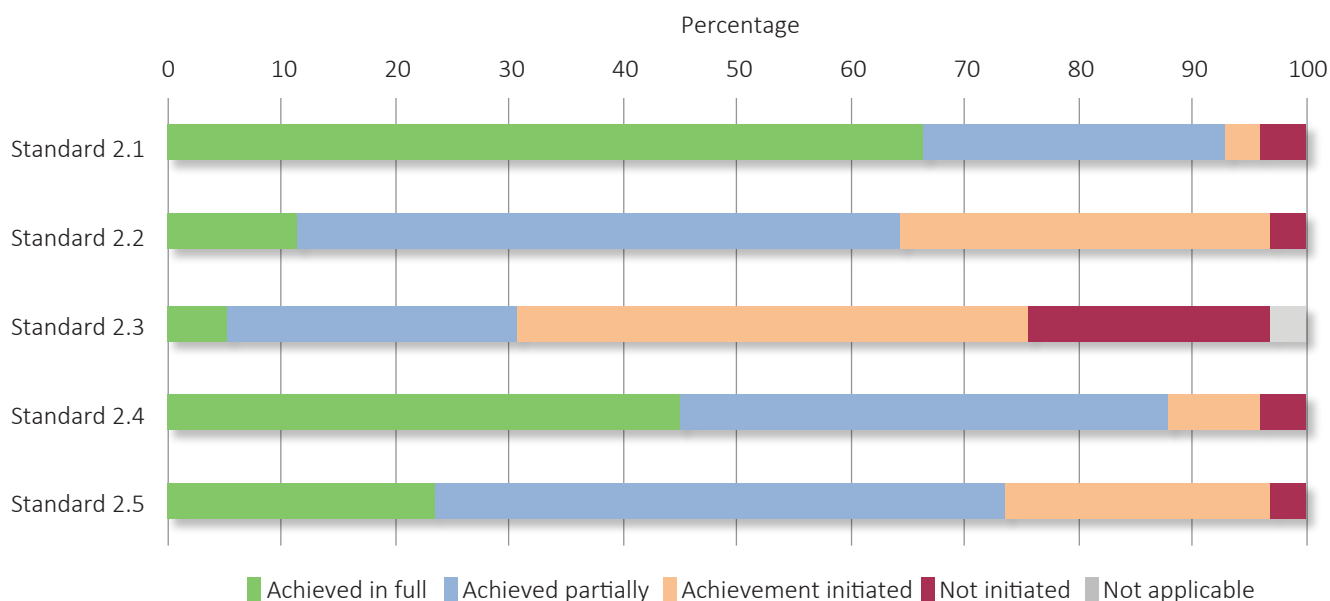
Standard 2.3: Treatment, psychosocial rehabilitation and links to support networks and other services are elements of a service user-driven recovery plan and contribute to a service user’s ability to live independently in the community.

Standard 2.4: Psychotropic medication is available, affordable and used appropriately.

Standard 2.5: Adequate services are available for general and reproductive health.

Standard 2.1 was most commonly assessed as “achieved in full” (66%, 65/98) and standard 2.3 the least commonly (5%, 5/98); in three facilities, it was scored as “not applicable” (Fig. 8); 7% (35/490) of scoring opportunities were assessed as “not initiated”, with 21 scores for standard 2.3 alone.

**Fig. 8. Theme 2. Scoring opportunities for each standard rated per category type**



**Physical and mental health**

Physical and mental health care services were generally provided in the facilities. Access to a specialist in the community was available if required, and specialists visited the facilities if several service users required their services. With a few exceptions, the health of service users was described by the assessment teams as good or similar to that of the general population. All service users had physical examinations and received vaccinations on entering a facility. Some facilities offered additional examinations and preventive screening to service users regularly or according to national policy. Some teams reported that facilities provided education to reduce smoking and improve the health literacy of service users.

Mental health service provision generally consisted of prescribing and supplying psychotropic medicines, which were reported to be “readily available”. Complementary treatment, such as cognitive behavioural therapy, was not available to most patients, and staff reported personnel shortages and limited access to a psychiatrist as reasons. Service users reported that the mental health care they received was not designed for rehabilitation.

The teams reported that staff required training in the provision of mental health services and therapy, especially in facilities that had access to a psychiatrist on only a few days a month.

**Sexual and reproductive health**

In most facilities, the sexual activity of service users was discouraged and sometimes not allowed. Service users were often actively discouraged from interacting with members of the opposite sex, and most facilities did not offer regular sexual health education or information. Staff appeared to lack the skills and training necessary to engage with issues of reproductive health, beyond contraception. Some staff stated that the service users did not require contraception “...because they are not sexually active”. At other facilities, instances of verbal and physical aggression were reported when service users were “...unable to communicate and satisfy their sexual needs”. Some facilities handled service users’ sexuality discreetly and respectfully, and some had private

spaces available for service users, access to a gynaecologist, regular screening and contraceptives. Overall, however, facilities provide inadequate reproductive health services.

### **Medications**

Psychotropic medications and benzodiazepines were found to be generally available to service users. Dosages were reviewed and adjusted regularly to minimize side-effects. A few assessment team members noted that the dosages of medication "...appeared to exceed the clinical needs" of service users. Other teams described occasional interruptions to the supply of medications and use of more cost-efficient medications according to health insurance policies.

Service users often did not understand the purpose of their medications and were not aware of their treatment plans. When there were treatment plans, the teams noted that service users lacked information about their medications and potential side-effects.

### **Rehabilitation**

Most facilities did not have rehabilitation programmes, or, if they were available, only a subset of service users could participate because of staff shortages. Certain rehabilitation activities, such as occupational therapy, art and music therapy, were available at some facilities but were provided only for groups, and service users reported that they were not tailored to their individual needs.

Nearly all facilities produced documents called "rehabilitation plans" for service users; however, they covered various levels of detail, and some were completely blank. The plans were not designed with the service users and therefore covered primarily what was considered to be important by staff. The plans were not updated regularly or implemented at most facilities.

Service users reported that staff focused mainly on their basic needs and made little effort to provide rehabilitation or to improve their lives. Staff justified their focus on the safety and care of service users by citing lack of community resources, such as grants, supported housing, employment agencies, day-care centres and assisted residential care. In some cases, staff sought to reconnect service users with their families or friends with a view to encouraging them to live with their relatives in the future.

### **Human rights**

The awareness and knowledge of staff about the universal human rights outlined in the CRPD varied. Many facility assessments showed that staff had no understanding whatsoever about human rights and could therefore not inform service users. Some facilities had trained staff in respecting human rights and had provided written material to service users about their rights. Easy-to-read versions, including drawings, were available; however, the written material was not always in the service users' native language. The teams noted that additional staff training on the rights outlined in the CRPD was required, perhaps combined with further training on deinstitutionalization.

### **Equality and diversity**

No discrimination against individuals was observed on the basis of race, ethnicity or religion within the facilities; however, service users reported some discrimination when they sought medical treatment outside the facilities, stating that health care providers did not treat them kindly because of their mental and psychosocial disabilities. This was not the case in all communities. For example, some assessment teams reported that the availability of health insurance for all service users ensured that they were treated equally.

In some countries, service users were admitted to certain facilities according to their financial means. Other facilities reported long waiting lists and geographical selection criteria that affected service users' admission. Conversely, some facilities reported that they accepted only service users who did not have the financial means or family support to be cared for elsewhere. Assessment team members noted that service users with dementia faced some discrimination due to their condition, such as being kept in locked wards, and did not have the same privileges as other service users.

# Theme 3.

## The right to exercise legal capacity and the right to personal liberty and the security of person

(Article 12 and 14 of the CRPD)

### Selected illustrative comments from the assessment reports

- Unclear records and procedures concerning involuntary admission.
- Lack of evidence of the “informed” part of consent.
- Most service users are admitted on the basis of a court decision.
- Service users are given no information about their rights upon admission.
- No evidence that service users’ preferences are the priority; the availability of services and professional decisions are the deciding factors.
- Clear information about the rights of service users is provided in written form.
- Contact details of legal representatives are posted in all areas of the institution.
- New legislation contains provisions on advance directives and agreements for provision of support as an alternative to restriction of legal capacity.
- The institution has a zero-tolerance policy for disrespectful communication.

**Theme 3. The right to exercise legal capacity and the right to personal liberty and the security of person (Articles 12 and 14 of the CRPD)**

Standard 3.1: Service users' preferences for the place and form of treatment are always a priority.

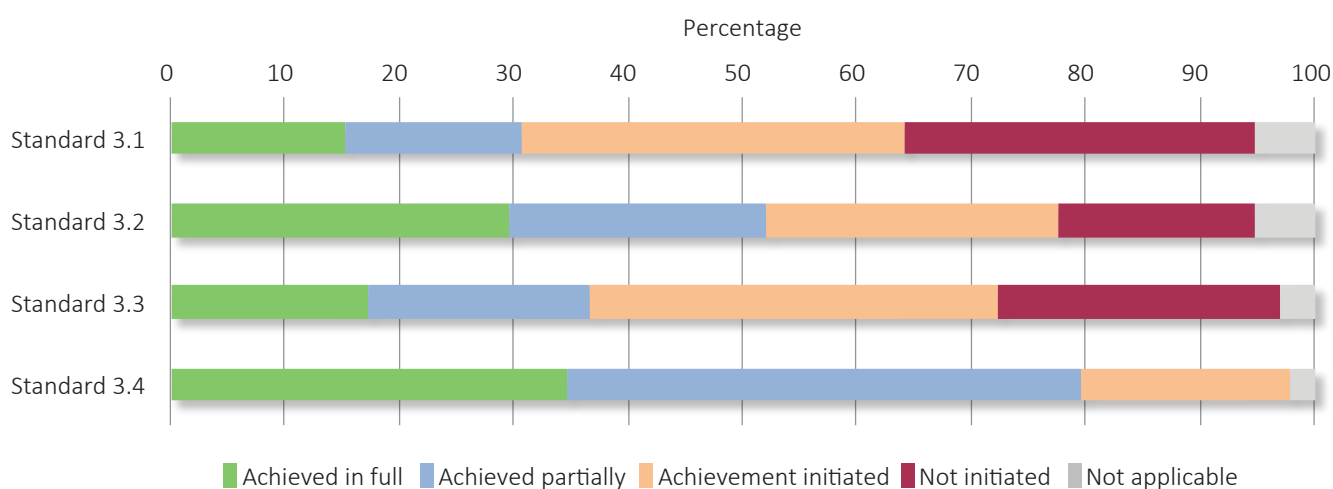
Standard 3.2: Procedures and safeguards are in place to prevent detention and treatment without free and informed consent.

