

Long-stay mental health care institutions and the COVID-19 crisis:

identifying and addressing the challenges
for better response and preparedness



Long-stay mental health care institutions and the COVID-19 crisis:

identifying and addressing the challenges
for better response and preparedness

Abstract

This report presents the results of a survey conducted by the Mental Health Programme, WHO Regional Office for Europe, with 169 long-stay institutions in the WHO European Region to assess the impact of the COVID-19 pandemic on services, staff, service users and residents with psychosocial and intellectual disabilities. Specific themes are how well the institutions were prepared for the crisis by authorities, the quality of communications within institutions and with service users and family members, the availability of personal protective equipment and challenges to the delivery of care, and the impact of the risk of infection and protective measures on staff and residents. The survey results are presented in four thematic sections through the lens of the United Nations Convention on the Rights of Persons with Disabilities. The report also presents some preliminary key considerations.

Keywords

Mental health; mental health services; psychiatric hospitals; social care homes; psychosocial disability; intellectual disability; COVID-19; communication; preparedness; infection prevention and control; PPE; delivery of care; case management; human rights; Europe

Address requests about publications of the WHO Regional Office for Europe to:

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>).

Document number: WHO/EURO:2020-40745-54930

© World Health Organization 2020

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; <https://creativecommons.org/licenses/by-nc-sa/3.0/igo>).

Under the terms of this licence, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that WHO endorses any specific organization, products or services. The use of the WHO logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: "This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition: Long-stay mental health care institutions and the COVID-19 crisis: identifying and addressing the challenges for better response and preparedness. Copenhagen: WHO Regional Office for Europe; 2020".

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization. (<http://www.wipo.int/amc/en/mediation/rules/>)

Suggested citation. Long-stay mental health care institutions and the COVID-19 crisis: identifying and addressing the challenges for better response and preparedness. Copenhagen: WHO Regional Office for Europe; 2020. Licence: **CC BY-NC-SA 3.0 IGO**.

Cataloguing-in-Publication (CIP) data. CIP data are available at <http://apps.who.int/iris>.

Sales, rights and licensing. To purchase WHO publications, see <http://apps.who.int/bookorders>. To submit requests for commercial use and queries on rights and licensing, see <http://www.who.int/about/licensing>.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

General disclaimers. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of WHO concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by WHO to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall WHO be liable for damages arising from its use.

The cover picture is a still from the short documentary film that accompanies this report, *Mental health institutions and the COVID-19 crisis*. © World Health Organization 2020.

Contents

| | |
|---|-----------|
| Acknowledgements | iv |
| Executive summary | v |
| Context | 1 |
| Approach | 1 |
| Main findings | 2 |
| Theme 1. Communication | 5 |
| Challenges and lessons | 5 |
| What helps | 5 |
| In their own words | 6 |
| Theme 2. Infection prevention and control, and PPE | 6 |
| Challenges and lessons | 6 |
| What helps | 7 |
| In their own words | 7 |
| Theme 3. Delivery of care | 8 |
| Challenges and lessons | 8 |
| What helps | 8 |
| In their own words | 9 |
| Theme 4. Impact on staff and residents (quality of experience) | 9 |
| Challenges and lessons | 9 |
| What helps | 9 |
| In their own words | 10 |
| Key considerations | 11 |
| References | 12 |

Acknowledgements

This project was generously supported by the Vulnerable Populations Group of the COVID-19 Incident Management System and Support Team, WHO Regional Office for Europe (Adelheid Marschang, Senior Emergency Officer). It was managed by the Mental Health Programme (Dan Chisholm, Programme Manager; Melita Murko, Technical Officer).

The WHO project team extends special thanks to the following contributors: Danny Angus, Lead Nurse for Quality & Innovation, Secure & Specialist Learning Disability Division, Mersey Care NHS Trust, United Kingdom; Roger Banks, National Clinical Director, Learning Disability and Autism, NHS England and NHS Improvement, United Kingdom; Jakub Bil, Deputy Regional Representative for Europe, Global Mental Health Peer Network; Dovilė Juodkaitė, President, Lithuanian Disability Forum; Jennifer Kilcoyne, Clinical Director, Deputy Chief Clinical Information Officer, Centre for Perfect Care, Mersey Care NHS Foundation Trust, United Kingdom; Desmond Maurer, freelance editor; Bojan Šošić, Member of the Board for Psychiatric and Neurological Research, Department of Medical Sciences, Academy of Sciences and Arts of Bosnia and Herzegovina; Robert van Voren, Chief Executive of Human Rights in Mental Health–Federation Global Initiative on Psychiatry; and Petr Winkler, Department of Public Mental Health, Head National Institute of Mental Health, Czechia.

