

## EUROPEAN EXPERT GROUP ON TRANSITION FROM INSTITUTIONAL TO COMMUNITY-BASED CARE

## Joint Statement:

## COVID-19 crisis: People living in institutions must not be written off

The European Expert Group on the Transition from Institutional to Community-based Care (EEG) calls on EU leaders to ensure its response to COVID-19 takes into consideration persons living in institutions in Europe as they face increased risks of abuse, neglect, health issues and mental distress. Adequate funding to social and care sector is needed, as well as support to families and carers. This can prevent an increase in institutionalisation and a worsening of the conditions of those who are living in residential segregating settings.

As the pandemic gathers pace, public authorities are struggling to protect the health and well-being of people in need of care and support and especially of those living in residential institutions.

Whilst governments have focused on addressing the health and economic aspects of the crisis, **the social care sector is being left behind**, with drastic consequences on service availability. Support services are adapting to respond to new needs; however the lack of flexibility in funding is putting many community-based services at risk of closure. Some services, including homeless shelters, are forced to stay open but lack public support for protective materials, and extra staff to compensate for sick staff and more users. Residential services are often the last receiving hygienic and personal protection equipment. This results in increased vulnerability for already vulnerable groups.

The current crisis also intensifies the problems of institutionalisation: the health risks are enhanced by the concentration of people, and countless are dying in institutions, isolated from their family members. **Children, older people, persons experiencing homelessness, persons with disabilities and mental health problems who are segregated in short-term and long-term residential institutions are now more vulnerable to human rights violations than ever. They face increased risks of**:

- **Infection:** overcrowding and sometimes unhygienic conditions, lack of personal protective equipment for residents and staff, and communal life typical of institutions mean that those inside are much more prone to becoming infected;
- Abuse, neglect, lack of care, and forced placement: there are potential staff shortages, and the isolation and ban on visits aimed at protecting the residents, hinders the supervision by families or support networks and there is also the increased risk of trafficking and exploitation;
- Forced medication and forced restraint measures: under the pretence of preventive measures, existing safeguards may be circumvented;
- **Mental distress**: preventive measures, isolation, lack of clear information, forced confinement leading to a lack of contact with the outside world, albeit necessary, impact severely on mental health of persons living in institutions;
- Denial of medical treatment, risk of severe and possibly lethal forms of the illness: many persons living in institutions have underlying health conditions with higher risk of health complications; in countries where health services are prioritising the provision of ventilators on the basis of a patient's expected lifespan, they can be forced to forego life-saving appliances
- Immediate and underprepared changes to care placements: residents risk being immediately moved to different placements with little preparation, monitoring and support, which can leave them in a more vulnerable position.

Families with members with care or support needs are losing their financial stability, physical and mental health; and increased incidence of domestic and gender-based violence has been reported. When the provision of care and support is interrupted, parents and family carers are left alone to cope with the needs of their family members (personal care, therapy and other) without adequate support, respite and social protection. There are also families, with children with and without disabilities, who did not need social assistance previously and that are now in need of support. However, as they are not currently supported by any service or EU programme, the system to support families and children is not aware of them. All of these issues may lead to increased family separation and abandonment, and enhanced risk of institutionalisation.

The European Union is based on common values which include equality, respect for human dignity, and human rights. This should not be forgotten in times of crisis. The EU must urgently act, by mobilising and directing funding to ensure the safety and respect of the human rights of persons with care and support needs, of family carers and staff.

We welcome that the EU took action to respond to the crisis coordinated by the European Commission, adapting its common fiscal and mobility rules to the current situation. We welcome the <u>Coronavirus Response Investment Initiative</u> that will provide resources to face

the immediate consequence of this crisis. This budget will help strengthen healthcare systems, support SMEs and short-term employment schemes. We regret, though, that the social care sector, part of the frontline of this emergency, was not explicitly mentioned.