Standard 3.3: Service users can exercise their legal capacity and are given the support they may require to exercise their legal capacity.

Standard 3.4: Service users have the right to confidentiality and access to their personal health information.

Within theme 3, standard 3.4 was the most commonly assessed as “achieved in full” (35%, 34/98) and standard 3.1 the least commonly (15%, 15/98); three facilities scored this standard as “not applicable” (Fig. 9); 18% (71/392) of scoring opportunities were assessed as “not initiated”, with 30 of these scores for standard 3.1 alone. In addition, 4% (15/392) of scoring opportunities were scored “not applicable”, with 10 for standards 3.1 and 3.2 combined. The reasons given for assigning a “not applicable” score were mainly prevailing national legislative frameworks on deprivation of legal capacity.

**Fig. 9. Theme 3. Scoring opportunities for each standard rated per category type**



**Legal capacity and shared decision-making**

Few service users were allowed to exercise their legal capacity, as they were considered or declared to lack capacity, and their families, friends or guardians made decisions for them. Agreement for admission to one of the facilities was therefore made by someone else on behalf of the service user, and this was stated to constitute “voluntary” admission.

Some facilities had no documentation of the legal status or capacity of the service users, and this information was missing from the service users' records or personal files.

At some facilities, service users did not have access to an advocate, while, at others, service users had access to independent legal representatives. In general, service users did not receive sufficient information from staff on how to exercise their rights and to nominate a support person to communicate their decisions. Service users lacked information about their treatment and recovery options. Assessment teams described staff attitudes to organizing a service user's life as “We know better”.

One facility facilitated the exercise of service users' legal capacity and their right to liberty and security of person. Specifically, staff were trained in managing situations and documenting their actions and treatments, and a “process map” was provided. The assessment team could not determine, however, whether the system had been fully implemented in practice.

A few facilities reported that decisions were made with some service users, primarily those who had capacity and could voice their opinions. In most other facilities, however, there was no shared decision-making.

One assessment team considered that the issue of legal capacity was “not applicable” to their service users as “...their well-being was in the hands of their parents or custodians. Due to the severity of their disability, they could not be involved in shared decision-making.”



In some instances, staff served as guardians for service users who did not have legal capacity. The assessment teams considered this to be a conflict of interest, which should be addressed.

### **Informed consent**

Nearly all facilities collected informed consent from the service users, their relatives or their assigned guardian before admission. The CRPD states that only the individual concerned can provide informed consent. The consent provided on admission includes the service user's agreement to stay and to receive treatment. Therefore, if practised, facilities could report that they had gained consent to subject service users to isolation and restraint. In some cases, service users could not exercise their right to refuse treatment later on. Service users were often not given clear, comprehensive information about their rights. While most facilities collected informed consent, staff at one institution stated that "...informed consent is not applicable for this institution". Other staff members expressed concern that "...some persuasion is probably in place in some cases" and "...some form of coercion might be involved".

### **Access to medical records**

Most facilities allowed service users to access their medical records or files; however, few service users were aware of their right to do so or how to request access. At most facilities, service users could not annotate or add to their records. Records were generally stored in a secure location, and staff sought to ensure their confidentiality.

### **Personal liberty**

The personal liberty of service users was severely restricted at most facilities, and they could not move within or beyond the facilities as they desired. Service users who were admitted voluntarily could not leave the facilities if they wished to do so.

Movement inside and outside the facilities was restricted in most cases. Only a few facilities allowed service users to move freely inside the facilities and their outdoor spaces. In some countries, staff cited relevant mental health acts or service users' safety as reason for restricting their movements. Some staff reported that individual assessments were conducted, and a decision to prohibit free movement was made case by case. The reasoning or criteria that affected the judgement to limit service users' mobility were not described.

Some facilities primarily inhibited movement within the buildings. This was achieved with physical barriers, such as locked wards, rooms that were locked during the day and locked front doors. Elsewhere, staff allowed movement only within the facility, with staff supervision, which was further limited by low staff numbers. In some facilities, service users could move inside the facilities only at certain times of the day.

Movement in facility-owned outside spaces and public spaces beyond the facility grounds was limited by staff. Some facilities did not have sufficient outdoor space or used wire fencing to keep service users from moving beyond the grounds. Outdoor access was possible mainly for those who could move freely and was restricted for users with limited mobility. Not all buildings were accessible by wheelchair. Access to the community was often allowed only with the support or supervision of staff, and staff were generally too busy with other duties to supervise movement outdoors. These restrictions meant that not all service users had daily access to fresh air or time outside.

Many facilities used restraint and isolation to manage the behaviour of service users or to ensure their compliance. At most facilities, staff documented use of these procedures meticulously; they explained that such measures were used only in "...exceptional circumstances" and that service users had been informed about how to file a complaint. One justification given for restricting the personal liberty of service users was that "...their right to personal liberty was provided in line with the service user's condition". Institutional culture and regimes were described as influencing restriction of the personal liberty of service users.

### **Discharge**

Service users were rarely discharged from facilities, mainly because of the absence of familial and social support. A few service users were discharged to live in the community at their expressed wish; however, the majority remained in the facilities, and no clear procedures or personalized plans for discharge were available at these facilities.

Assessment team members reported that few facilities have begun deinstitutionalization; however, no details were provided on progress towards discharge of service users.

When possible, staff sought to reconnect service users with their families or friends, so that users could be discharged into their care; however, such instances were rarely reported. Staff explained that it was often the relatives who had sent service users to the facilities in the first place.

Some staff helped service users to obtain or replace documents, such as identity papers or passports, which would ultimately enable them to live in another setting.

While some staff supported service users in the initial steps towards discharge, others explained that the users in their facility were incapable of living elsewhere or participating in community activities. Staff cited the lack of infrastructure in the community, such as supported housing and day-care centres, as a reason for not discharging their service users. Other staff said that national or regional mental health policies discouraged discharge.

# Theme 4.

## Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse

(Article 15 and 16 of the CRPD)

### Selected illustrative comments from the assessment reports

- Service users are often subjected to physical restraint and are medicated while restrained.
- There is no procedure to allow service users in the facility to appeal confidentially or to file a complaint to an outside, independent legal body.
- Certain drugs are frequently given on an as needed basis.
- Staff do not take residents' complaints seriously.
- The staff here have never heard of the CRPD.
- Disciplinary and legal action is taken against any person found to be abusing or neglecting service users. Such cases are well documented in this institution.
- Staff are trained in alternative interventions to deal with crises. They claim that, in most cases, a conversation alone helps to calm a person down.
- Alternatives to coercive practices (de-escalation plans) are discussed and prepared jointly by the team and the service user.

**Theme 4. Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 and 16 of the CRPD)**

Standard 4.1: Service users have the right to be free from verbal, mental, physical or sexual abuse and physical or emotional neglect.

Standard 4.2: Alternative methods are used in place of seclusion and restraint as means of de-escalating potential crises.

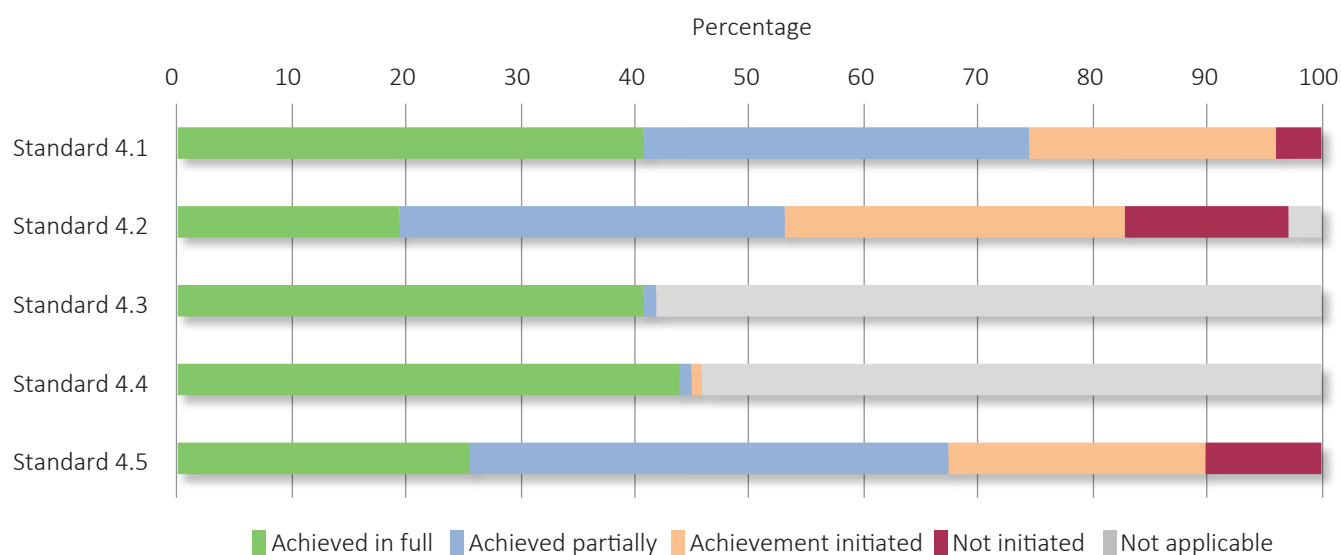
Standard 4.3: Electroconvulsive therapy, psychosurgery and other medical procedures that may have permanent or irreversible effects, whether performed at the facility or referred to another facility, must not be abused and can be administered only with informed consent.

Standard 4.4: No service user is subjected to medical or scientific experimentation without his or her informed consent.

Standard 4.5: Safeguards are in place to prevent torture or cruel, inhuman or degrading treatment or other forms of ill-treatment and abuse.

