

Persons with developmental disabilities were socially isolated during the pandemic, Norwegian study finds

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In a new study [published](#) in the *Tidsskrift for omsorgsforskning (Journal of Care Research)*, researchers from the Regional Center for Obesity

Research and Innovation (ObeCe) at St. Olavs Hospital and the University of Agder uncovered human rights violations in five assisted living facilities for people with developmental disabilities in Central Norway.

According to data from the National Institute on Intellectual Disability and Community (NAKU), there are an estimated 19,500 individuals with developmental disabilities over the age of 16 in Norway. Data from 2017 reveals that around 80% of them reside in group homes.

"In 4 out of 5 group homes we studied, residents were socially isolated during the pandemic. In one of the homes, 13 residents were isolated in their apartments from March to August 2021. Social isolation of people with developmental disabilities violates human rights and is illegal," says Postdoctoral Research Fellow Ellen Margrete Iveland Ersfjord from the University of Agder's Department of Health and Nursing Sciences.

All five group homes were found to have violated human rights in various ways. Norway has ratified the [UN Convention on the Rights of Persons with Disabilities](#). The researchers identified violations of several rights, most notably:

- The right to all [human rights](#) and fundamental freedoms (Article 1).
- The right not to be subjected to deprivation of liberty (Article 14)
- The right to the highest attainable standard of health without discrimination on the basis of disability (Article 25)

In the new research article, it is revealed that staff at one of the group homes received instructions from the municipal medical officer to isolate the residents in their apartments. They were denied access to communal kitchens, living rooms, and other common areas for a period

of six months in 2021. Staff utilized personal protective equipment when feeding and caring for the residents.

When the manager and staff raised concerns regarding the appropriateness of this practice, they were instructed by the municipal medical officer to continue enforcing these measures.

"It was distressing for the staff to isolate the residents, but they were directed to do so and followed the instructions given," says Associate Professor Hege Mari Johnsen from the University of Agder's Department of Health and Nursing Sciences.

Another identified challenge was that this part of the health care services was not prioritized for digitalization, leading to significant communication difficulties among staff. Thirty staff members could be sharing two [desktop computers](#), and many substitute staff members did not have work emails.

The researchers emphasize that there is little reason to blame the staff in the group homes.

"These are employees who want to perform their jobs well and create the best possible conditions for the residents. However, there is a lack of knowledge in this sector. Only 10% of employees in these services are social educators, and a third of them do not have education or sufficient knowledge about people with developmental disabilities. Even municipal medical officers do not have adequate knowledge about people with developmental disabilities," says Ersfjord.

Human rights violations

People with developmental disabilities living in group homes rent municipal apartments and receive municipal services. The municipal

health care services in the five group homes investigated were lacking for a prolonged period during the pandemic, such as annual check-ups with their general practitioner and physiotherapy.

Staff members had contact with the residents, which occurred either while wearing full [personal protective equipment](#) or with face masks and gloves. Hugging was also prohibited, so the residents did not have physical contact with others for an extended period of time. This did not apply to all five group homes continuously, but during different periods.

A group home consists of apartments and common areas. In 4 of the 5 group homes investigated, the common areas were eventually opened, so the residents could interact with each other and the staff. Visitor restrictions were introduced at a later time or after the staff had been vaccinated.

'Chaotic conditions'

The researchers conclude that numerous individuals with developmental disabilities encountered [human rights violations](#). They call for increased knowledge about developmental disabilities within the health care sector.

"In the early stages of the pandemic, managers at several group homes were unsure how to comply with the infection control regulations. The managers described chaotic conditions and receiving a multitude of different instructions. This resulted in widely differing interpretations of the infection control regulations," says Ersfjord.

Staff members reported that the residents are still struggling with psychological repercussions.

Shut out the world

In one of the group homes, the manager opted for a completely different approach to isolating the residents within their apartments. Based on their professional knowledge and conversations with the residents, they decided to close the group home to all visitors. While the staff members could come and go, the residents were not allowed to leave the group home. This allowed the residents and staff to interact nearly unrestricted within the confines of the home. The manager chose to rather shut out the world.

"In this way, the residents were able to cultivate a social community among themselves and the staff, which proved to be invaluable throughout the pandemic, especially given the prolonged closure of their day programs and recreational activities. Maintaining social contact with others is just as important for individuals with developmental disabilities as it is for others," explains Ersfjord.

However, she also emphasizes that there is no legal basis for locking the front door in this manner.

A call for increased knowledge

One of the main findings of the study is that clear municipal contingency plans for assisted living facilities were lacking during the pandemic. Therefore, the researchers conclude that the government's measures were inadequate in ensuring the delivery of quality municipal services for individuals with developmental disabilities residing in group homes. At present, too much depends on the proactive initiatives of managers.

"We cannot have it this way in future pandemics. This sector needs a major knowledge boost, from municipal medical officers to substitute staff. There was no justification for isolating individuals with [developmental disabilities](#) longer or in a different way than the general population during the pandemic. We must also ensure that they receive

adequate health care services," says Ersfjord.

More information: Ellen Margrete Iveland Ersfjord et al, Ansattes erfaringer og strategier for å opprettholde omsorg for personer med utviklingshemming som bodde i tilrettelagt bolig under covid-19-pandemien, *Tidsskrift for omsorgsforskning* (2023). [DOI: 10.18261/tfo.9.2.2](https://doi.org/10.18261/tfo.9.2.2)

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