## We call on the European Commission and Member States to mobilise this budget to guarantee the continuity of care and support and to take the following measures:

- Provide extra funding to support services and ensure they can meet the increased costs associated with this crisis (medicines, protective materials and staff costs);
- Ensure services can keep on receiving their funding even in cases of online support forms which are currently not recognised by their contracts;
- Continue the provision of family support services during the pandemic;
- Designate providers of support services (including care, support workers and personal assistants) as 'key workers' who can safely work and travel to their workplace;
- Ensure services receive personal protective equipment and other relevant medical material as needed;
- Avoid new admissions in institutions and forced treatment by ensuring continuous access to community-based support services;
- Introduce **proactive**, **widespread testing and stricter preventive measures** for people living in institutions, staff and support networks;
- Ensure that persons living in institutions have equal access to treatment and ventilators;
- Ensure that residents can contact their families and support networks outside the facility in privacy via to accessible means of communication (including for those who use non-verbal forms of communication);
- Provide information to persons living in institutions on their rights and means to report violations, to avoid coercive measures and prevent abuse;
- **Carry out independent monitoring of the activities of institutional care facilities** to ensure that residents are not abandoned or put in danger by staff shortages;
- Support relevant agencies in developing continuity plans for situations in which the number of available staff may be reduced: reducing bureaucratic recruitment barriers and maintaining protection measures;
- Include urgent measures to **protect people experiencing homelessness** living rough and in homeless shelters;
- Allow all children and persons with care/support needs who can safely return to their families for the duration of the epidemic to do so, while providing the families with the support they need and allow children assessed for family-based care to move to their foster families;

- Plan measures to identify emerging families at risk and contact them before family separation takes place due to increased risk of poverty, violence, mental health issues, etc.;
- Apply **emergency social security measures to families** caring for people with long-term needs;
- Involve persons in need of care or support, families and their representative organisations in the planning and implementation of emergency measures
- Activate **preventative measures** to strengthen families, communities and marginalized groups of society, to avoid increases in institutionalisation.

We welcome that the <u>Solidarity Fund</u> can now be used for major public health emergencies and that it will be mobilized to support the most affected countries. We call on the use of part of this fund for the protection of the social and care sector:

- To take measures to promote the **prioritisation of personal protective equipment for professionals working in social services** and **residential facilities**, in daily contact with Europeans most at risk;
- To provide countries which lack personal protection kits with the equipment and materials they need to avoid infection, prioritising frontline employees, including staff of the social care sector;
- To provide **emergency housing**, so that people are not forced into institutions.

We welcome the proposal for a <u>Council Regulation</u> for temporary Support to mitigate Unemployment Risks in an Emergency (SURE) to help protect jobs and workers affected by the coronavirus pandemic. Part of SURE should go to the social and care sector to keep in employment the staff of the services that had to suspend their activities, and to allow increasing income support, flexibility and take of leaves for family carers.

We welcome the actions from the **European Central Bank** and of the **European Investment Bank** to give loans to SMEs hit by the corona crisis. These **funds should also be made available to the social care sector** to comply with the new needs emerging from this crisis.

We remind the European Union and its Member States that they ratified the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Convention on the Rights of the Child, legal instruments that need to be respected. The <u>report</u> *Coronavirus pandemic in the EU - Fundamental Rights Implications*, released by the European Union Agency for Fundamental Rights, can be a good starting point for appropriate response to the impact of COVID19 on the most vulnerable people, including people in institutions. These are humanitarian steps to prevent immediate harm of the most vulnerable in society in addressing this health crisis. The EEG calls on the EU to use this crisis to continue its process of transition from institutional to community-based services.



The European Expert Group on the Transition from Institutional to Community-based Care (EEG) is a broad coalition gathering stakeholders representing people with care or support needs and their families, including children, people with disabilities, homeless people, and people experiencing mental health problems; as well as service providers, public authorities and UN organisations. The Group has as its mission the promotion of person-centred, quality and empowering models of services and formal and informal care that fully respect the human rights of all people with care or support needs. The Group supports national efforts to implement the necessary reforms, in compliance with the United Nations Convention on the Rights of the Child and the European Charter of Fundamental Rights.

For more information:

EEG scope www.deinstitutionalisation.com

**EEG webpage on COVID 19** <u>http://deinstitutionalisation.com/2020/04/24/eeg-members-are-collecting-resources-about-the-covid-19-health-crisis/</u>

Joint Statement: "COVID-19 crisis: People living in institutions must not be written off" (<u>HTML version</u>)

Contacts: <a href="mailto:condinator@deinstitutionalisation.com">condinator@deinstitutionalisation.com</a>

EEG co-chairs (January-December 2020)

Irene Bertana ibertana@coface-eu.org

Aaron Greenberg <u>agreenberg@unicef.org</u>

Irina Papancheva irina.papancheva@wearelumos.org