Within theme 4, standard 4.4 was the most commonly assessed as “achieved in full” (44%, 43/98) and standard 4.2 the least commonly (19%, 19/98); three facilities scored standard 4.2 as “not applicable” (Fig. 10); 15% (28/490) of scoring opportunities were assessed as “not initiated”, with 14 scores for standard 4.2 alone. In addition, 23% (113/490) of scoring opportunities were scored as “not applicable”, with 110 for standards 4.3 and 4.4 combined. A score of “not applicable” was given because electroconvulsive therapy, psychosurgery and medical experimentation were not practised in the assessed institutions, especially those under the sole responsibility of the social care sector.

**Fig. 10. Theme 4. Scoring opportunities for each standard rated per category type**



**Absence of abuse**

Abuse and maltreatment of service users varied considerably among the institutions. Assessment teams at some institutions described no occurrences of abuse, restraint, isolation or neglect and zero tolerance of abuse by management teams. In some instances, staff who had been found to be abusive towards service users were dismissed. In general, assessment team members found that staff treated service users well and strived to be friendly, humane and supportive.

Instances of abuse from staff and from other service users were, however, described at some facilities. These included shaming of service users for engaging in sexual activities and using restraints, isolation and “over-medication” to manage behaviour. At one group of facilities, service users felt pressured by their psychiatrist to take medications. Sexual abuse of many female service users was described in another group of facilities, which had not been formally investigated and therefore not prosecuted. Service users who had been sexually abused did not have access to support to help them cope with their experience.

Other forms of maltreatment included neglect, creation of hierarchies of service users and different treatment that depended on their place in the hierarchy. Some staff viewed or treated service users “...like children”. While this is not a form of maltreatment or abuse in itself, such a view or lack of respect may make it easier for staff to behave towards service users in an abusive manner when they are distressed or when the staff are under pressure.

Some facilities had guidelines to reduce or prevent abuse and had provided staff training in the past. Legal safeguards were described in some countries. Training included teaching de-escalation techniques, such as soothing communication and use of a Snoezelen® room (a controlled multisensory environment). Some facilities posted information on the likes, dislikes and triggers of service users on the doors to their rooms to assist and inform staff.

The assessment teams in several countries suggested that additional training be provided in de-escalation techniques and to increase respect or compassionate care for service users. One assessment team noted that “...devotion and affection” towards service users should be increased.

### **Complaints mechanism**

Many facilities had a formal mechanism in place to allow service users to file a complaint. In others, there was no mechanism such as a box or monthly meetings to discuss complaints, and not all service users were aware of the process or could file a complaint independently. Some facilities offered support from an independent advocate to assist service users in submitting a complaint, although not all facilities offered such support. In addition, service users at a few facilities reported being “...discouraged from filing a complaint” or having “...experienced negative repercussions” after making a complaint. As a result, at some facilities, “complaints were not made in practice”, even though service users were aware of the process.

Not all facilities took complaints seriously. One facility allowed only users with legal capacity to file a complaint; a guardian or family member was required to submit a complaint on behalf of someone without legal capacity. The assessment team did not report how complaints were handled if the staff or the director of a facility was the legal guardian of the service user.

Some facilities encouraged service users to file complaints and provided access to independent advocates. In a few facilities, the service users knew that they could make their complaints directly to the director and had made use of the opportunity. Although some assessment teams reported that staff sought to consider the wishes and opinions of service users in their work, they could not provide evidence or examples. Similarly, staff did not describe how they had responded to or addressed complaints in the past.

One institution gave service users the telephone number of an independent complaints hotline, and mobile phones were distributed to facilitate making complaints. Another group of institutions assessed user satisfaction twice a year.

### **Electroconvulsive therapy, psychosurgery, abortion and sterilization**

Assessment teams at most facilities said that invasive and irreversible procedures, such as psychosurgery, abortion and sterilization, were not used. Legislation was cited as preventing use of these procedures.

In the few facilities in which electroconvulsive therapy and abortion were used, they were reported as being done in a “...very respectful way” and “...only on extremely rare occasions”. Informed consent was obtained before the procedures, but they did not report how informed consent was obtained from service users without legal capacity. One facility was reported to conduct forced abortions of pregnancies that had resulted from sexual abuse.

# Theme 5.

## The right to live independently and be included in the community

(Article 19 of the CRPD)

### Selected illustrative comments from the assessment reports

- This institution is the end station in the existing care pathway.
- Many staff believe that people have to be well enough to live in the community.
- There is a shortage of independent housing options in the community.
- There are no assisted-living programmes, not even for those who own property.
- There are major systemic obstacles to employment of people with mental disabilities.
- Investments for providing housing for more residents in the community are planned.
- Career development is part of recovery plans, and the staff are supportive in this respect.
- The policy of the institutions is to grant paid employment to as many residents as possible.
- Service users participate in community activities, and some work in the community.

**Theme 5. The right to live independently and be included in the community (Article 19 of the CRPD)**

Standard 5.1: Service users are supported in gaining access to a place to live and have the financial resources necessary to live in the community.

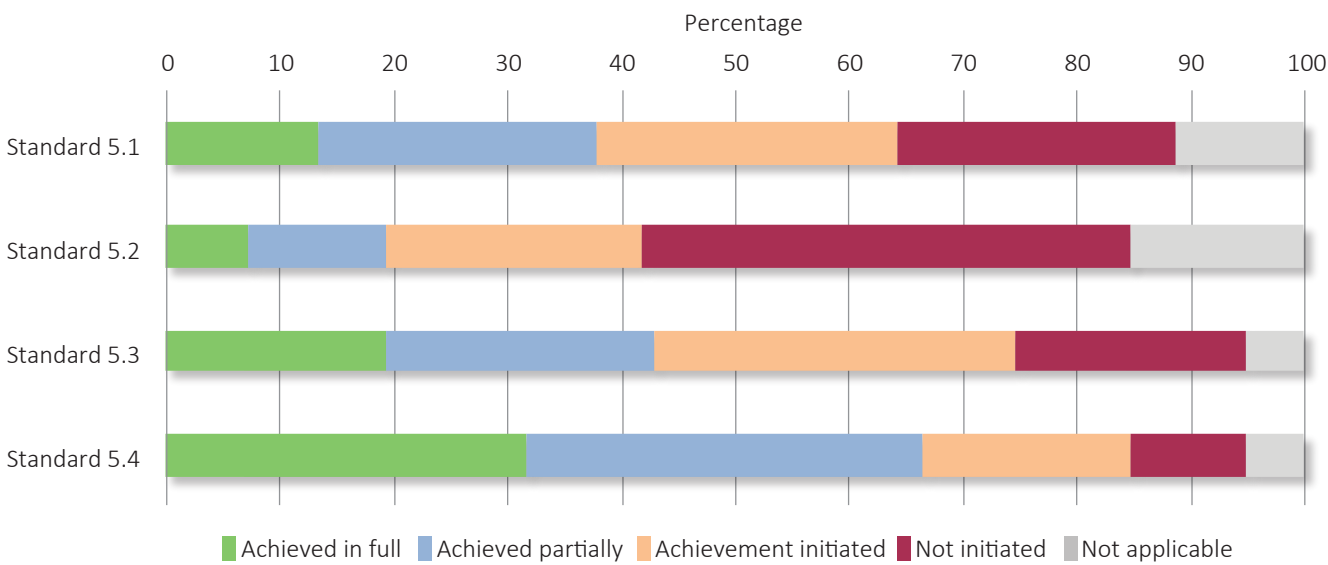
Standard 5.2: Service users can access education and employment opportunities.

Standard 5.3: The right of service users to participate in political and public life and to exercise freedom of association is supported.

Standard 5.4: Service users are supported in taking part in social, cultural, religious and leisure activities.

Within theme 5, standard 5.4 was most commonly assessed as “achieved in full” (32%, 31/98) and standard 5.2 the least commonly (7%, 7/98); three facilities scored this standard as “not applicable” (Fig. 11); 24% (96/392) of scoring opportunities were assessed as “not initiated”, and 66 of these scores were for standards 5.1 and 5.2. In addition, 9% (36/392) of scoring opportunities were scored as “not applicable”, with 26 for standards 5.1 and 5.2 combined. The commonest reason given for assigning a “not applicable” score was that the facilities were end-points in existing care pathways.

**Fig. 11. Theme 5. Scoring opportunities for each standard rated per category type**



**Access to supported housing**

Service users at very few facilities had access to supported housing to which those judged as less dependent could be discharged from the facilities in which they lived. When supported housing was available, it was provided primarily by the facilities themselves, which either built or leased new buildings in which they could provide care to service users in a community setting. Differences in the care provided in larger and smaller facilities were not described.

In most countries or regions, there was no infrastructure for supported or assisted community housing, and none was planned in the near future. Plans for additional supported housing were generally drawn up by the facilities. Concern was raised at some facilities that no financial support would be provided to residents who were discharged, which might encourage facilities to create their own, smaller models of supported community housing.

In some facilities, the staff culture or attitude was described as a barrier towards preparing service users for discharge. For example, some staff considered that “...by design, their facilities in essence provided supported housing for service users” or that service users “...lived as close as possible to a normal environment”. Some staff thought that service users could not be integrated into assisted community housing or that it was not applicable because of the severity of the service users’ disabilities. Other staff considered that users could be discharged only if family members were willing to take them in and support them, which was rarely the case, because of the “...responsibility and burden of care”. At one group of facilities, staff were against “...reorganization of institutions” and “...retraining to provide care in the community”.

Many facilities had no clear policies or plans for the discharge of service users. Individualized recovery plans were not available for all service users. In some instances, staff lacked information about community-supported housing or how to obtain the financial resources to enable service users to live in the community. Social workers were described as having an important role

in providing information and support to service users when planning for discharge. Whether social workers were available in facilities remained unclear.

### **Access to employment and education**

At many facilities, service users were given no education or employment opportunities, for a variety of reasons, including policy constraints, inability of employers to adapt their standards or practices to accommodate service users and consideration of service users as “...unable to be employed or educated” as a result of living in a facility. Employment and education programmes were available and included in recovery plans at very few facilities. Some reported having had a programme but that it had had to be stopped shortly after its inception because of lack of funding. Other facilities had employment or education programmes, but they were available to only a few participants because of scarce funding. The programmes that were available provided job skills or vocational training, life skills and social skills.

