

INCLUSION OF PEOPLE WITH CHRONIC CONDITIONS IN THE WORKPLACE AND COMBATting DISCRIMINATION

EPF Multi-Stakeholder Meeting Report

21 May 2019

Radisson Red Hotel, Brussels



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2. Introduction

While some people with chronic conditions cannot continue their professional activity due to their health condition, many continue working or wish to do so. Employment can contribute significantly to well-being, quality of life and inclusion, provided adequate support is received.

Discrimination has been identified in many instances as a principal obstacle to employment for people with chronic conditions. Successful inclusion and non-discrimination of people with chronic conditions in the workplace depends on many factors, including appropriate rights for employees with chronic conditions, information and awareness of chronic conditions in the workplace and co-operation across sectors and policies.¹

Combatting these types of non-discrimination is one of EPF's core values and strategic goals.² EPF advocates for the development and implementation of policies, strategies and initiatives at national and EU level that eliminate discrimination, reduce stigma³ and promote the inclusion of patients with chronic diseases in employment and other sectors.

In 2016, EPF highlighted this topic in its position "Equal treatment for patients in education and employment"⁴ and set up in 2017 a temporary task force⁵ which developed a set of materials. These included recommendations to promote better inclusion of people with chronic conditions in the workplace in the context of the European Pillar of Social Rights.⁶ EPF continues to co-operate with the Fundamental Rights Agency (FRA)⁷ in relation to the EU anti-discrimination legislation framework, and works with partners on several initiatives, including the CHRODIS Plus Joint Action work package on employment and chronic conditions.⁸ EPF also runs the Youth Group, which addresses, amongst others, employment and discrimination issues from the perspective of young European patients.⁹

The "Multi-Stakeholder Roundtable on the Inclusion of People with Chronic Conditions in the Workplace and Combatting Discrimination" built on these initiatives and actions. The event was a natural next step for EPF and a milestone for Patient organisations¹⁰ that have to date played an important role in carrying out research in this field, applying it to advocate for the rights of patients in the workplace and combatting experienced stigma and discrimination.

The main objectives of the Multi-Stakeholder Roundtable were to discuss ongoing interesting initiatives, provide a platform where different actors can exchange and identify potential opportunities, revisit challenges faced by people with chronic conditions and identify how to overcome them together and to put forward recommendations for the new Commission. The event was attended by 29 stakeholders, including patient representatives from different disease-areas, policy makers, business representatives, civil society representatives and academics.

¹ <http://www.eu-patient.eu/globalassets/policy/employment/recommendations-for-policy-makers.pdf>

² <http://www.eu-patient.eu/globalassets/library/strategic-planning/epf-strategic-plan-2014-2020-final.pdf>

³ <http://www.eu-patient.eu/globalassets/policy/employment/recommendations-for-employers.pdf>

⁴ http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper_equal-treatment-in-education-and-employment.pdf

⁵ <http://www.eu-patient.eu/whatwedo/Policy/employment/>

⁶ <http://www.eu-patient.eu/globalassets/policy/employment/recommendations-for-policy-makers.pdf>

⁷ <https://fra.europa.eu/en>

⁸ <http://chrodis.eu/08-employment/>

⁹ <http://www.eu-patient.eu/About-EPF/whoware/Youth-Strategy/>

¹⁰ <http://www.eu-patient.eu/whatwedo/Policy/employment/patient-organisations-initiatives/>

3. Summary report

3.1 WELCOME AND INTRODUCTORY REMARKS

Elisabeth Kasilingam, Treasurer, European Patients' Forum, Managing Director of the European Multiple Sclerosis Platform



Chair Elisabeth Kasilingam opened the event, reminding participants that patients have been fighting against discrimination in the workplace for a long time and highlighted that discrimination is not a patient issue but a societal issue. To this end, all stakeholders must work together to create a solution. Stating that we need to achieve a broader impact on the mindset of society, Ms Kasilingam then put forward the question of how we can reach the missing stakeholders, such as employers and member states.