Executive summary

The COVID-19 pandemic encompasses not only the threat of infection, but also the psychological, social and economic effects of quarantine, self-isolation and lockdown countermeasures, all of which affect the most vulnerable in society disproportionately. This is especially true of those who live in care homes, psychiatric hospitals and other forms of residential institution.

The WHO Regional Office for Europe used its technical network of partners and collaborators to reach out to these institutions to offer support and gather feedback on the current crisis. This was done through a rapid appraisal, which included 19 direct questions and a narrative section addressing issues such as how the crisis has affected staff and residents, how well they were prepared for it, and how they coped with a range of potential challenges. In total, 169 institutions (facilities managers and directors) in at least 23 countries (not all institutions revealed their country of origin) participated. The report presents a summary analysis of their responses.

Institutions tended to report reasonable satisfaction with the clarity of information, instructions from government and the degree of preparedness achieved. While the survey did not ask for quantitative data on the number of COVID-19 positive cases, it is clear from the qualitative responses that few institutions suffered a serious outbreak of the disease. There nevertheless were strong indications that implementing the preventive measures had put considerable additional strain on already overstretched resources and systems.

There is little doubt that: (1) providing individualized person-centred care and support under crisis conditions is significantly more challenging to deliver in large-scale institutions than in community settings or at home; and (2) this puts people with psychosocial and intellectual disabilities at considerable risk of inequities in care and treatment.

The experience of containing the spread of the virus in these institutions has provided valuable insights into the weaknesses and vulnerabilities of the system and made clear the need to use the current situation to put in place comprehensive and practical plans to facilitate management and day-to-day operations under crisis conditions. The keys to this are:

- having clear guidelines and tested systems in place, encompassing multisectoral perspectives;
- ensuring clarity of communication on the part of authorities, management and staff, especially with service users, residents and their families;
- implementing a comprehensive and facility-based infection prevention and control plan, including training in the use of personal protective equipment and protocols;
- establishing clear procedures and protocols to ensure safe environments and alleviate potential problems arising from necessary measures and their consequences (especially behavioural restrictions and isolation, communication with family, stress and burnout);
- being able to increase staff capacities according to need; and
- having a clear focus on ensuring person-centred and human rights-based care in all decision-making.

It is particularly important that work commences on preparing such plans and protocols now, given the probability of further waves of the COVID-19 pandemic.



Context

“COVID-19 is a test of societies, of governments, of communities and of individuals. Now is the time for solidarity and cooperation to tackle the virus, and to mitigate the effects, often unintended, of measures designed to halt the spread of the virus.”

(Office of the United Nations High Commissioner on Human Rights, 2020 (1))

COVID-19’s impact on every aspect of people’s lives can hardly be overestimated. As the above quotation makes clear, this impact extends well beyond the rate – and fear – of infection to far-reaching psychological, social and economic effects of quarantine, self-isolation and lockdown countermeasures. Both the disease and the measures required to counter its spread seem to affect disproportionately the most vulnerable in society.

No groups are more at risk from the impacts than those who live in care homes, psychiatric hospitals and other forms of residential institution. The WHO *Mental health, human rights and standards of care* report describes adults with psychosocial and intellectual disabilities living in institutions in the WHO European Region as “a highly marginalized, vulnerable group whose quality of life, human rights and reinclusion in society are compromised by outdated, often inhumane institutional practices” (2). Overcrowding and lack of facilities for personal and environmental hygiene, insufficient isolation and cohorting facilities and inadequate numbers of supervising staff mean infection prevention and control measures may be compromised in some institutions.

Institution residents depend upon the daily, and in some cases constant, care of others and can find it hard to understand and adjust to the changes to which they now find themselves subjected. It is in the very nature of these institutions that staff and patients or residents will come into close physical proximity and that revised rules and protocols, even for basic areas of operation, will be challenging to introduce or even explain.

The COVID-19 pandemic has laid bare several long-standing concerns in relation to social and health services in Europe in general and long-stay institutions in particular, including chronic underfunding, low-paid or insufficient staff, outdated procedures and care approaches, lack of clear management systems and dilapidated infrastructure. A further concern relates to the quality and standards of care in relation to upholding human rights in such institutions in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (3), with hundreds of thousands of adults and children with psychosocial and intellectual disabilities in Europe living in close proximity and at heightened risk of neglect or abuse (2).

Building on earlier efforts across its Member States to promote deinstitutionalization and rights-based standards of care using the QualityRights assessment toolkit (4), the WHO Regional Office for Europe utilized its network of partners and collaborators to reach out to these institutions to offer support and gather their feedback regarding the current crisis, including how it has affected staff and residents, how well they were prepared for it and how they coped with a range of potential challenges.