Some facilities did not provide occupational therapy, reporting that service users were “...not capable of these aspects of living [employment]”. Occupational therapy that included pottery and knitting was provided in many facilities, although the service users could not sell the goods they made because of their status. This was noted as a limitation to the development of self-care skills and autonomy. Other formal education was generally available only to service users who were not yet considered to be adult.

A few service users were described as being engaged in formal or gainful employment, in either the community or the facility. Many were described as being engaged in informal employment such as gardening, farm work, unskilled construction labour, and cleaning in the community. They received meals, cigarettes or a small amount of money, such as 5 €, for a day of work.

Some facilities reported that they engaged service users in tasks such as laundry, cleaning and gardening. The tasks were unpaid, and the amount of time spent was not described. Some team members cautioned that such tasks might constitute exploitation, as the users often worked a full day without payment or for only a very small payment.

### **Voting and participation in the community**

While the right of service users to participate in the community was reported to be respected, in practice, they had limited involvement in activities organized by and within the communities surrounding the facilities. A few facilities encouraged service users to take part in activities and provided transport, but most facilities did not encourage participation in external activities and struggled to provide transport because of limited staff. Transport links were not always available between facilities and communities. In some communities, opportunities were lacking, and staff described stigmatization of service users by community members.

Service users in some facilities were more involved in community activities, including attending church and participating in sporting events and other leisure activities. At some facilities, staff organized day trips or activities for users; however, these often did not involve members of the community. Some staff described an “open door” policy whereby community members were encouraged to visit facilities, and this was seen as an element of community participation.

In some countries, laws bar people without legal capacity from voting. In others, their right to vote has recently been reinstated. At some facilities, staff supported service users in voting, and polling stations were set up to encourage participation. At other facilities, staff supported the idea that service users could vote but did not assist them in pre-election activities or transport to polling stations. Some staff justified the fact that they provided only limited or no support by saying that service users showed “... little interest in political activities” or “...did not have the capacity to vote”.

## **Summary score (index)**

To determine potential predictors of better quality standards, univariate analysis was conducted of the results of phase 1 (characteristics of each country’s current situation) and phase 2 (ratings of quality standards). The dependent variable or “index” in this analysis is the proportion of scoring opportunities categorized as “achieved in full”. Six CIS, 10 European Union (1 pre-2004) and nine SEE respondents provided phase 1 assessments, which were aligned to gross domestic product, the existence of a funding plan and other characteristics (Table 5). The aggregated scoring index (the number of scoring opportunities rated as “achieved in full”) was 0.280 (on a scale of 0–1; median per country = 0.150; range 0–0.848). Although there was variation in the absolute value at group level, it was not statistically significant (Kruskal-Wallis test,  $X^2 = 0.75$ ,  $df = 2$ ,  $P = 0.687$ ).



**Table 5. Index of scoring opportunities assessed as “achieved in full”, by country group**

| Country group (number of respondents) | Gross domestic product (million US\$) | Population (thousands) | National deinstitutionalization plan (no. stating yes) | Funding in place | Index        | Median | Minimum | Maximum |
|---------------------------------------|---------------------------------------|------------------------|--|------------------|--------------|--------|---------|---------|
| <b>CIS (6)</b>                        | 348 566                               | 84 759                 | 2  | 2                | <b>0.212</b> | 0.149  | 0.000   | 0.560   |
| <b>EU (10)</b>                        | 1 223 510                             | 83 328                 | 10   | 8                | <b>0.377</b> | 0.207  | 0.000   | 0.848   |
| <b>SEE (9)</b>                        | 11 390                                | 2 923                  | 6  | 4                | <b>0.229</b> | 0.150  | 0.000   | 0.469   |
| <b>All (25)</b>                       | 1 936 1901                            | 220 500                | 18   | 14               | <b>0.280</b> | 0.150  | 0.000   | 0.848   |

CIS, Commonwealth of Independent States; EU, European Union; SEE, south-eastern Europe  
Gross domestic product and population from WHO sources, except for one country, for which World Bank data were used.

Univariate testing (alpha 0.05) indicated that none of the predictor variables could justify rejection of the null hypotheses of no difference or no association, with the exception of whether the model for ownership of facilities included the ministry of social affairs: those countries in which there was such ownership attained a higher index ( $F= 5.71$ ,  $df =1$ ,  $P = 0.025$ ). After control for the number of multiple tests, however, the effect was not maintained, and the Holm-Bonferroni method failed to reject the first null hypothesis at the modified threshold of  $0.05/(19-1+1) = 0.0026$ , ruling out all others as not significant. Inclusion of the series mean to fill in missing values had no impact on the significance of any variable as compared with removal of cases for which variables were missing: all remained nonsignificant.

Multivariable testing was not done, because only one candidate variable met that threshold for inclusion in a model. Thus, the regression model is equivalent to the univariate test.

## Discussion and conclusions

This project for institutional assessments in participating countries and Kosovo (in accordance with United Nations Security Council resolution 1244 (1999)) lists the number and type of facilities providing long-term care for people with psychosocial and intellectual disabilities and a synthesis of the quality of care and respect for human rights. The findings represent a starting-point for more data collection and monitoring and for immediate interventions to improve care.

A report published in 2017 on human rights in the European Region indicated that substantial improvements are required,<sup>18</sup> not only in central and eastern Europe. The findings provide an overview of the main areas for improvement in respect for human rights and considerations for deinstitutionalizing common, large, long-term care facilities. Thematic observations from the institutional assessments are outlined below, with the strengths and limitations of the approach and implications for policy and service.

### Main thematic observations

The following observations are based on the results of the qualitative analyses of the institutional assessments.

#### Restriction of communication by service users

Communication was found to be restricted or did not meet the needs of service users, who said that they would like to receive more information from staff about their treatment and their medications and their side-effects. Service users noted that relational aspects of care were lacking at times, especially emotional warmth. Several assessment teams reported that the service users were deeply unhappy about staying in the facilities; they were often bored and did not have enough to do.

Communication and interactions between service users were sometimes discouraged or restricted by staff, especially when they involved members of the opposite sex. Communication with people outside the facilities was severely restricted in some cases,

<sup>18</sup>Turnpenny A, Petri G, Finn A, Beadle-Brown J, Nyman M. Mapping and understanding exclusion in Europe. Brussels: Mental Health Europe; 2017 (<https://mhe-sme.org/mapping-exclusion/>, accessed 2 April 2018).

and service users had no access or privacy for telephone, postal and online communications. A possible link between the desire of service users to leave a facility and the staff's decisions to restrict their communication outside may be explored in future research or during local improvement.

#### **Lack of staff knowledge about consent for admission and treatment**

Consent for admission is given either by service users themselves or by their legal guardians. The consent covers the users' stay in the facilities and any treatment that might be required. Some facilities collected additional informed consent for further treatment. Service users were, however, not always clear about how they could revoke their consent or how to access assistance in revoking consent for treatment or their stay in the facilities. As the ability to revoke consent at any time is a component of free, informed consent, additional staff training may be required to assist staff in informing service users about their entitlement to consent, make decisions and make complaints.

#### **Lack of supported decision-making for service users**

Formal models of supported decision-making were not used to assist service users without legal capacity to express their wishes. Nevertheless, staff at many facilities sought the opinions of service users and tried to respect them in their treatment and care. The results suggest that this approach primarily benefited those service users who could express themselves well, and it is unclear how those who were less able to express their wishes were supported in sharing their opinions. In addition, it is not clear whether lack of staff or of staff time further limited the involvement of the most vulnerable service users in their treatment and care.

#### **Potential exploitation of service users' labour**

In many facilities, most service users were either not employed or were considered to be unemployable. Yet, many of them were in informal working relationships, as cleaners, gardeners or unskilled labourers on construction sites, for which they received a meal, some cigarettes or a small payment for a day of work. This represents potential exploitation of service users who work recurrently but are not paid enough to become independent.

#### **Lack of detail and of individualized treatment and recovery plans**

Most service users had not been given individualized treatment or recovery plans, and those that existed were not regularly updated or used to inform care and rehabilitation. Service users had limited opportunities to contribute to their treatment and recovery plans. This observation is consistent with a staff perception that their facilities represent the end stage of care for most service users, as most could not be discharged because of a lack of community-supported housing. Hence, staff may not recognize the value or opportunities provided by individualized plans, for both service users and their work. Additional staff training would be beneficial.

#### **Access to supported community housing**

While many countries indicated that they had begun deinstitutionalization, the process was severely hindered by limited availability of supported community housing. As a result, in practice, staff did not work towards discharge for most service users. They perceived the facilities as still necessary and as the end of the care pathway for many users.

Staff could recall a few discharges in the past, which had been primarily into the care of relatives. Staff helped service users to reconnect with family members and to obtain missing identity documents when possible to allow them to be discharged into the care of relatives. This was possible only for certain service users, as most had been admitted to the facilities by their relatives, and staff reports indicated that they would be unwilling to provide care again.

Because of the lack of community housing, some facilities provide such accommodation. The care given in smaller facilities with the same ownership would, however, differ from that of larger facilities. Without additional staff training and clear leadership, human rights might be violated.

## **Strengths, limitations and challenges**

The strengths, limitations and challenges associated with the method of countrywide assessments should be considered in future work to improve respect of human rights throughout the WHO European Region. Strengths, limitations and challenges are presented separately for phases 1 and 2 in view of the different approach to data collection.

#### **Phase 1**

The data submitted by the 32 respondents in phase 1 varied in content and quality. National governments throughout the Region hold information about their institutions for adults with psychosocial and intellectual disabilities in various formats, which affected the extent to which the data could be disaggregated to fit the categories in the questionnaire. This, in itself, is a

noteworthy finding of the project: there is a general lack of policies and procedures for standardized data collection both within and between countries.

Specific issues affect the availability of data.

- Some respondents were able to provide data only about institutions owned or managed by the ministry of health. This skews the findings to residents of predominantly clinical institutions and may have underestimated the number of institutions in the Region, the nature of the residents' conditions and the average duration of stay.
- Focal points in countries with federalized governments had little or no access to information about individual institutions and generally responded only to questions on the national context.
- Some respondents had access only to demographic information (e.g. age, length of stay, diagnosis) in predefined categories that could not be disaggregated to fit the categories in the questionnaire.

