



Declassified¹
AS/Soc (2020) PV 06add
9 October 2020
Asocpv06add_2020

Committee on Social Affairs, Health and Sustainable Development

Minutes

Public hearing on “Discrimination against persons dealing with long-term illness”, held via videoconference, on Tuesday, 22 September 2020

In the framework of the report currently in preparation on “Discrimination against persons dealing with long-term illness” with Ms Martine Wonner (France, ALDE) as rapporteur, the Committee held a public hearing with the participation of:

- ✓ Ms Matilde Leonardi, Director – Neurology and public health unit, IRCCS Foundation Carlo Besta Neurological Institute (Italy)
- ✓ Mr Kawaldip Sehmi, Director General, International Alliance of Patients' Organisations (IAPO)
- ✓ Mr Ignacio Doreste, Adviser, European Trade Union Institute, European Trade Union Confederation (ETUI)

Mr Leite Ramos, the Chairperson, briefly introduced the guest speakers and gave the floor to the rapporteur.

Ms Wonner pointed out that there was a wide range of long-term illnesses causing physical disorders which were often disabling, affecting the way their sufferers were perceived by society, preventing them from exercising their rights fully and leading to their exclusion. She had decided to broaden this report to cover all the types of stigmatisation affecting people with disorders associated with psychiatric disease, which could sometimes result in exclusion, since they were also denied dignity and self-fulfilment. The theme of the report was relevant to the current context of the Covid-19 pandemic. New challenges had been added on top of deeply entrenched problems. Associations of Covid-19 victims were likely to emerge given the impact of the illness. She welcomed the ideas provided by the experts on these major challenges, along with their recommendations, which reflected the viewpoint of research, trade unions and patients. These recommendations would complement the information passed on by parliaments through their answers to a questionnaire submitted to the European Centre for Parliamentary Research and Documentation (ECPRD).

Ms Leonardi took the floor to describe the work of the European Commission in this sphere, illustrating her words through the results of two European projects whose aim was to develop ground-breaking approaches to promoting the vocational integration of persons with chronic illnesses, enhancing their employability, improving their access to employment and fostering their participation – Pathways² and Chrodis.³

These projects supported the European Commission's ambition to establish an inclusive labour market, enabling employers and employees to know and understand more about patients' situations.

Although, in some countries, patients were protected by their disabled status, protection was often partial and did not include long-term protection of employment. These illnesses did not always prevent patients from working. Stigmatisation, discrimination, and lack of awareness-raising severely affected the effectiveness of strategies to improve these persons' vocational integration. It was regrettable that there was no protection based on a human right and she proposed a pragmatic approach that would mean that nobody would feel left by the wayside. If it was impossible to change the illness, then the job should be changed through organisational adjustments. Attempts to protect people could actually compound discrimination. This was all

¹The minutes were approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 9 October 2020, held by videoconference.

² <https://pathwayproject.eu/>

³ <http://chrodis.eu/>

the more blatant when persons suffered dual discrimination because they were already part of vulnerable groups (women, children, migrants or minorities).

Mr Sehmi insisted, in his introduction, on the impact of the Covid-19 pandemic on sufferers of chronic and long-term illnesses. The furlough systems set up by European governments had provided protection but had only been a qualified success. The situation also generated additional stress because it forced patients to pay more attention to risks, putting them in danger of losing their jobs if they could not go to work anymore. Some patients were effectively prevented from going into work and could no longer access medical care. Alongside these indirect forms of discrimination, there were direct forms such as that suffered by parents of children with chronic or long-term illnesses who could no longer go to work because schools and care facilities could no longer accept children with illnesses owing to their excessive vulnerability. The Covid-19 crisis had merely highlighted and exacerbated existing forms of discrimination. In his view, Europe should be more empathic. Persons with chronic or long-term illnesses felt that they had been tolerated but never accepted over all these years. There was a need to start from scratch to “build back better” the system, listening to the people concerned and involving them in policy making so that they could help their employers to become more productive.

Mr Doreste noted that there was no single definition for chronic and long-term illnesses. This room for interpretation was the reason why the legislation differed between EU member states. For many countries, these illnesses were associated with disability. In his view, each illness should correspond to a disability, as the United Nations had suggested and had been recognised in Directive 2000/78/EC of the European Union on equal treatment in employment and occupation. To take workers with disabilities into account, Article 5 demanded that “reasonable accommodation” should be made for them, but the European legal framework was not sufficiently clear, particularly with regard to funding for such accommodation. The Commission had started consultations with a view to revising this directive.

Mr Kruglyi suggested that it should be discussed why it was so difficult for patients suffering from rare illnesses to access gene therapy.

Baroness Massey asked how the checklist mentioned by Ms Leonardi which set out the criteria by which to gauge inclusivity and avoid exclusion worked. Excluding children from schools because of their vulnerability was traumatic for children.

Ms Leonardi announced that the checklist would be available in eight languages from October onwards, and accessible to all on the project website.

Mr Amraoui emphasised the need to allow occupational medicine to play its role. Employers should guarantee the health and safety of “all employees” in the sphere of work.

Ms Wonner thanked the experts for outlining their viewpoint. She would draw on this information to continue her work on the report.

The Chairperson warmly thanked the experts for their contributions and closed the hearing.

Committee on Social Affairs, Health and Sustainable Development
Commission des questions sociales, de la santé et du développement durable

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| Mme Edite ESTRELA | Portugal |
| Ms Nina KASIMATI | Greece / <i>Grèce</i> |

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