Approach

A two-part rapid-appraisal tool was developed by an international team of experts and shared with a convenience sample of institutions across Europe via existing partner networks. The rapid-appraisal tool adopted the themes of WHO’s interim guidance on infection control and prevention procedures for long-term care facilities in the context of COVID-19 (5) and consisted of:

- a quantitative section with 19 questions (see Fig. 1) addressing four themes: (1) communication; (2) infection prevention and control; (3) delivery of care; and

(4) impact on staff and service users/residents – the aim of this section was to provide a standardized assessment of conditions faced during the COVID-19 outbreak; and

- a qualitative section for respondents to present their experience of the outbreak in their own words and identify major challenges, outcomes and useful practices.

Responses prepared by facilities managers and directors were received from 169 institutions in at least 23 countries (institutions that completed the online survey were guaranteed anonymity and 11 did not supply their country of origin), with good geographical coverage across the WHO European Region and a good mix of countries by size. While a few countries were strongly represented, this did not significantly skew the results, which generally were consistent across the entire sample, both in regional terms and in relation to country size.

By contrast, there were significant differences between the types of institution reporting. These included: (1) psychiatric hospitals; (2) care homes; and (3) other settings for mental health care, such as supported accommodation and residential institutions for people who are deaf or blind and people with multiple disabilities, forensic psychiatric institutions and palliative care institutions. Type (1) institutions provided 39% of responses, type (2) 46.2% and type (3) just 14.8%. About half (46.5%) were urban, with the remainder in rural or semi-rural communities. Fewer than 20% were gender-segregated institutions. In terms of size, 23.5% had fewer than 50 residents, 45% between 50 and 250 residents, and the remaining 31.5% more than 250 residents. Most institutions were in the public

sector, but there was no definitive indication of this in the questionnaire.

This situation report summarizes the feedback and comments received. It does not provide a detailed analysis of each country's or institution's situation or explicit recommendations on how to deal with this and similar crises. Like the accompanying short documentary film on the topic commissioned by the WHO Regional Office for Europe (6), the report seeks to illuminate how the virus and the response to it have affected such institutions, and to inform planning on how to limit or pre-empt its negative impacts.

Following a general summary of the main findings, responses to each of the four themes described above are summarized. The theme chapters contain "At a glance" sections to highlight key findings, and some also have "Focus on human rights" boxes to link findings to specific articles of the CRPD. These chapters include sections on "Challenges and lessons", "What helps" (both drawn from responses to the survey) and "In their own words", which presents some of the responses received from participants in the qualitative section of the survey.

Main findings

The timing of the survey, in late May and early June, was important. The spread of the outbreak, the different intensities with which it affected countries and the differences in national strategies meant that conducting the survey too early would have produced results that were either irrelevant or of questionable comparability. By the time the survey was administered, most of the countries had already exited the initial response phase and entered one of containment or mitigation. As a result, satisfaction levels with governmental and institutional responses expressed in the quantitative section are probably higher than they would have been even a week or two earlier. This is balanced by the very uniform and more critical tone of the qualitative section, which allows some general observations to be drawn.

While the survey did not ask for quantitative data on the number of COVID-19 positive cases, it is clear from the qualitative responses that few institutions suffered a serious outbreak of the disease. The major difficulties arose from challenges in implementing preventive measures and procedures under difficult circumstances, rather than in coping with large numbers of cases and a highly

infectious environment. While this suggests that preventive measures were effective, the overall picture indicates that a serious outbreak during a subsequent wave could seriously test the capacity of already stretched institutions and their ability to surge/mobilize adequate numbers of additional staff.

After some initial challenges and confusion, the guidelines and procedures seem to have been clear enough and generally could be implemented by management, staff and residents. Key concerns seem to have related to difficulties dealing with particular categories of service user, enabling them to understand and comply with regulations, or coping with new restrictions that interrupted their routine and increased their isolation. The increased stress on staff means clearer protocols are needed, alongside ways to address valid safety concerns and counter burnout.

Specific differences in responses across types of institution are summarized in Box 1. A summary of the rapid appraisal responses to the quantitative section of the survey is shown in Fig. 1.

Box 1. Differences in responses across types of institution

Responses from psychiatric, intellectual disability and autism services were broadly consistent with those from social care homes, except for the following significant areas of difference.

- Social care homes were happier with information from the authorities and the information they provided for residents in accessible formats.
- Care-home staff reported challenges with more workload, stress, frustration and burnout.
- Care homes were understandably less likely to use discharge to reduce numbers and manage the virus.
- Care homes were more likely to report an increase in the use of restrictive measures.