The responses received to the questionnaire provide insights into the policy and institutional contexts; however, there were varying amounts of missing data, preventing comparisons among countries, and the results did not offer sufficient insight into the quality of care provided.

## Phase 2

Phase 2 of the project involved assessment of facilities with a standardized approach and method, the WHO QualityRights toolkit. The toolkit requires multidisciplinary assessment teams that include mental health professionals, lawyers, defenders of human rights, social workers and people who have lived the experience being assessed. The generalizability of the findings is limited, as there were different assessment teams, and WHO had limited control over the selection of institutions and team members. This may explain why ownership of an institution by a ministry of social affairs was associated with more frequent attainment of "achieved in full". For instance, the facilities visited were probably not a random sample of all facilities, constraining inferential statistical testing, which requires samples to be drawn at random from populations to allow generalization without bias. Similarly, the wide variation in contextual factors (e.g. team composition, facility culture, service and system factors, national frameworks) implies that the assigned ratings are not necessarily equivalent among countries. The findings indicate factors that should be documented and investigated in more detail in multinational follow-up.

In all the participating countries, few interviews were conducted, in part because limited funding was available from WHO to make visits. Furthermore, all the teams found difficulty in recruiting family members or carers to be interviewed, and few were available at the time of visits. Most service users had few family members living nearby.

As the standards in the WHO QualityRights toolkit apply in all circumstances, the percentage of "not applicable" ratings (particularly for themes 3 and 5) indicates that many assessment teams did not fully understand the CRPD. This conclusion is supported by the finding that the reported ratings were sometimes apparently at odds with the qualitative findings. This may be due to differences in understanding of the terminology used in the WHO QualityRights toolkit. Identification of training needs in this regard would help to standardize international assessments and raise awareness in countries of how the CRPD is intended to function within national legislation and policy.

Both the ratings returned by assessment teams and the feedback and reflections encountered during the country training sessions indicate that it was challenging for some teams to be able to apply the perspective and standards of the CRPD and associated toolkit in an objective and impartial manner. Without a strong external point of reference and reflection, teams could find themselves drawn into the internal systemic culture of the institutions and of the wider national expectations and stigmatization of people with mental disabilities, their place in society and their perceived limitations. For example, when rating standards in theme 5, the right to live independently and be included in the community, some assessors were drawn into rating this as not applicable as a result of the institutional perception, and that of the community, that people who are placed there were not employable and were to live their lives solely within the institution. Implementation of the QualityRights toolkit required the external support to enable assessors to "stand back" and think about the universality of human rights against which they were measuring people's lives and opportunities.

*Roger Banks, External Project Advisor*

## Implications for policy and service: from assessment to improvement of quality

The results of this project indicate a number of priorities or steps to be taken to continue progress towards deinstitutionalization and to ensure respect for the human rights of people with psychosocial and intellectual disabilities.

### *Continuous assessments and monitoring of progress*

Continuous assessments are required to collect evidence and document progress towards deinstitutionalization and to ensure that human rights are respected in accordance with the CRPD. The WHO QualityRights toolkit provides a standardized framework for continuous data collection. With consistent observations, the evidence from this project may serve as a baseline for future comparisons. Continuous measurement will demonstrate improvements made since the initial assessment visits. Longitudinal evidence and a record of improvements at local or institutional level may be beneficial for shaping national policies.

### *Staff training*

Facility staff and leadership would benefit from continued training and professional development to ensure the human rights of service users. The project revealed gaps in staff knowledge about the CRPD and its practical application to day-to-day work. New QualityRights capacity-building and guidance materials should guide improvements in mental health and related services.<sup>19</sup>

### *Exchange of knowledge and learning*

A number of practical challenges were documented that affect the quality of life and human rights of service users in facilities. Although most staff genuinely cared about the users and wanted to provide them with high-quality care, they had limited time and funds to maintain or improve building standards. For example, some countries with deinstitutionalization plans have committed funding to improve the infrastructure of community-supported housing, leaving limited funds to improve existing buildings in which service users currently live, such as by removing mould or bed bugs.

Staff and facility leaders would benefit from informal exchanges of information and knowledge with other countries so that teams can learn from each other, share good practices and overcome difficulties.

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<sup>19</sup> WHO QualityRights guidance and training tools. Geneva: World Health Organization; 2018 ([http://who.int/mental\\_health/policy/quality\\_rights/guidance\\_training\\_tools/en/](http://who.int/mental_health/policy/quality_rights/guidance_training_tools/en/), accessed 2 April 2018).

# Annex I. Questionnaire for phase I of the WHO regional survey of institutions for adults with disabilities in European Member States

## Aims of the project

The objective of this WHO project is to identify the number and characteristics of institutions and the long term places they provide for adults with intellectual disabilities and/or long-term mental disorders. This questionnaire is divided into two sections: national context and data on individual institutions.

In a second stage, more detailed institutional assessments will be conducted in a sample of institutions in countries.

## Guidance for completion

The first section of this survey relates to the context of the country as a whole. Key terms for the project are defined below. Additional definitions are provided throughout.

The term “mental disability” is used at times to indicate both intellectual disabilities and long-term mental disorders, including psychiatric disorders. Elsewhere, a distinction is made between these categories. For the purposes of this survey, they are defined in accordance with existing WHO definitions (<http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/mental-health/key-terms-and-definitions-in-mental-health>).

Facilities in which solely people with dementia are cared for are **excluded** from the survey; however, institutions that care for both people with dementia and patients with other conditions **may be** included.

For the purposes of this survey, an “institution” is defined as having the following characteristics:

- a staffed establishment;
- providing care only for adults (see definition below);
- having at least 30 places for long-term care (i.e. provided for > 1 year); institutions that also provide short-term care **may be** included but must have at least 30 long-term places; and
- at least 80% of residents are mentally or intellectually disabled.

Such institutions may be mental hospitals and/or social care homes, in the public and/or private sector, for profit or not for profit.

Specialist institutions for the elderly **should not** be included, but elderly patients being cared for in institutions housing people of mixed ages may be included.

“Adults” are people over the age of 18 and below 65 years (see below). Some countries may have different or flexible lower age limits, and the lower age threshold for adult homes in the country should be applied and specified.

Some institutions care for a mix of age groups. Specialist provision for older people only (over about 65 years), particularly for people with dementia, are **excluded**. Institutions that care for people of mixed ages and that admit people in old age should be included.

## Part I. Context

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### 1. What age bands are used to define different client groups?

Specifically, what is the age of transition to adulthood?

16  18

Other: please state .....

And what is the age of transition to elderly care homes?

60  65  None

Other: please state .....

### 2. Who owns institutions? (tick all that apply)

Ministry of Health  Ministry of Social Affairs

Municipalities  Private sector

Nongovernmental organization

### 3. To what agencies are the management of institutions accountable? (tick all that apply)

Ministry of Health  Ministry of Social Affairs

State regulatory agency  Municipality

Other (please state) .....

### 4. Please state the agency responsible for inspection and the frequency of inspection:

.....

### 5. Is there an independent complaints mechanism?

Yes (please give details) .....

No

**If yes, how many complaints were dealt with in the past year?** .....

### 6. Financing system (national):

a. What agency pays for care (please state)? .....

b. How is finance allocated (e.g. block grant for total institution, pay per bed per day or other period, diagnosis or disability related) (please state)? .....

c. What is the equivalent payment per bed day in euros (please state)?.....

d. Is there funding from charities or foundations, and what are the amounts?.....

**7. Deinstitutionalization plans:**

a. Has a national strategy or action plan been adopted to start deinstitutionalization:

Yes (give details):.....

No

b. Has funding been committed:

Yes (give details).....

No

If yes, how much, and who provides it: .....

c. Has the plan been implemented? If so, how many people with mental disabilities are recipients of community living arrangements? .....

**Part 2. Data on institutions**

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**8. Number of institutions (as defined above) (please state)**.....

**9. Total number of adults with mental disabilities living in institutions in the country (please state)**.....

.....

## Part 2a. Characteristics of residents

| Institution name | Total number of residents | Gender of residents |        | Age of residents (per age group) (years) |       |       |       |       |      |  |
|------------------|---------------------------|---------------------|--------|--|-------|-------|-------|-------|------|--|
|                  |                           | Male                | Female | ≤ 21                                     | 21–30 | 31–40 | 41–50 | 51–60 | ≥ 61 |  |
|                  |                           |                     |        |  |       |       |       |       |      |  |

## Part 2b. Entry criteria and length of stay

| Institution name | Entry criteria   | Length of stay of residents (years) |     |      |      |
|------------------|--|-------------------------------------|-----|------|------|
|                  | On what basis are people admitted? (e.g. only those with a specific condition, legal requirement or mixed admission) | 1–2                                 | 3–5 | 6–10 | > 10 |
|                  |  |                                     |     |      |      |

## Part 2c. Diagnoses of residents

| Institution name | Diagnoses of residents (number of residents with each condition) |                                      |   | 15a. Co-morbidities – number of residents who also have the following conditions |          |
|------------------|--|--------------------------------------|---|--|----------|
|                  | Psychiatric disorders <sup>a</sup>                               | Intellectual disability <sup>b</sup> | Both psychiatric disorder and intellectual disability | Physical disability  | Dementia |
|                  |  |                                      |   |  |          |

<sup>a</sup> e.g. schizophrenia, depression, bipolar disorder

<sup>b</sup> including Down syndrome, autism and other intellectual disabilities caused by e.g. environmental factors or brain damage

### Building and services

| Institution name | Type of building (tick all that apply) |                           |         |          |                                   |                    | Are community services <sup>a</sup> offered? | 17a. By whom? |
|------------------|--|---------------------------|---------|----------|-----------------------------------|--------------------|--|---------------|
|                  | Newly built (post-1990)                | Purpose-built psychiatric | Adapted | Pre-1900 | Centralized (all in one building) | Separate buildings |  |               |
|                  |  |                           |         |          |                                   |                    |  |               |

<sup>a</sup> Defined as recreation, educational or other services provided outside the institution setting (e.g. by the local authority, charities)

### 18. Staffing

| Institution name | Number of psychiatrists | Number of other doctors | Number of nurses | Social workers | Other clinical staff <sup>a</sup> | Non-clinical staff <sup>b</sup> |
|------------------|-------------------------|-------------------------|------------------|----------------|-----------------------------------|---------------------------------|
|                  |                         |                         |                  |                |                                   |                                 |

