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### OPEN LETTER TO LEADERS AT THE EU AND IN EU COUNTRIES: COVID-19 – DISABILITY INCLUSIVE RESPONSE

13 March 2020

In the light of the current pandemic and its disproportionate impact on persons with disabilities, the European Disability Forum (EDF) has developed the following recommendations for policy makers, through discussion with our members., based on our members' current work, and priorities. These recommendations aim to address the range of risks persons with disabilities face. Persons with disabilities face the same risk as the rest of the population, compounded by many other issues: disruption of services and support, in some cases, pre-existing health conditions which leave them more at risk of developing serious illness or dying, being excluded from health information and mainstream health provision, living in an inaccessible world where barriers to good and services are everywhere, being disproportionately more likely to live in institutional settings.

## **Making public health communication accessible**

Every person has the right to immediate and correct information on the epidemic and the measures they and their families should take. This includes:

ensuring all information is in plain language and easy to read

providing alternative and accessible methods of accessing general information, not only relying on websites (automatic phone lines, videos, leaflets, etc)

appropriate sign language interpretation and captioning

information provided in plain language and in easy to read format

use of fully accessible digital technology

ensuring telephone numbers and other direct channels providing public health information are fully accessible, including relay services for deaf and hard of hearing people

ensuring emergency numbers (both 112 and specific phone numbers set up for this pandemic) are fully accessible, including relay services for deaf and hard of hearing people

Special attention must be paid to the accessibility needs of deafblind people, as they will be very negatively impacted by social isolation measures – authorities must provide websites with plain text and sign language interpretation in larger size (as opposed to small windows on the corner of the image)

This applies to all public and private information including national and local news providers (both live and recorded) and health services. Specific web pages with frequently asked questions for concerns of persons with disabilities and their families can be also useful.

## **Non-discriminatory ethical medical guidelines**

In countries where healthcare professionals will not be able to provide the same level of care to everyone due to lack of equipment and underfunding of the healthcare sector, medical guidelines need to be non-discriminatory and follow international law and existing ethics guidelines for care in the event of disaster and emergencies. These are clear: persons with disabilities cannot be discriminated against.

In producing these guidelines authorities must take into account their commitment to the UN Convention on the Rights of Persons with

Disabilities, especially [article 11](#) - situations of risk and humanitarian emergency.

They must also following existing best practice such as:

the [World Medical Association Statement on Medical Ethics in the event of disasters](#) - “in selecting the patients who may be saved, the physician should consider only their medical status and predicted response to the treatment, and should exclude any other consideration based on non-medical criteria.”;

the [Bioethics Committee of the San Marino Republic](#) produced guidance specifically for COVID-19: “The attribution of priority of treatments to be deliver as well as the victims to be treated cannot fail to take into account the fundamental ethical principles, which materialize in a correct application of triage, trying to optimize the allocation of resources. The only parameter of choice, therefore, is the correct application of triage, respecting every human life, based on the criteria of clinical appropriateness and proportionality of the treatments. Any other selection criteria, such as age, gender, social or ethnic affiliation, disability, is ethically unacceptable, as it would implement a ranking of lives only apparently more or less worthy of being lived, constituting a unacceptable violation of human rights.”

### **Accessible, inclusive, hygienic health services and other facilities**

Facilities and services involved in providing quarantine should be fully accessible to persons with disabilities, including full accessibility of information.

Sign language interpreters, personal assistants and all others that support persons with disabilities in emergency and health settings should be given the same health and safety protections as other health care workers dealing with COVID19.

Health care workers should be informed about the risks facing people with pre-existing conditions which leave them vulnerable to respiratory conditions.

Instructions to health care personnel should highlight equal dignity for people with disabilities, that communication should be done directly with the person with disabilities whenever possible. They should include safeguards against disability-based discrimination. Rapid awareness-raising of key medical personnel is essential to ensure that persons with disabilities are not left behind or systematically deprioritized in the response to the crisis.

All entry points to health facilities (including those which may have been deemed 'secondary' entrances and which are, in fact, the only accessible approach) should be treated with the same hygiene protocols as all other parts of the service. This includes cleaning handrails of ramps or staircases, accessibility knobs for doors, etc.

Sterilisers and other hygiene materials should be equally available for persons with disabilities. They should be located in an accessible place, there should be accessible information to point to its location, and the mechanism to dispense the product should be accessible.

EU should provide countries with a lack of personal protection kits with kits to avoid infection. This equipment should be for frontline employees such as healthcare staff, social workers, law enforcement officers, etc.