No significant differences were reported in the provision of personal protective equipment (PPE), or restrictions to visiting, transfers or testing of residents.

Fig. 1. Rapid appraisal responses (%)

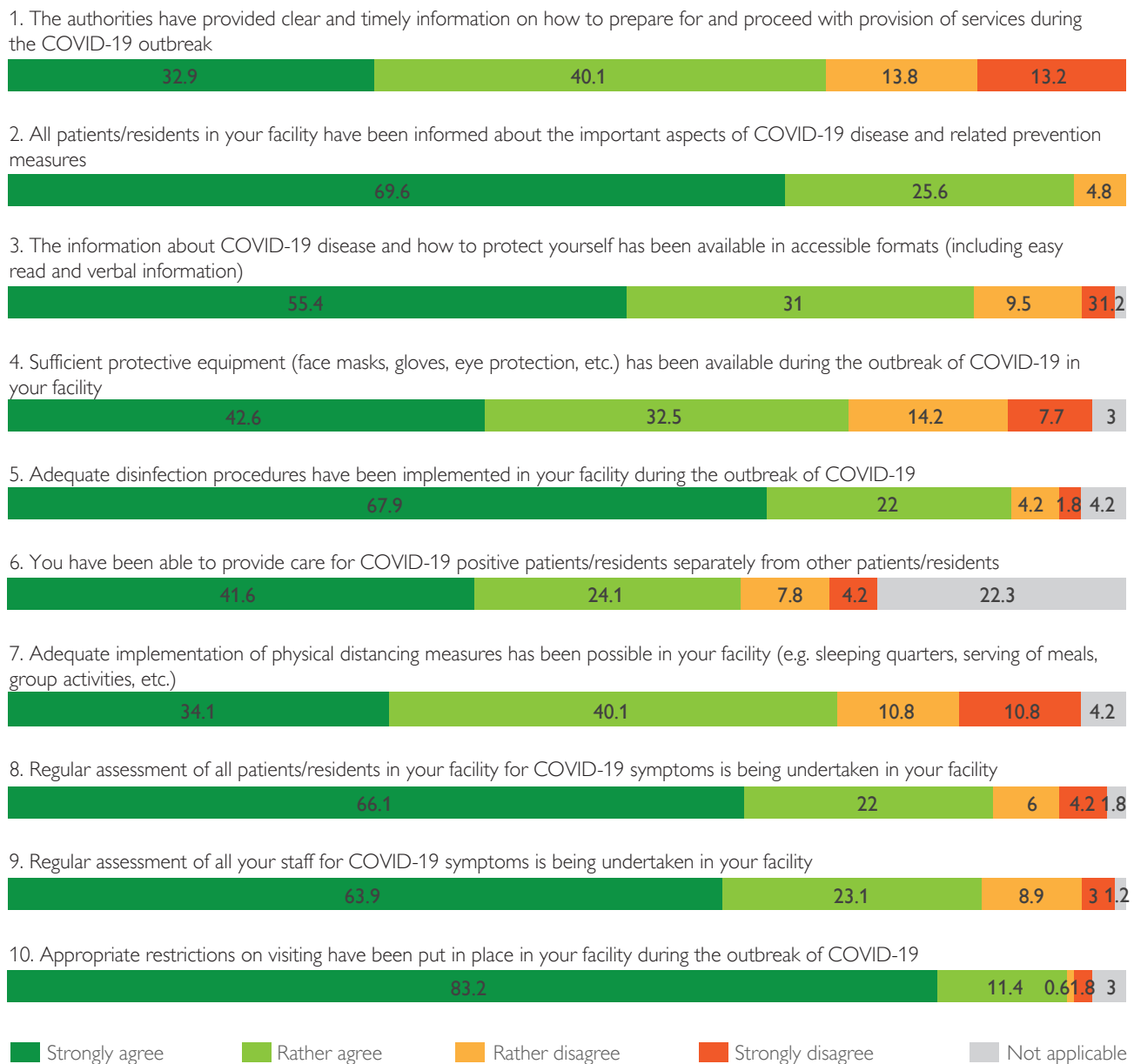


Fig. 1. Rapid appraisal responses (%) (cntd)



Theme 1. Communication

Challenges and lessons

Communication is key to good processes, reducing anxiety, ensuring compliance, and creating a happy and trusting environment. This is true whether it is communication with government authorities (such as through strategies, guidelines and situation assessments), with patients/residents and their families, or between staff.

At a glance

73% of institutions received clear and timely information from the government on dealing with the outbreak.