<sup>a</sup> With medical responsibilities not classed among those listed, e.g. health care assistants, occupational or physical therapists, pharmacists

<sup>b</sup> With no direct medical responsibilities, e.g. administrative staff, catering staff, cleaning staff



## Annex 2. Subregional grouping of countries

Countries are mapped to four sub-regional groups for the purposes of phase one reporting:

- Commonwealth of Independent States (CIS), including Georgia as a former member and Turkmenistan and Ukraine as associate states; these countries cover a large part of Central Asia and eastern Europe.
- Countries forming the South-eastern Europe (SEE) Health Network and Kosovo (in accordance with United Nations Security Council resolution 1244 (1999)).
- Countries that joined the European Union (EU) after 2004, covering a large part of central and eastern Europe, and are not a part of the CIS or SEE.
- Countries that joined the European Union before 2004, plus Switzerland, representing a major part of western Europe, and are not a part of the CIS or SEE.

| CIS          | SEE                                       | EU (post-2004) | EU (pre-2004) |
|--------------|---|----------------|---------------|
| Armenia      | Albania                                   | Cyprus         | Austria       |
| Azerbaijan   | Bosnia and Herzegovina                    | Czech Republic | Belgium       |
| Georgia      | Bulgaria                                  | Estonia        | Denmark       |
| Kazakhstan   | Croatia                                   | Hungary        | Finland       |
| Kyrgyzstan   | Moldova                                   | Latvia         | France        |
| Turkmenistan | Romania                                   | Lithuania      | Germany       |
| Ukraine      | Serbia                                    | Poland         | Luxembourg    |
|              | The former Yugoslav Republic of Macedonia | Slovakia       | Portugal      |
|              |   | Slovenia       | Switzerland   |

# Annex 3. Coding framework

A coding framework for each theme was developed on the basis of the qualitative data to guide the analysis.

## Theme 1

- Environment
  - Building quality
  - Accessibility
  - Cleanliness
  - Fire safety
  - Areas for improvement
- Personal hygiene
  - Cleanliness
  - Help from staff
  - Set times for bathing
  - Access to warm water and toiletries
  - Privacy
- Movement
  - Restrictions within facilities
  - Restrictions beyond facilities
  - Justifications from staff for making restrictions
  - Access and availability of outdoor space
  - Lack of staff to support movement
- Communications
  - Availability of phones, mail and Internet
  - Restrictions by staff
    - Privacy
    - Censorship
    - Access
  - Staff justifications for restrictions
- Interactions
  - Types of interactions
  - Staff support for interactions
  - Limitations to interactions with opposite sex
  - Space for visitors
  - Privacy
  - Staff language skills
- Food and drink
  - Quantity
  - Quality
  - Food hygiene
  - Dietary requirements addressed
- Clothing
  - Personalization and choice
  - Quality
  - Cleanliness
  - Fit for service users and seasons

## Theme 2

- Physical and mental health
  - Location of service provision
  - General health of service users
  - Regular screening
  - Psychotropic medications
  - Access to complementary therapy
  - Need for staff training
- Sexual and reproductive health
  - Access to reproductive health services
  - Provision of oral contraceptives
  - Acceptance of interactions
  - Sexual health education or information
  - Staff address sexual activity
- Medications
  - Access to psychotropic medications
  - Review and adjustment of dosages
  - Complementary therapy
  - Understanding of purpose and side-effects
- Rehabilitation
  - Individualized treatment and recovery plans
  - Use of plans
  - Rehabilitation activities
  - Limitations of rehabilitation activities
- Human rights
  - Familiarity with the CRPD
  - Application of the CRPD articles to own practice
  - Provision of information to service users
  - Need for staff training
- Equality and diversity
  - Respect within and beyond facilities
  - Extent of discrimination
  - Financial means
  - Privileges within facilities

## Theme 3

- Legal capacity and shared decision-making
  - Documentation
  - Support for persons who do not have legal capacity
  - Use of shared decision-making
  - Staff serving as guardians for service users

- Informed consent
  - Collected from service users or relatives upon admission
  - Consent for isolation and restraint
  - Possibility to revoke consent
  - Persuasion and coercion
- Access to medical records
  - Availability
  - Service user awareness
  - Storage and confidentiality
  - Possibility for annotation
- Personal liberty
  - Extent of restrictions
  - Staff justifications of restrictions
- Discharge
  - Procedures and plans
  - Progress towards de-institutionalization
  - Obtaining documentation
  - Staff perceptions of discharge

## Theme 4

- Absence of abuse
  - Type of abuse or neglect reported
  - Staff abusing service users
  - Service users abusing staff
  - Service users abusing each other
  - Zero tolerance policies
  - Safeguarding
  - De-escalation techniques
  - Need for training
- Complaints mechanism
  - Availability of mechanism
  - Awareness of mechanism
  - Use of mechanism
  - Support for filing a complaint
  - Factors hindering or preventing complaints
- Electroconvulsive therapy, psychosurgery, abortions and sterilization
  - Use of procedures
  - Legal framework
  - Safeguards

## Theme 5

- Access to supported housing
  - Availability and existing infrastructure
  - Staff perceptions of feasibility
  - Level of staff information
  - Importance of social workers
- Access to employment and education
  - Limited opportunities
    - Policy constraints
    - Funding
    - Stigmatization
  - Occupational therapy
    - Limited possibility to sell products
    - Limited independence
  - Informal employment
    - Small payments
    - Potential exploitation
- Voting and participation in the community
  - Limited participation
  - Lack of transport
  - Lack of staff to supervise and assist
  - Users not interested
  - Support in voting from staff
  - Legal right to vote
  - Staff perceptions of voting
  - Interest in voting

# Annex 4. Scores for all facilities for all standards

AF = achieved in full; AP = achieved partially; AI = achievement initiated; NI = not initiated; NA = not applicable