3.2 EMPLOYMENT, CHRONIC CONDITIONS AND NON-DISCRIMINATION

Katie Gallagher – Policy Advisor, European Patients' Forum



Katie Gallagher told the participants that 1 in 4 people are estimated to have long standing health problems that restrict their daily activities and that a majority of these are caused by from chronic diseases. She also said that disability and ill-health are both a cause and consequence of poverty, with incomes of persons with disabilities in Europe generally 12% lower. This is a major issue also financially because of the impact systemically excluding people with partial capacity from the workforce has on public expenditure: In some countries, the public spend on disability benefits is more than 2.5 times what is spent on unemployment benefits.¹¹

Following this introduction, Ms Gallagher gave an overview of the relevant legislation at international and EU level, discussing the UN Convention on the Rights of Persons with Disabilities (UNCPRD),¹² the Treaty on the Functioning of the European Union¹³ and the Charter of Fundamental Rights of the European Union.¹⁴ She told the participants that while these agreements address many areas of discrimination, persons with chronic conditions are not explicitly mentioned in them.

¹¹ Sickness, Disability and Work: Keeping on Track in the Economic Downturn, Background Paper OECD 2009 <https://www.oecd.org/els/emp/42699911.pdf>

¹² <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

¹³ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A12012E%2FTXT>

¹⁴ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12012P/TXT>

Ms Gallagher also discussed the Employment Equality Framework Council Directive of 27 November 2000, which establishes a general framework for equal treatment in employment and occupation, and addresses discrimination on grounds of disability.¹⁵ However, the key shortcoming of this directive is that it does not harmonise definitions of disability, which means that there is no common EU definition of disability. This creates ambiguity as to whether the Directive applies to people with chronic conditions, and, therefore, people with chronic and/or long-term conditions should be protected from discrimination on the ground of health status. Thus one of the key challenges is promoting the development of EU legislations and policies on discrimination, with a focus on employment and on the ground of health status. To this end, participants were also reminded that appropriate provisions already exist in the legislation of some Member States and need to be replicated in all Member States and at EU level.

As a way forward, Ms Gallagher said that in addition to establishing appropriate employment-related rights and legislation, there needs to be co-operation across the Health, Education, Employment, and Justice and Finance sectors. Further, this needs to be accompanied with information, training and awareness-raising, as well as creating supportive working environments for people with chronic conditions.

“Many patients wish to continue working and, with adequate support, they can. We also must be well aware of the exact definitions of discrimination, stigma and invisible disability.¹⁶ It is fundamental for people with chronic conditions to stay included in the community. It has a beneficial impact on recovery, especially for patients with mental health issues.”

3.3 KEYNOTE SPEECH: THE PATIENT’S EXPERIENCE

Peter Boyd – European League Against Rheumatism (EULAR), Young PARE and Arthritis Ireland



Peter Boyd told the participants that each patient experiences discrimination uniquely. Speaking from personal experience, he explained that in many cases patients want to continue working but cannot due to unsuitable accommodation,¹⁷ accessibility issues and social isolation in the workplace. His advice for situations such as these is to reassess, upskill and retrain: Mr Boyd told the participants that he had to give up his job after falling ill, and following this, he had to reassess what his future looked like, both from a personal and professional perspective. He realised that he would have to upskill as to what had worked up until that point would no longer be effective. This meant that he had to find new coping skills, new management skills and new planning skills. Mr Boyd explained that to gain these skills, he needed to retrain: Some of this was done in college through education so that he would be qualified for different careers. In the other retraining, he taught himself to cope and work around obstacles.