95% of respondents believed they had managed to keep all service users/residents adequately informed.

86% provided information in accessible formats.

Communication with national health authorities

Information flow appears to have been good overall, with reasonably clear provision and updating of government guidelines, but there was a degree of so-called information chaos, especially early on, compounded by inaccurate and conflicting media coverage. The unprecedented nature of the situation meant legal frameworks and authority were often unclear. This contributed to the fragmented response, as independent processes were developed in isolation from each other.

Communicating with patients/residents

The information to be communicated to service users was complex. It included the basics about the disease, new isolation processes, restrictions on activity, and changes to service, contact and visiting patterns and routines. Transmitting this information to families, visitors and, most importantly, service users, including those with severe intellectual disabilities and/or autism, patients with psychosis, children, and people with dementia and other cognitive difficulties, was challenging. Masks and protective equipment affected communication with patients who are deaf, as did excessive reliance on phones and digital technology for communication with communities and outpatients with mental health difficulties.

What helps

Communication with staff

- Clear and consistent messaging to staff and service users from the outset is key.
- Targeted and consistent use of social networks and social media and daily updates/regular newsletters help keep guidance up to date, lower anxiety, improve cohesion and collaboration and promote a common sense of purpose and a positive culture under stress and uncertainty.

Getting information across to patients/residents, family and friends

- Regular and clear communication that addresses anxieties and explains changes to service practices and contact restrictions is key to cooperation.

Focus on human rights

Two key areas under this theme involve questions on the human rights of service users with intellectual or cognitive disabilities.

The first is easy-read and verbal information. Lack of information or information provided in a way that is neither accessible nor understandable violates the rights of persons with disabilities to proper information (Article 9 of the CRPD (3)) and to informed decision-making (Article 12).

The second is communication with family, which potentially involves violations of the rights of persons with disabilities to, for instance, liberty and security of person (Article 14), living independently (Article 19), and respect for home and the family (Article 23).

- Clear, standardized and adaptable information guidelines and tools from a centralized source that are available early on are useful.
- Having the information available in a range of formats and media, including daily tailored verbal messages in accessible forms (easy-read, videos, drawings, social stories and visual repetition), is helpful.
- Promoting communication with loved ones is important: some services stressed the role of digital forms, while others promoted writing letters home.

In their own words

“There has been too much information at times. Information needs to be clear and to the point, as in times of stress it needs to be easy to process.”

“[Institutions were left by themselves] to adapt and provide information to persons with disabilities, explain the situation regarding quarantine, visits, wearing protective equipment, [but there were] no resources to translate the informative materials developed by other countries in easy-to-read format and limited resources to develop new ones. [There was] limited human resources for conducting informative activities with residents, weak staff capacity to conduct informative activities in easy-to-read format and to use technologies, [and] lack of technologies to be used for informative purposes.”

“Visual information should be prepared [and] presented with the help of symbols or pictures. It would be good to have such materials available online already prepared and adapted for people with intellectual disabilities. There could also be short videos with explanations on how to proceed.”

Theme 2. Infection prevention and control, and PPE

Challenges and lessons

Prevention and protection protocols are key to keeping contagious diseases contained. This requires clear procedures and standards, adequate facilities, access to PPE, management of the environment (cleaning and disinfection), and testing, training and isolation protocols.

At a glance

75% reported having access to sufficient PPE (such as face masks, gloves and eye protection).

89% implemented adequate disinfection procedures, 94% imposed restrictions on visiting, and 73% implemented adequate physical distancing measures.

88% did regular assessment of all patients and residents and 86% did so for all staff.

61% were able to transfer a COVID-19 patient to a health facility when indicated.

Most institutions maintained generally adequate standards of **infection prevention and control**, but some reported challenges with:

- environmental infection control procedures and water, sanitation and health (WASH) guidelines;
- overcrowding, insufficient space and poor facilities (lack of adequate space, the layout of buildings and wards, and shared sleeping spaces, dining areas, bathrooms and toilets increase risk and hamper physical distancing, isolation and cohorting); and
- users finding it hard to follow guidance or retain information.

Again, institutions tended to report having adequate access to **PPE**, but unfamiliarity with it and its use increased the anxiety of staff at all types of institution. Institutions also tended to report:

- high costs, slow provision, insufficient supply and contradictory information on use;
- receiving lower priority, especially psychiatric hospitals;

- poor infection control knowledge, leading to single-use equipment being reused; and
- equity issues, with some professionals opting not to work with patients even with PPE.

Most facilities could provide some form of **testing** for patients and staff with positive symptoms but had difficulties testing service users and patients with mental health difficulties, who found the tests intrusive. Keeping them on the ward while waiting for test results also posed difficulties, as it increased the risk of transmission.