| Group code | Facility code | 1.1 | 1.2 | 1.3 | 1.4 | 1.5 | 1.6 | 1.7 | 2.1 | 2.2 | 2.3 | 2.4 | 2.5 | 3.1 | 3.2 | 3.3 | 3.4 | 4.1 | 4.2 | 4.3 | 4.4 | 4.5 | 5.1 | 5.2 | 5.3 | 5.4 |    |
|------------|---------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|----|
| 1          | RF98          | AI  | AI  | AI  | AI  | NI  | NI  | AI  | AP  | AI  | AI  | AP  | AI  | NI  | AI  | NI  | AI  | AI  | AI  | NA  | NA  | NI  | AI  | NI  | AI  | AI  |    |
| 1          | RF97          | NI  | AI  | AI  | AI  | NI  | NI  | AI  | AP  | AI  | AI  | AP  | AI  | NI  | AI  | NI  | AI  | AI  | AI  | NA  | NA  | AI  | AI  | NI  | AI  | AI  |    |
| 2          | RF96          | AI  | NI  | AI  | AI  | AI  | AI  | AI  | AI  | AI  | NI  | AP  | AI  | NI  | NI  | NI  | AI  | AP  | AP  | NA  | NA  | AI  | NI  | NI  | NI  | AI  |    |
| 2          | RF95          | NI  | NI  | NI  | NI  | NI  | NI  | AI  | AI  | AI  | NI  | AI  | AI  | NI  | NI  | NI  | AI  | NI  | NI  | NA  | NA  | NI  | NI  | NI  | NI  | NI  |    |
| 2          | RF94          | AI  | AI  | NI  | AI  | AI  | AI  | AI  | NI  | AI  | NI  | AP  | AI  | NI  | NI  | NI  | AP  | NI  | NI  | NA  | NA  | NI  | NI  | NI  | NI  | NI  |    |
| 3          | RF93          | AF  | AP  | AF  | AF  | AI  | AI  | AI  | AP  | AP  | AI  | AP  | AP  | AI  | AI  | AI  | AP  | AF  | AP  | AF  | AF  | AP  | AP  | NI  | NI  | AP  |    |
| 3          | RF92          | AF  | AP  | AF  | AF  | AI  | AF  | AP  | AP  | AP  | AI  | AP  | AP  | AI  | AI  | AI  | AP  | AF  | AP  | AF  | AF  | AP  | AP  | NI  | AI  | AP  |    |
| 3          | RF91          | AF  | AP  | AP  | AF  | AI  | AI  | AI  | AF  | AP  | AI  | AI  | AP  | AI  | AI  | AI  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | AI  | AI  | AP  |    |
| 3          | RF90          | AF  | AP  | AP  | AF  | AI  | AP  | AI  | AP  | AI  | AI  | AI  | AP  | AI  | AI  | AI  | AP  | AI  | AP  | AF  | AF  | AP  | AP  | NI  | AI  | AI  |    |
| 3          | RF89          | AF  | AP  | AP  | AF  | AI  | AI  | AI  | AP  | AP  | AI  | AP  | AP  | AI  | AI  | AI  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | NI  | NI  | AI  |    |
| 3          | RF88          | AF  | AP  | AP  | AF  | AP  | AI  | AP  | AP  | AP  | AI  | AP  | AP  | AI  | AI  | AI  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | AP  | NI  | AF  |    |
| 3          | RF87          | AF  | AP  | AF  | AF  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | AF  | AP  | AI  | AP  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | AF  | AI  | AF  |    |
| 3          | RF86          | AF  | AP  | AF  | AF  | AP  | AP  | AP  | AF  | AF  | AI  | AP  | AP  | AI  | AI  | AI  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | AP  | NI  | AP  |    |
| 3          | RF85          | AF  | AP  | AF  | AF  | AP  | AP  | AI  | AP  | AP  | AP  | AP  | AP  | AI  | AI  | AI  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | AI  | AI  | AP  |    |
| 3          | RF84          | wAF | AP  | AF  | AF  | AI  | AP  | NI  | AF  | AP  | AI  | AP  | AP  | AI  | AI  | AI  | AP  | AP  | AP  | AF  | AF  | AP  | AP  | NI  | NI  | AP  |    |
| 3          | RF83          | AF  | AP  | AF  | AF  | AI  | AP  | NA  | AF  | AF  | AI  | AP  | AP  | NA  | NA  | AP  | AP  | AF  | AP  | AF  | AF  | AP  | AP  | AP  | NI  | AP  |    |
| 3          | RF82          | AF  | AP  | AF  | AF  | AI  | AP  | NA  | AF  | AF  | AI  | AP  | AP  | NA  | NA  | AP  | AP  | AF  | AP  | AF  | AF  | AP  | AP  | NI  | NI  | AP  |    |
| 4          | RF81          | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AP  | AI  | AF  | AI  | AP  | AF  | AP  | NA  | NA  | AP  | AP  | AF  | NA  | AF  |    |
| 4          | RF80          | AP  | AP  | AP  | AF  | AP  | AP  | AP  | AF  | AP  | AP  | AP  | AP  | AI  | AP  | AI  | AP  | AP  | AP  | NA  | NA  | AP  | AP  | AP  | AP  | AP  |    |
| 4          | RF79          | AI  | NI  | AI  | AP  | AI  | NI  | AI  | AF  | AI  | NA  | AF  | AP  | NA  | NA  | NA  | NA  | AF  | AP  | NA  | NA  | AF  | NA  | NA  | NA  | NA  |    |
| 4          | RF78          | AP  | AF  | AP  | AF  | AF  | AP  | AP  | AF  | AI  | AP  | AF  | AF  | AF  | AP  | AF  | AF  | AF  | AP  | NA  | NA  | AP  | NA  | NA  | AF  | AP  |    |
| 4          | RF77          | AI  | AI  | AP  | AF  | AF  | AF  | AP  | AF  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AF  | AP  | AF  | NI  | AF  | AF  |    |
| 4          | RF76          | AP  | AP  | AP  | AF  | AF  | AF  | AP  | AF  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AF  | AP  | AF  | NI  | AF  | AF  |    |
| 4          | RF75          | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AF  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AF  | AP  | AF  | NI  | AF  | AF  |    |
| 5          | RF74          | AI  | AP  | AP  | AP  | NI  | NI  | AP  | AP  | AP  | AI  | AF  | AP  | NI  | AP  | AI  | AP  | AP  | NI  | AF  | AP  | AP  | NI  | NI  | AP  | AP  |    |
| 5          | RF73          | AF  | AP  | AP  | AP  | AI  | AP  | AP  | AF  | AP  | AI  | AF  | AP  | NI  | AP  | AI  | AP  | AP  | AI  | AF  | AF  | AP  | NI  | NI  | AP  | AP  |    |
| 5          | RF72          | AI  | AP  | AP  | AP  | AI  | AI  | AP  | AF  | AP  | AI  | AF  | AP  | NI  | AP  | AI  | AP  | AP  | AI  | AF  | AF  | AP  | NI  | NI  | AP  | AP  |    |
| 5          | RF71          | AP  | AP  | AP  | AP  | AI  | AI  | AP  | AF  | AP  | AI  | AF  | AP  | NI  | AP  | AI  | AP  | AP  | AI  | AF  | AF  | AP  | NI  | NI  | AP  | AP  |    |
| 6          | RF70          | AP  | AP  | AP  | AP  | AI  | AP  | AP  | AP  | AP  | AI  | AI  | AP  | AP  | NI  | NI  | NI  | AP  | AP  | AI  | NA  | NA  | NI  | AI  | NI  | AI  | AP |
| 6          | RF69          | AP  | AI  | AP  | AF  | AI  | AP  | AP  | AP  | AP  | AP  | AP  | AI  | NI  | NI  | AI  | AP  | AP  | AI  | NA  | NA  | NI  | AP  | AI  | AP  | AP  |    |
| 6          | RF68          | AP  | AI  | AI  | AP  | AI  | AI  | AI  | AP  | AI  | AI  | AP  | AI  | NI  | NI  | NI  | AP  | AI  | NI  | NA  | NA  | NI  | NI  | NI  | AI  | AI  |    |
| 6          | RF67          | AP  | AI  | AI  | AP  | AI  | AI  | AI  | AP  | AI  | AI  | AP  | AI  | NI  | NI  | NI  | AP  | AI  | NI  | NA  | NA  | NI  | NI  | NI  | AI  | NI  |    |
| 7          | RF66          | AI  | AI  | AI  | AP  | NI  | NI  | NI  | AP  | AI  | NI  | AI  | AI  | NI  | NI  | NI  | AI  | AI  | NI  | NA  | NA  | AI  | NI  | NI  | NI  | AP  |    |
| 8          | RF65          | AI  | AI  | AI  | AP  | AP  | AI  | AI  | AF  | AI  | AI  | AP  | AP  | AI  | AP  | AP  | AF  | AP  | AP  | AF  | NA  | AP  | AI  | AI  | AI  | AP  |    |
| 8          | RF64          | AP  | NI  | AP  | AI  | AI  | AP  | AI  | AF  | AI  | AI  | AP  | AP  | AI  | AP  | AI  | AF  | AP  | AI  | NA  | NA  | AP  | AP  | AP  | AP  | AP  |    |
| 8          | RF63          | AF  | AF  | AP  | AF  | AP  | AP  | AP  | AP  | AI  | AI  | AP  | AF  | AI  | AI  | AP  | AP  | AF  | AP  | NA  | NA  | AI  | NI  | AI  | AI  | AI  |    |
| 9          | RF62          | AP  | AP  | AF  | AF  | AP  | AI  | AP  | AF  | AI  | NI  | AF  | AP  | AI  | AF  | AI  | AF  | AF  | AI  | NA  | NA  | AF  | AI  | NI  | AI  | AI  |    |
| 9          | RF61          | AI  | NI  | AF  | AI  | AI  | AI  | AP  | AF  | AI  | NI  | AF  | NI  | NI  | NI  | AI  | AF  | AP  | NI  | NA  | NA  | AP  | NI  | NI  | AI  | AP  |    |
| 9          | RF60          | AP  | AP  | AP  | AP  | AF  | AI  | AP  | AF  | AI  | AI  | AF  | AP  | AI  | AF  | AP  | AF  | AF  | AP  | NA  | NA  | AF  | AI  | AP  | AP  | AF  |    |
| 10         | RF59          | AI  | AI  | AI  | AP  | AP  | NI  | AI  | AP  | AP  | AI  | AP  | AI  | AI  | AI  | AP  | AI  | AP  | AI  | NA  | NA  | AP  | AI  | NI  | NI  | NI  |    |
| 10         | RF58          | AP  | AP  | AP  | AP  | AI  | AI  | NI  | AP  | AP  | AI  | AP  | AP  | AI  | AP  | AI  | AP  | AP  | AI  | NA  | AF  | AP  | AI  | NI  | NI  | NI  |    |
| 10         | RF57          | AP  | AF  | AP  | AF  | AP  | AP  | AP  | AP  | AP  | AI  | AP  | AP  | AP  | AF  | AP  | AF  | AP  | AP  | NA  | NA  | AP  | AP  | AI  | AI  | AI  |    |
| 11         | RF56          | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AF  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | NA  | NA  | AF  | AP  | AF  | AP  | AF  |    |
| 11         | RF55          | AP  | AP  | AP  | AF  | AF  | AP  | AP  | AP  | AP  | AP  | AP  | AP  | AI  | AP  | AI  | AF  | AP  | AP  | AF  | AF  | AF  | AI  | AP  | AP  | AF  |    |
| 12         | RF54          | AF  | AP  | AF  | AF  | AP  | AF  | AP  | AP  | AF  | AP  | AF  | AF  | AP  | AF  | AF  | AF  | AF  | AF  | NA  | NA  | AF  | NA  | NA  | AF  | AF  |    |