¹⁵ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32000L0078>

¹⁶ <http://www.eu-patient.eu/globalassets/policy/employment/recommendations-for-policy-makers.pdf>

¹⁷ <https://ec.europa.eu/social/main.jsp?catId=1473>

Mr Boyd reminded the audience that this approach also makes sense from the financial perspective: With support, persons with chronic conditions can help themselves and lead independent lives, instead of having to rely on welfare systems. In his inspiring story he shared how retraining and changing his career to suit his condition has also had a positive effect on his personal well-being, reminding the participants that some people struggle with depression, anxiety and mental issues because of their chronic condition.

“Your condition might not kill you, but social isolation, misconceptions and discrimination can. At the same time, don’t go into the employment field with a problem; go in with a solution.”

3.4 THE INCLUSION OF PEOPLE WITH CHRONIC CONDITIONS IN THE WORKPLACE AND COMBATting DISCRIMINATION – DG EMPLOYMENT PERSPECTIVE

Hana Velecká, Policy Officer, Disability and Inclusion Unit, DG for Employment, Social Affairs and Inclusion, European Commission



Hana Velecká told the participants that the employment prospects of persons with disabilities can be improved through legislation and reasonable accommodation,¹⁸ policy monitoring and financial support. She presented major EU policy initiatives in this area, including the European Accessibility Act, aimed at increasing the number of accessible products and services in the market (including transport) that will reduce barriers for people with disabilities, and the European Disability Strategy 2010-2020, in which employment is one of the main topics. Furthermore, the European Commission has launched an anti-discrimination awareness campaign, with main outputs

including a dedicated website, an informational leaflet available in 23 languages, videos and upcoming local events for national employers on reasonable accommodation.¹⁹

The very definition of disability was also one of Ms Velecká’s focus areas: She noted that there is no common EU definition of disability and that to this end, the 28 EU Member States have ratified the UNCRPD, the UN Convention on the Rights of Persons with Disabilities.²⁰ She also presented some examples in which the definition of disability and what counts as discrimination have become a matter of dispute in national courts, leading to rulings at the European Court of Justice. More rulings could help reassess the limitations of the term “disability” in the future. Ms Velecká also said that there is a need to face and fully examine the differences in the definitions of a person with a chronic condition and a person with a disability.

In what concerns policy monitoring, among the initiatives Ms Velecká discussed is the implementation report of the Employment Equality Directive 2000/78/EC,²¹ to which the Members States are required

¹⁸ <https://ec.europa.eu/social/main.jsp?catId=1473>

¹⁹ <https://ec.europa.eu/social/main.jsp?catId=1437&langId=en>

²⁰ <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

²¹ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32000L0078>

to contribute, with publication planned for end of 2020. To this end, she reiterated that the primary responsibility for application of the Directive 2000/78/EC is with the Member States.

Concerning main financial EU policy tools, for the period of 2021-2027, one of these will be the European Social Fund Plus. This programme has a budget of 101.2€ billion, with 25% of investments targeting social inclusion, including specific actions reserved for people at risk of discrimination.

3.5 CHRONIC DISEASES, WORK ENVIRONMENT ADAPTATION AND ABILITY TO WORK – FINDINGS FROM EUROFOUND RESEARCH AND SURVEYS

Tina Weber – European Foundation for the Improvement of Living and Working Conditions (Eurofound)



Tina Weber presented some main findings from surveys Eurofound has conducted over the years, including the European Quality of Life Survey (2016)²² and the European Working Conditions Survey (2015).²³ She said that the results of this research show that employment rates of persons with chronic conditions tend to be lower, noting that there are large differences between countries and regions, as well as between employment sectors.

Some of the reasons for lower employment rates include employers' lack of understanding of the disease and its impact, and perceived costs and perceived poor productivity levels. Employees living with a chronic condition may also end up withdrawing due to the complexity of adjusting their situation to the demands of working life. In conjunction to this, Ms Weber noted that there are significantly fewer workplaces adapted²⁴ than there are requests for adaptations from employees. The most common adjustments needed in the workplace relate to adaptations in the working time, workloads or workplace – with possibility of teleworking (home office).