Overall, knowledge and understanding of effective infection prevention and control was good, but mental health staff reported a need for **training** in physical health skills. This requires national guidance.

Most institutions reported having **risk management plans** to care for COVID-19 positive residents and staff and prevent onward transmission, but this was not universally the case. Some reported difficulty keeping up with changing guidance. More attention is clearly needed in this area.

What helps

Scheduled cleaning, infection prevention and control, routine procedures and physical distancing

- Regular cleaning and disinfection procedures and fixed routines (concerning, for example, laundry, size of groups at mealtimes and activities) are key.
- Staff and patients following the same infection prevention and control procedures provides positive role-modelling.
- Keeping the number of visits down where possible, including by external professionals, limits the potential for infection.
- Cohorting reduces the risk of spread.
- Accelerated discharge procedures and reducing capacity keep patient numbers down.

Maintaining PPE

- Creative strategies to ensure supply, such as making face masks to the required standards in hospital workshops, are helpful.
- Training with putting on and taking off PPE is essential, especially for mental health staff.
- Rigorous procedures for infection control and prevention should be in place.
- Disinfection stations should be sited on wards.
- Infection control nurses can provide advice, deliver training and inform decision-making processes.

Screening and testing

- Staff and patient temperatures should be monitored daily.
- Keeping teams consistent is important.
- Staff and service users should be educated about symptoms.
- Patients should be isolated on admission until test results are known.
- Patients should be screened for mental and physical health symptoms on admission.

In their own words

“In the early days we had very little PPE; only what was left from our earlier regular supply. We made masks, as they couldn’t be bought anywhere. After 2–3 weeks everything stabilized and the ministry began providing PPE regularly in almost sufficient quantities. The problem was to create a so-called isolation space in each ward and to limit mixing of staff from different parts of the institution. Another problem was socializing among service users. Service users with mental disabilities live in groups and find it difficult to organize their day meaningfully on their own.”

“A major problem for our institution was the lack of doctors and nurses, so that staff were concerned about recognizing COVID 19 symptoms in residents in time.”

Theme 3. Delivery of care

Challenges and lessons

Care provision was affected by:

- restrictions on activities, including closure of services and institutions;
- reduced human and physical resources, including staff and clinical input;
- limitations of the built environment;
- changes to procedures and routines; and
- intrusive or restrictive infection control policies and procedures.

Discontinued services included:

- psychiatric consultations
- education and rehabilitation services
- day centres
- employment opportunities.

Other service provision was reduced to minimal or “only essential”. Digital technologies helped but were not always or consistently available.

At a glance

65% of institutions surveyed said they could provide separate care for COVID-19 patients.

79% were able to transfer them to a health facility/ acute unit.

73% said new admissions were substantially down.

30% said discharges were substantially up.

82% reported that mental health services and activities had been cut.

What helps

- Clarity of information and communication is important.
- There should be flexibility over staff recruitment and deployment and over working practices, including targeted extra support and reprioritization for particular areas.
- The physical environment should be reorganized to control movement and ensure isolation.
- Appropriately accelerated discharge procedures should be in place to reduce bed numbers.

Focus on human rights

The major areas of concern here are the right to health (Articles 25 and 26 of the CRPD (3)) and infringement of the rights of persons with disabilities to decision-making and choice of the place to live (Article 19), respect for privacy (Article 22), freedom from torture or cruel, inhuman or degrading treatment or punishment (Article 16), and the right to an adequate standard of living (Article 28). Also relevant is that staff shortages may result in persons with disabilities lacking care and being left unattended, which could constitute violations of Articles 15, 16 and 25.

Respondents expressed human rights concerns over blanket policies and responses, decisions on access to services, treatment and continuity of care, lowering of the highest available standards of health, including mental health care, and the ability to exercise personal choice and autonomy.

Many such infractions may be the result of poorly thought-out policies or their unintended consequences. Examples include accelerated discharge and cutting beds to facilitate social distancing, which may also lead to negligence and limiting support and services for persons with disabilities. Other restrictions (such as confining residents to their rooms and making common areas off-bounds) probably accelerated social isolation and worsened conditions within institutions.

- Admissions should be isolated for the requisite period.
- Input from medical staff should be reorganized and prioritized, including improved collaboration with family doctors (primary care) and consultations with physicians for health care decisions.
- Introducing digital and remote solutions quickly and helping staff to be innovative in using them for clinical work and to communicate with patients and families is helpful.