| Group code | Facility code | 1.1 | 1.2 | 1.3 | 1.4 | 1.5 | 1.6 | 1.7 | 2.1 | 2.2 | 2.3 | 2.4 | 2.5 | 3.1 | 3.2 | 3.3 | 3.4 | 4.1 | 4.2 | 4.3 | 4.4 | 4.5 | 5.1 | 5.2 | 5.3 | 5.4 |    |
|------------|---------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|----|
| 12         | RF53          | AF  | AP  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AP  | AF  | AF  | AI  | AF  | AF  | AF  | AF  | AF  | NA  | NA  | AF  | NA  | NA  | AP  | AF  |    |
| 12         | RF52          | AF  | AI  | AF  | AF  | AP  | AF  | AP  | AP  | AF  | AP  | AF  | AF  | AP  | AF  | AP  | AI  | AF  | AF  | NA  | NA  | AF  | NA  | NA  | AP  | AF  |    |
| 13         | RF51          | AP  | AI  | AI  | AF  | AP  | AI  | AI  | AF  | AP  | AI  | AP  | NI  | NI  | AF  | NI  | AP  | AP  | AI  | NA  | NA  | AP  | NA  | NA  | AP  | AF  |    |
| 13         | RF50          | AI  | AI  | AI  | AP  | AP  | AI  | NI  | AF  | AF  | NI  | AF  | AP  | AP  | AF  | AP  | AF  | AF  | AI  | AF  | NA  | AF  | NA  | NI  | AP  | AP  |    |
| 13         | RF49          | AP  | AP  | AF  | AP  | AF  | AF  | AF  | AF  | AI  | NI  | AF  | AI  | AI  | AI  | AP  | AP  | AF  | AP  | NA  | NA  | AI  | NI  | NI  | AI  | AI  |    |
| 13         | RF48          | AP  | NI  | AI  | AP  | AP  | AI  | NI  | AF  | AP  | NI  | AF  | AF  | AI  | AF  | AI  | AP  | AI  | AI  | AF  | NA  | AP  | NI  | NI  | AF  | AF  |    |
| 13         | RF47          | AI  | AI  | AP  | AI  | AI  | AI  | AI  | AF  | AI  | AI  | AP  | AI  | NI  | AP  | NI  | AI  | AI  | AI  | NA  | NA  | AI  | NI  | NI  | AF  | AF  |    |
| 14         | RF46          | AI  | AP  | AI  | AP  | AI  | NI  | AI  | AF  | AI  | NA  | AI  | AI  | NI  | NI  | NI  | AP  | AI  | NA  | NA  | NA  | AI  | NA  | NA  | NA  | NA  |    |
| 14         | RF45          | AI  | AP  | AI  | AP  | AI  | NI  | AI  | AF  | AI  | NA  | AI  | AI  | NI  | NI  | NI  | AP  | AI  | NA  | NA  | NA  | AI  | NA  | NA  | NA  | NA  |    |
| 15         | RF44          | AP  | AP  | AP  | AF  | AP  | AI  | AI  | AP  | AP  | NI  | AP  | AP  | NI  | AI  | NI  | AI  | AI  | AI  | NA  | NA  | AI  | AI  | NI  | AI  | AI  |    |
| 15         | RF43          | AP  | AP  | AP  | AP  | AP  | AI  | AP  | AF  | AP  | NI  | AP  | AP  | AI  | AI  | AI  | AI  | AI  | NI  | AF  | NA  | AI  | AI  | AI  | AI  | AI  |    |
| 15         | RF42          | AP  | AP  | AF  | AF  | AF  | AF  | AP  | AF  | AF  | AP  | AF  | AP  | AP  | AF  | AI  | AP  | AP  | AF  | NA  | AF  | AP  | AP  | AI  | AF  | AF  |    |
| 15         | RF41          | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AF  | AF  | AP  | AF  | AP  | AP  | AF  | AI  | AP  | AP  | AF  | NA  | AF  | AP  | AP  | AI  | AF  | AF  |    |
| 16         | RF40          | AP  | AP  | AF  | AF  | AP  | AP  | AP  | AI  | AI  | AI  | AI  | AP  | AI  | AI  | NI  | AP  | AP  | AP  | NA  | NA  | AI  | AI  | AI  | AI  | AI  |    |
| 16         | RF39          | AP  | AP  | AP  | AP  | AI  | AI  | AP  | AP  | AP  | NI  | AP  | AI  | NI  | AI  | NI  | AP  | AF  | AI  | NA  | NA  | AI  | AI  | AP  | AI  | AI  |    |
| 16         | RF38          | AF  | AP  | AF  | AF  | AP  | AP  | AI  | AF  | AI  | AI  | AP  | AP  | NI  | AI  | NI  | AP  | AF  | AI  | AF  | AF  | AI  | AP  | NI  | AI  | AP  |    |
| 16         | RF37          | AP  | AP  | AP  | AP  | AP  | AI  | AP  | AF  | AP  | AI  | AP  | AI  | NI  | NI  | AP  | AI  | NI  | AF  | AF  | AI  | AI  | NI  | AI  | AP  |     |    |
| 17         | RF36          | AI  | NI  | AI  | NI  | AI  | AI  | NI  | NI  | AI  | AI  | NI  | AI  | AI  | NI  | NI  | AI  | AI  | AI  | NA  | NA  | AI  | AP  | AI  | AI  | AI  |    |
| 17         | RF35          | AI  | NI  | AI  | NI  | AI  | AI  | NI  | NI  | AI  | NI  | NI  | AI  | AI  | NI  | NI  | AI  | AI  | NI  | NA  | NA  | AI  | AI  | AI  | AI  | AI  |    |
| 17         | RF34          | AI  | AI  | AI  | NI  | AI  | AI  | NI  | NI  | NI  | NI  | NI  | AI  | NI  | NI  | NI  | AI  | NI  | NI  | NA  | NA  | AI  | AI  | AI  | AI  | NI  |    |
| 18         | RF33          | AI  | AI  | AI  | AI  | AP  | AI  | AI  | AF  | AI  | NI  | AF  | AI  | AF  | AF  | AI  | AF  | AP  | AI  | NA  | AF  | AP  | AI  | NI  | NI  | NI  |    |
| 18         | RF32          | AI  | AI  | AI  | AI  | AP  | AI  | AI  | AF  | AI  | NI  | AF  | AI  | AF  | AF  | AI  | AF  | AP  | AI  | NA  | AF  | AP  | AI  | NI  | NI  | NI  |    |
| 18         | RF31          | AI  | AI  | NI  | AI  | AI  | AI  | NI  | AF  | AI  | NI  | AP  | AP  | NA  | AI  | NA  | AI  | AF  | AP  | AF  | AF  | AP  | AI  | NI  | NI  | NI  |    |
| 19         | RF30          | AF  | AP  | AF  | AF  | AP  | AF  | AP  | AF  | AP  | AI  | AF  | AP  | AI  | AP  | AP  | AP  | AF  | AI  | NA  | NA  | AP  | AI  | AI  | AP  | AF  |    |
| 19         | RF29          | AP  | AP  | AF  | AF  | AP  | AP  | AP  | AF  | AP  | AI  | AF  | AP  | AP  | AF  | AP  | AF  | AF  | AF  | NA  | AF  | AF  | AI  | AI  | AP  | AP  |    |
| 19         | RF28          | AP  | AP  | AF  | AP  | AP  | AF  | AP  | AF  | AP  | AI  | AF  | AP  | AI  | AP  | AI  | AP  | AP  | AP  | NA  | NA  | AP  | AI  | AP  | AP  | AF  |    |
| 20         | RF27          | AP  | AP  | AP  | AF  | AP  | AP  | AP  | AP  | AP  | AI  | AF  | AF  | AP  | AP  | AP  | AF  | AP  | AP  | NA  | AF  | AP  | AF  | AP  | AP  | AF  |    |
| 20         | RF26          | AI  | AI  | AI  | AI  | AI  | AI  | AI  | AP  | NI  | NI  | AI  | AI  | NI  | NI  | AI  | AI  | NI  | NI  | NA  | AI  | NI  | NI  | AI  | AI  | AP  |    |
| 20         | RF25          | AP  | AI  | AP  | AP  | AI  | NI  | NI  | AF  | AP  | NI  | AF  | AP  | NI  | AP  | AI  | AP  | AP  | AP  | AF  | AF  | AI  | NI  | NI  | NI  | NI  |    |
| 21         | RF24          | AP  | AP  | AP  | AP  | AP  | AI  | AI  | AF  | AP  | AI  | AF  | AP  | AI  | AF  | AP  | AF  | AF  | AI  | AF  | NA  | AF  | NI  | NI  | AP  | AI  |    |
| 21         | RF23          | AP  | AF  | AP  | AF  | AF  | AP  | AF  | AF  | AP  | AP  | AF  | AP  | AI  | AP  | AP  | AF  | AF  | AI  | AP  | NA  | AF  | NI  | AI  | AP  | AP  |    |
| 21         | RF22          | AF  | AF  | AF  | AF  | AP  | AF  | AP  | AF  | AP  | AI  | AF  | AF  | AI  | AF  | AP  | AF  | AF  | AI  | AF  | NA  | AF  | NI  | AI  | AP  | AP  |    |
| 22         | RF21          | AP  | AP  | AF  | AF  | AP  | AP  | AP  | AF  | AP  | AI  | AP  | AP  | AP  | AP  | AP  | AP  | AP  | AP  | AF  | AF  | AP  | AF  | AI  | AP  | AP  |    |
| 22         | RF20          | AP  | AP  | AF  | AP  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AP  | AP  | NA  | AP  | AF  | AF  | NA  | NA  | NA  | AP  | AF  | AI  | AF  | AF  |    |
| 22         | RF19          | AF  | AP  | AF  | AF  | AP  | AF  | AF  | AF  | AP  | AI  | AF  | AP  | AP  | AP  | AP  | AF  | AF  | AP  | AF  | AF  | AF  | NI  | NI  | AF  | AF  |    |
| 22         | RF18          | AP  | AP  | AP  | AP  | AP  | AP  | AP  | AF  | AP  | AP  | AP  | AP  | AP  | AP  | AF  | AF  | AF  | AP  | AF  | AF  | AF  | NI  | NI  | AI  | AP  |    |
| 23         | RF17          | AP  | AI  | AI  | AP  | AP  | AI  | AF  | AF  | AP  | AI  | AP  | AP  | NI  | AI  | AI  | AI  | AI  | AI  | NA  | NA  | AI  | AI  | AI  | NI  | AP  |    |
| 23         | RF16          | NI  | NI  | AI  | AP  | AP  | NI  | AF  | AF  | AP  | AI  | AP  | AP  | NI  | AI  | AI  | AI  | AI  | AI  | NA  | NA  | AI  | AI  | AI  | NI  | AP  |    |
| 23         | RF15          | NI  | NI  | AP  | AP  | AP  | AI  | AP  | AF  | AI  | AI  | AP  | AP  | NI  | AI  | NI  | AP  | AI  | AP  | NA  | NA  | AI  | AI  | AP  | AI  | AI  |    |
| 23         | RF14          | NI  | AI  | AP  | AP  | AP  | AI  | AP  | AF  | AI  | AI  | AP  | AP  | NI  | AI  | AI  | AI  | AI  | AI  | NA  | NA  | NI  | AI  | AP  | AI  | AP  |    |
| 24         | RF13          | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AF  | NA  | NA  | NA  | NA  | AF  | AF  | AF  | AF  | AF  | NA  | NA  | NA  | NA  |    |
| 24         | RF12          | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  |    |
| 24         | RF11          | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  |    |
| 24         | RF10          | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  |    |
| 24         | RF9           | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AP  | AF |
| 24         | RF8           | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AF  | AF |
| 24         | RF7           | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AF  | AF |
| 24         | RF6           | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AF  | AF  |    |
| 24         | RF5           | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | NA  | AF  | AF  |    |
| 24         | RF4           | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AP  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  | AF  |    |
| 25         | RF3           | AI  | AI  | AP  | AP  | AI  | NI  | AI  | AF  | AI  | NI  | AP  | AI  | AI  | AI  | NI  | AP  | AI  | NI  | NA  | NA  | AI  | NA  | NA  | NI  | NA  |    |
| 25         | RF2           | AI  | AI  | AI  | AP  | AI  | AI  | AI  | AF  | AP  | AP  | AP  | AP  | AP  | AP  | AI  | AP  | AP  | AI  | NA  | NA  | AP  | NI  | NI  | AI  | AP  |    |
| 25         | RF1           | AP  | AP  | AI  | AI  | AP  | AP  | AP  | AF  | NI  | NI  | NI  | NI  | NI  | NI  | NI  | AI  | AI  | NI  | NA  | NA  | NI  | NI  | NI  | AI  | AP  |    |

## The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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ISBN 9789289053204



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