Persons with disabilities should not be segregated into separate facilities, where healthcare for COVID-19 is often of a lower standard.

### **Invest in provision of services and support - European solidarity is needed to ensure strengthening of essential services**

Health and social care systems are consistently underfunded across the EU. Investment in these services is essential and urgent to ensure they can meet the increased costs associated with the crisis, including medicines, protective materials and overtime of staff, in a way that is inclusive of everyone in the affected population.

EU needs to provide additional emergency financial support to help Member States at this extremely difficult time for some countries.

### **Involving persons with disabilities**

Persons with disabilities, through their representative organisations (Disabled People's Organisations - DPOs), are the best placed to advise authorities on the specific requirements and most appropriate solutions when providing accessible and inclusive services.

All COVID-19's containment and mitigation activities (not only those directly related to disability inclusion) must be planned and implemented with the active participation of persons with disabilities and DPOs - this applies to community and population wide initiatives as well as to individual situations.

## **Ensuring marginalised and isolated people are not left without essential goods, support and human contact**

Put in place flexible mechanisms to authorise persons with disabilities to be able to leave their homes during mandatory quarantines, for short periods and in a safe way, when they experience particular difficulty with home confinement.

Check and guarantee that residents are not being abused and neglected and that forced seclusion, forced restraint and forced medication are not being used or escalated during this crisis

Introduce proactive testing and more strict preventive measures for groups of persons with disabilities, including those living in institutions, who are more susceptible to infection due to the respiratory or other health complications. This measures should extend to their support network.

Ensure that persons with disabilities in residential institutions have equal access to treatment in

Persons with disabilities should not be institutionalised as a consequence of quarantine procedures beyond the minimum necessary to overcome the stage of their illness, and should be treated on an equal basis with others. Authorities should take measures to drastically reduce the number of people in residential institutions and psychiatric units and institutions: it is not only an infringement on human rights, but they are also settings with higher likelihood of infection.

If residential and psychiatric institutions are not closed, authorities should urgently ensure that strict hygiene and prevention measures are guaranteed.

Authorities should conduct visits and carefully monitor the activities of institutional care facilities to ensure that residents are not left abandoned or put in danger by staff shortages and absence. Residents should have access to information on their rights and means to report violations.

Government planners must consider that mobility and business restrictions disproportionately impact persons with reduced mobility and other persons with disabilities and allow for adaptations. Examples of such adaptations can include specific opening hours to persons with disabilities and older persons or priority delivery services.

When visits to care facilities are banned and social distancing is recommended, people who are already more isolated will be among those most impacted. Nobody should be left without support, food and essential services. Planners must ensure that no-one is left behind.

The EU guidelines should ensure that EU countries focus on particularly vulnerable groups, such as persons with disabilities and their families. They need to make sure they receive all the support they may need as a result of their greater vulnerability.

Provide an accessible hotline for disability services so that service users and people in the support network are able to communicate with government and raise concerns.

Provide persons with disabilities and their family members with information and guidance on what steps they can take in case their personal assistants, carers or other professionals providing support become ill with COVID-19.

In case of food or hygienic products shortage, immediate measures must be taken to ensure that people with disabilities are not left out and receive essential goods and services as a matter of priority.

Any program to provide support to marginalised groups should be disability-inclusive.

All plans to support women should be inclusive of and accessible to women with disabilities and, conversely, programs to support persons with disabilities should include a gender perspective

Conduct community outreach activities to identify and rescue persons with disabilities deprived of their liberty or ill-treated at home or within communities and provide adequate support to them in a manner that respects their human rights.

## **Support networks and assistive devices**

Earmark EU funding from the European Coronavirus Response Investment Initiative specifically to support community-based disability support services.

Funding and practical solutions must be available to ensure that persons with disabilities are not negatively affected by the temporary loss of people from their support networks (including personal assistants, family, and specific professional services) through illness or indirect impact of COVID-19.

Designate providers of support services (including care, support workers and personal assistants) as 'key workers' who should continue to work and be provided with the personal protective equipment and instructions needed to minimise exposure and spread of infection, as well as be proactively tested for the virus. Workers should be allowed to travel to and from the workplace (both organisations or clients' homes).

Urgently provide personal protection kits to persons with disabilities (including those in residential institutions), their carers and support workers, including personal assistants and deafblind interpreters.

Provide persons with disabilities and their family members with information and guidance on what steps they can take in case their personal assistants, carers or other professionals providing support become ill with COVID-19.