In their own words

“Lack of staff, or insufficient staffing; in effect, one third of the staff left and had to be replaced by someone; various professionals refused to work with service users and

some have not worked directly with patients despite being given PPE.”

“Due to the interruption of work in hospitals, we had problems with several service users – cancellation of follow-up appointments, diagnostics and surgeries. No treatment of other medical conditions. No inpatient services for rapidly deteriorating health, no counselling services for oncology, etc. Consultations of medical specialists in medical institutions are difficult to access, and more responsibility was placed on the medical staff of care homes.”

“There was no occupational therapy, psychiatrist consultations were discontinued. All education and rehabilitation services were discontinued. The COVID-19 outbreak has reduced the volume of mental health services or activities provided to the population to a minimum.”

Theme 4. Impact on staff and residents (quality of experience)

Challenges and lessons

Regular checks for symptoms and infection control procedures exacerbated the general anxiety. As behavioural problems, aggression and conflict increased, some patients resisted or refused isolation. All of this caused significant disruption and distress and made it difficult to maintain safe therapeutic environments and interventions. Restricted access to the local community or resources and visiting restrictions/bans affected quality of life and activities. The usual admission and discharge processes were disrupted and even suspended. In some cases, patients could not be discharged, as their families or other placements feared infection. In some countries, the cut in admissions and discharges affected finances adversely.

Restrictive practices were also used more, particularly in cases of heightened emotional distress and challenging behaviour. Other areas affected included community working, outpatient follow up, monitoring and prescribing, and some areas saw shortages of certain drugs.

Specific issues that seemed to affect the mental health and well-being of service users and staff are shown in Box 2.

At a glance

63% said challenges or problems with service users (anxiety, distress, agitation, challenging behaviour) were up.

78% reported new challenges or problems among staff (such as increased workload, stress, frustration and burnout).

47% had problems securing enough staff, while 23% had no such problems.

44% reported increased use of restrictive measures (such as seclusion and chemical or physical restraint), but 28% reported no increase.

What helps

Informal responses

Informal responses include:

- developing creative initiatives to provide activities for patients/residents and staff

- managing with limited resources, such as shortages of face masks
- relaxing behavioural policies and being more flexible about use of the facilities.

Communication with patients/residents and family

Communication can be promoted by:

- providing information in varying formats
- setting up patient helplines
- organizing community meetings
- increasing the emphasis on person-centred support and treatment plans
- developing creative solutions that enable contact with relatives/families.

Supporting staff

Staff can be supported through:

- more and better communication and good, well-coordinated teamwork;
- clear policies, procedures, and leadership and command structures;
- flexible working practices, including remote and home-based working;¹
- video-conferencing for reviews, team meetings and briefings from managers; and
- discussion of ethical concerns to assist decision-making on clinical treatment and restrictions.

For some, these changes resulted in a greater feeling of unity and of being valued, as did collaboration and sharing good practices with other organizations.

In their own words

“The residents display behavioral problems caused by restrictions forbidding them to go outside the institution and disruption of their daily routine. Human resources and the capacity to respond to their behavioral issues are limited. There is no psychosocial support to deal with panic attacks or to overcome the fear of being infected and isolated.”

“Residents, closed in groups, lacked different employment activities, communication with others, trips to the city. Residents could no longer go to day-care centres and events in the city, due to the restrictions of walks and visits. Clients were in complete self-isolation and could not meet loved ones, relatives.”

“Due to isolation, bans on visits and restricted access to outside the institution generated conflicts between residents and staff.”

Box 2. Factors that affected the mental health and well-being of service users and staff

Service users' mental and physical health and well-being were affected by:

- fear over the pandemic
- major changes in society and services
- difficulty understanding the new restrictions
- reduced activity levels
- lack of family contact
- loneliness.

Staff mental health and well-being were affected by:

- anxieties over the virus
- fear of infection
- lack of equipment
- higher workloads
- staff shortages.

This resulted in:

- high stress levels
- a need for psychological support
- fatigue over infection control measures
- compassion fatigue
- scepticism over, and non-adherence to, guidance or instructions.

¹ Responses from institutions indicate that psychologists were able to work remotely from home. Managers also had such opportunities, and while some chose to operate on-site, others were able to work from home. There may be other workers for whom remote and home-based working is an option in future.

Key considerations

The survey on which this report is based adopted the themes of WHO's interim guidance on infection control and prevention procedures for long-term care facilities in the context of COVID-19 (5) and was conducted through the lens of institutions' compliance with the CRPD (3). The key considerations raised by the survey reflect the responses of the participants – it is their perceptions, experiences and narratives that have guided the conclusions.

