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(Final version)

Discrimination against persons dealing with chronic and long-term illnesses

Contents	Page
A. Draft Resolution	2

A. Draft Resolution

1. Chronic and long-term illnesses are non-communicable diseases that often require long and expensive treatment for the community. They are the main causes of general and premature mortality. They alter the lives of at least a third of the European population. This percentage increases with age as these diseases strike the most vulnerable more frequently. They are more common in women than in men and are particularly frightening when children are concerned. The prevalence of multi-morbidity is increasing due to the ageing of the population, but also to the combined effects of poverty, pollution and global warming.
2. Chronic and long-term illnesses are obstacles to dignity, well-being and self-fulfilment. Often difficult to diagnose, they can be particularly disabling in their most critical expressions, when they are not fatal. They are a source of discrimination and hinder the affected who may be deprived of their autonomy, their participation and their full integration into society. Because of their direct and indirect effects, they harm the "full and equal enjoyment of all human rights and all fundamental freedoms", fall within the scope of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and involve obligations on the part of the States Parties to the convention.
3. Through their various public policies (health, social, research, employment, education, etc.), the authorities are able to limit the number and consequences of chronic and long-term illnesses. The CRPD offers an innovative vision of disability and disabilities. Some countries have indeed taken up this challenge, applying different strategies. Others have chosen to deny the existence of these diseases, at the risk of leaving patients to face their vulnerabilities alone and maintaining inequalities.
4. Neither are chronic and long-term illnesses the result of a reasoned choice. It is thus not acceptable that they are considered by certain actors in society as risk factors. In order to fight against the arbitrariness suffered by patients, it is necessary not only to adopt the paradigm shift proposed by the CRPD, but also to systematically tackle the obstacles caused by these diseases, which prevent patients from living their lives, and to rally around a common objective: the preservation of their dignity and well-being. The voice of patients must be heard throughout the preparation, implementation and evaluation of public policies related to chronic and long-term diseases. Patients cannot be satisfied with equality when their wish is primarily to preserve their right to well-being and self-fulfilment. It is not for them to adapt to society, but for society to adapt to them, with due regard for reasonable accommodation.

Amendment 1 **Tabled by the Committee on Equality and Non-Discrimination**

In the draft resolution, paragraph 2, after the words "They are a source of" insert the following word:

"multiple"

Amendment 2 **Tabled by the Committee on Equality and Non-Discrimination**

In the draft resolution, paragraph 3, after the word "disabilities" add the following sentence:

"It makes full and effective participation and inclusion in society a priority."

Amendment 3 **Tabled by the Committee on Equality and Non-Discrimination**

In the draft resolution, paragraph 4, after the word "obstacles" add the following words:

"and discrimination"

Amendment 4 **Tabled by the Committee on Equality and Non-Discrimination**

In the draft resolution, at the end of paragraph 4, after the words "reasonable accommodation" insert the following words:

"and the principles of equality and non-discrimination."

5. Each individual is called to contribute to the general well-being, without hindrance. In order to remedy the profound social disadvantage experienced by people with chronic and long-term illnesses, the Parliamentary Assembly reminds Council of Europe member States of their commitments made on the occasion of the ratification of the CRPD. It invites them to continue their efforts in the fight against exclusion, by adopting strategies that revive the spirit that marked the birth of our public health systems and are aimed at strengthening the role of the welfare State, in order to improve the effectiveness and resilience of health systems, and ensuring universal access to health. The current health crisis has reminded us that administrations must be prepared to respond to the unexpected while being attentive to changes in society and eliminating obsolete regulations. The Assembly invites Liechtenstein to accede to the CRPD so that no European country remains outside this framework, which is innovative and adapted to the needs expressed by people encountering obstacles in their immediate social and physical environment.
6. The Assembly urges member States, on the basis of the provisions contained in the CRPD and examples of good practice resulting from co-operation between peers:
 - 6.1. to strengthen the capacities of screening and prevention concerning chronic and long-term illnesses and to adopt a holistic approach, which is regularly reviewed and adjusted, and involves all sectors of the administration for the well-being of individuals, the fight against inequalities and vulnerabilities. The authorities must fight against diagnostic delays so that, after a certain period, which should not be longer than one year, each patient is able to exercise their rights again without hindrance;
 - 6.2. to support and develop the offer of care and services allowing the preservation of well-being and self-fulfilment, while allocating sufficient resources and funds to achieve this objective, which is legitimate for everyone within the jurisdiction of the European Court of Human Rights, in particular when it comes to the professional sphere, by strengthening the resources of occupational medicine, which is often the patient's first interlocutor at the time of diagnosis or return to work. The Assembly calls once again on the national authorities to establish access to universal health care;
 - 6.3. to ensure that the obstacles preventing chronic and long-term patients from exercising their legitimate right to dignity, well-being and self-fulfilment are subject to sufficiently dissuasive sanctions to enable patients to exercise their rights to well-being and fulfilment, in their professional or private life;
 - 6.4. to conduct, in partnership with civil society, evidence-based and effective awareness-raising campaigns on chronic and long-term illnesses among the general public, ensuring the right to a normal life through the full enjoyment of human rights and fundamental freedoms;
 - 6.5. to involve all stakeholders in policy development, evaluation and implementation, including people with chronic and long-term illnesses and their families, including by sharing the results of impact evaluations. The

Amendment 5**Tabled by the Committee on Equality and Non-Discrimination**

In the draft resolution, paragraph 5, after the words "social disadvantage" add the following words:

"and discrimination"

Amendment 6**Tabled by the Committee on Equality and Non-Discrimination**

In the draft resolution, paragraph 6.1, replace the word "vulnerabilities" with the following words:

"the taking into account of vulnerabilities."

Amendment 7**Tabled by the Committee on Equality and Non-Discrimination**

In the draft resolution, paragraph 6.2, after the words "return to work" insert the following sentence:

"Adaptation of the workstation should be offered where possible."

real consequences of certain diseases still seem too little-known (Lyme disease, etc.).

7. The Assembly suggests that member States do more to control the removal of obstacles to the rights of patients living with chronic and long-term illnesses, in order to encourage actors in the private sector to share the same approach with a view to fighting against discrimination suffered by patients because of their status. It recommends evaluating patient protection systems such as the "right to be forgotten".
8. The Assembly stresses the important role of parliaments. It invites them to promote the principles contained in the CRPD, to adopt legislation in line with the convention, to ensure the allocation of sufficient budgetary resources, to encourage the public authorities to adopt appropriate national strategies and action plans, and to demand accountability for their effective implementation. It also encourages parliamentarians to contribute to awareness-raising actions on an individual basis.
9. The Assembly recognises that people with chronic and long-term illnesses and their families are severely and disproportionately impacted by the measures taken to combat the novel coronavirus during the current pandemic. Thus, it calls on member States to pay particular attention to their needs, in view of these circumstances, including after their recovery, insofar as Covid-19 could be the cause of chronic illnesses.
10. Finally, in the context of the Covid-19 pandemic and in anticipation of the revision of Directive 2000/78/EC, the Assembly encourages the European Union to accede to the European Social Charter (revised) (ETS No. 163) before extending its powers in the area of health, in order to monitor and improve the state of health in the European Union. It also reiterates its encouragement to the remaining Council of Europe member States to sign and ratify, as soon as possible, the revised European Social Charter.

Amendment 8

Tabled by the Committee on Equality and Non-Discrimination

In the draft resolution, paragraph 7, replace the last sentence with the following sentence:

"It calls on the national authorities not only for the adoption of a clear definition of the right to be forgotten but also for the effective and uniform implementation of this protection. It recommends the evaluation of patient protection systems."