Support to agencies providing disability support, and user-led organisations, in developing continuity plans, for situations in which the number of available caregivers may be reduced. This includes reducing bureaucratic recruitment barriers while still maintaining protection measures, such as background checks for caregivers.

Invest in support services and ensure they can meet the increased costs associated with this crisis, including medicines, protective materials and overtime of staff, in a way that is inclusive of everyone in the affected population;

Ensure that support services have hygiene supplies and that strict hygiene and prevention measures are undertaken. These supplies should also be available to residents and posted in accessible formats publicly in the institutions

Similarly, services involved in the provision and repair of essential assistive devices must be prioritised

Deafblind interpreters and support staff often need to be physically close to deafblind people— authorities must ensure they receive adequate physical protection equipment and that social isolation measures allow them to do their job.

Authorities should provide an accessible hotline for disability services so that service users and people in the support network are able to communicate with government and raise concerns.

Crisis and confinement measures will greatly deteriorate mental health and generate fear and anxiety; demonstrating solidarity and community support is important for all.

## **Income protection**

Authorities need to put in place financial measures (commonly within a broader-based economic stimulus package) to support persons with disabilities. These measures may include but are not limited to as lump sum payments for qualifying individuals, tax relief measures, subsidisation of goods or leniency for the payment of specific expenses.

Authorities need to ensure that persons with disabilities and underlying health conditions can work from home, and, if this is not possible due to the nature of the job or any other reason, need to ensure a special leave that guarantees 100% of the employee's income.

Remote work or education services must be equally accessible for employees/students with disabilities. Authorities, organisations and educational institutions should ensure sign interpretation, live captioning, adapted work and any other measures in close consultation with employees and students with disabilities.

Many persons with disabilities with underlying health conditions may need to stay at home for longer periods than average. Organisations and educational institutions must ensure that the remote systems will be kept in place to ensure persons with disabilities can still work and study during these extended periods.

In many countries there are radical changes being made in public services, including closure of education and rehabilitation services, day care facilities and crèches. It is essential that people who must leave work in order to support their family members, or others they may be assisting, continue to receive an acceptable level of income during this period

### **Ensuring that public health communication messages are respectful and non-discriminatory**

Many people with pre-existing health conditions, older people, and people with complex needs are more at risk of serious health complications due to COVID-19. However, public messaging on the topic must be respectful and free of bias, avoiding potential of discrimination towards any part of the population based on age or disability.

Ensure that public health messages in accessible format reach persons with disabilities segregated in institutions (including psychiatric institutions).

Use images that are inclusive and do not stigmatise people.

### **Guaranteeing the rights of women and girls with disabilities**

Ensure data disaggregated by sex and disability is available when compiling information: include differentiated infection rates, information on barriers faced by women when accessing available humanitarian aid, and the rates of domestic and sexual violence.

Consult directly with organisations of women with disabilities concerning the situation faced by women and girls with disabilities, and in particular their needs and the steps that must be taken to face the pandemic.

Include the gender dimension in the responses you are offering to people with disabilities. Responses should differentiate the particular needs of women and girls with disabilities, but also the specific needs they may have within each specific disability group.

Involve women with disabilities in all stages of your responses and in all decision-making processes.

Ensure women with disabilities working in all essential sectors (including healthcare, social services providers, shops, farming, sanitation, food production) are adequately taken care of and protected in the face of potential infection. This includes access to information, to personal protective equipment and hygiene products (including menstrual products).

Support local organisations of women with disabilities or community-based groups of women with disabilities in developing accessible messages about prevention strategies and responses.

Ensure access to sexual and reproductive health services, including prenatal and postnatal healthcare for women.

Adopt measures to provide direct compensation to informal women workers, including healthcare staff, domestic staff, migrants and those in other sectors most affected by the pandemic.

Foster policies to recognise, reduce and redistribute the unpaid work inside homes for healthcare reasons and to look after persons with disabilities, work mostly carried out by women, including women with disabilities.

Ensure services in response to violence against women and girls stay available, including to women and girls with disabilities, or introduce them where they do not currently exist (helplines, shelters, etc).

### **Ensuring persons with disabilities are counted**

Health information systems and monitoring, and new systems used to monitor and contain the spread and effect of COVID-19 should be disaggregated by age, sex and disability.

### **Ensuring non-nationals are protected**

The EU should guarantee Member states pay due attention, without discrimination of any kind, to every person regardless of their nationality.



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