Institutions surveyed tended to report reasonable satisfaction with how they were informed and instructed by their governments and the degree of preparedness they achieved. Qualitative responses indicated that very few institutions had had to deal with major outbreaks, large numbers of staff or service users/residents falling ill, or deaths. Their preparedness no doubt saved lives, but it is likely that they were less severely tested than other parts of the health and social care systems in badly hit countries, and how they will perform under similar acute crisis conditions in future cannot be confirmed.

Comments and the narrative sections of responses add nuance and are more revealing of difficulties and challenges. Interestingly, most relate less to managing the disease and more to managing the institutions under lockdown conditions, which is suggestive of where systems need to be strengthened.

There can be little doubt about how challenging it is to provide individualized person-centred care and support in large-scale institutional settings, or that people with intellectual disabilities in institutional care are particularly vulnerable to inequities in care and treatment under crisis conditions. It is also clear that not all responses to the pandemic are or should be driven by large-scale actions and policies. The drawn-out tragedy of the pandemic has inspired significant new modalities, forms of collaboration and ways of working – as well as uplifting accounts of human interaction, creativity and compassion – and care must be taken to harness and develop them to ensure more focused, human rights-based and recovery-oriented care in the community is available for people with psychosocial and intellectual disabilities in the future. A further lesson is that the vulnerabilities highlighted during

the pandemic and identified from previous research (2), including systemic discrimination, discriminatory legislation and practices of exclusion and coercion, cannot be ignored. Sustained action is required, both during the emergency and afterwards.

Experience in containing the spread of the virus has provided valuable insights into weaknesses and vulnerabilities and made clear the need for comprehensive and practical plans that facilitate management and day-to-day operations under crisis conditions. The keys to this are:

- having clear guidelines and tested systems in place, encompassing multisectoral perspectives;
- ensuring clarity of communication on the part of authorities, management and staff, especially with service users, residents and their families;
- implementing a comprehensive and facility-based infection prevention and control plan, including training in the use of PPE and protocols;
- establishing clear procedures and protocols to ensure safe environments and alleviate potential problems arising from necessary measures and their consequences (especially behavioural restrictions and isolation, communication with family, stress and burnout);
- being able to increase staff capacities according to need; and
- having a clear focus on ensuring person-centred and human rights-based care in all decision-making.

It is particularly important that work commences on preparing such plans and protocols now, given the probability of further waves of the COVID-19 pandemic. The survey findings also reflect the need for mental health care institutions to be considered in planning measures to combat COVID-19 and for communication products to be tailored to the requirements of patients/residents, families and staff of institutions.

References

1. COVID-19 and its human rights dimensions. In: Office of the United Nations High Commissioner on Human Rights [website]. Geneva: Office of the United Nations High Commissioner on Human Rights; 2020 (<https://www.ohchr.org/EN/NewsEvents/Pages/COVID-19.aspx>).
2. 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. Copenhagen: WHO Regional Office for Europe; 2018 (<https://www.euro.who.int/en/publications/abstracts/mental-health,-human-rights-and-standards-of-care-2018>).
3. Convention on the Rights of Persons with Disabilities (CRPD). In: United Nations [website]. New York (NY): United Nations; 2020 (<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>).
4. WHO QualityRights tool kit. Geneva: World Health Organization (https://www.who.int/mental_health/publications/QualityRights_toolkit/en/).
5. Infection prevention and control guidance for long-term care facilities in the context of COVID-19. Interim guidance, 21 March 2020. Geneva: World Health Organization; 2020 (<https://apps.who.int/iris/handle/10665/331508>).
6. Mental health institutions and the COVID-19 crisis [video]. Copenhagen: WHO Regional Office for Europe; 2020 (<https://youtu.be/D28Kz4B3G1s>).

All weblinks accessed 12 August 2020.

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.

Member States

Albania
Andorra
Armenia
Austria
Azerbaijan
Belarus
Belgium
Bosnia and Herzegovina
Bulgaria
Croatia
Cyprus
Czechia
Denmark
Estonia
Finland
France
Georgia
Germany
Greece
Hungary
Iceland
Ireland
Israel
Italy
Kazakhstan
Kyrgyzstan
Latvia
Lithuania
Luxembourg
Malta
Monaco
Montenegro
Netherlands
North Macedonia
Norway
Poland
Portugal
Republic of Moldova
Romania
Russian Federation
San Marino
Serbia
Slovakia
Slovenia
Spain
Sweden
Switzerland
Tajikistan
Turkey
Turkmenistan
Ukraine
United Kingdom
Uzbekistan



World Health Organization Regional Office for Europe
UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark
Tel.: +45 45 33 70 00 Fax: +45 45 33 70 01
Email: eurocontact@who.int