To this end, Eurofound is planning to publish a policy brief on chronic disease and ability to work, in autumn 2019. This brief will focus on the prevalence of chronic diseases and profile of workers, limitation of daily activities, accommodation of the workplace, and the difference between workers with and without chronic disease in relation to sustainable work.

“There is a need to adopt personalised, flexible solutions to support persons with chronic conditions stay in employment. Suitable policy responses are lacking despite non-discrimination legislation. This is partly related to the issue of definition of chronic disease.”

²² <https://www.eurofound.europa.eu/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2016>

²³ <https://www.eurofound.europa.eu/surveys/european-working-conditions-surveys/sixth-european-working-conditions-survey-2015>

²⁴ <https://www.eurofound.europa.eu/publications/report/2014/employment-opportunities-for-people-with-chronic-diseases>

3.6 THE BUSINESS CASE FOR INCLUSIVE AND SUPPORTIVE WORKPLACES

Richard Southorn – Head of Workplace Adjustment Services, Remploy Ltd, UK



Richard Southorn presented an inspiring practice from the UK focusing on helping persons with disabilities and chronic conditions access and stay in employment. In his introduction, he said that by a broad definition of disability using the social model,²⁵ 1 in 5 of people in the UK population has a disability. He also stated that the UK health system focus is not set on getting persons back to work, despite the welfare system requirements that many of them find work or placements. Further, there are no direct quotas or subsidies for employers engaged with people with chronic conditions, although some government-funded support programmes exist for individuals with disabilities to find work.

Mr Southorn then introduced the Disability Confident campaign,²⁶ which was launched in 2012 and now has over 10.000 UK businesses as members. The campaign is free, voluntary and entirely paid for by private companies. It helps employers draw from the widest possible pool of talent and secure high-quality staff who are skilled, loyal and hardworking. It can also help improve employee morale and commitment by demonstrating that all employees are treated fairly. Furthermore, the campaign helps customers and other businesses identify those employers who are committed to equality in the workplace.

Mr Southorn also argued for empowering persons with disabilities by focusing on their talent instead of their limitations, and also made the economic case for this: the cost of adjustment for businesses is very low compared with the cost of absences.

“Don’t recruit people like you, because that way you recruit somebody with the same strengths and weaknesses. Employees with chronic conditions must get the right support in order to do their best at work. This is a business necessity.”

²⁵ https://ec.europa.eu/eurostat/statistics-explained/index.php/Disability_statistics_introduced#Disability_models

²⁶ <https://www.remploy.co.uk/employers/leadership-and-management/disability-confident>

3.7 PRELIMINARY RESULTS FROM THE CHRODIS PLUS WP8 TRAINING TOOL

Prof Matilde Leonardi – WP8 Leader, Director Neurology, Public Health, Disability Unit and COMA Research Centre, Carlo Besta Neurological Institute, Italy



Prof Leonardi introduced her topic by presenting some of the current main issues, including the European labour markets' inability to manage the growing number of workers with chronic conditions, and healthcare systems' limited resources to address this. Prof Leonardi noted that disability is defined by the interaction between the health condition and the environment surrounding the patient, and that the disability can be reduced by acting on the environment. A bad employment sector on the other hand increases the disability in people with chronic conditions.

In this conjunction, Prof Leonardi drew on some of the results of another project called Pathways, which focused on employment and non-communicable diseases.²⁷ In it, the three leading barriers reported by people with chronic health conditions were fatigue, feelings of depression and stigma. She then reminded the audience that employment and schools are the institutions that can actually help persons with disabilities.

Prof Leonardi argued that a successful welfare reform must consider that work should be adaptable to people's health needs and not the other way round. In this regard, the role of social partners as well as taking into account the demographic changes in European societies is also significant. She then presented in detail Work Package 8 in the “CHRODIS-PLUS: Implementing good practices for chronic diseases” Joint Action.²⁸ This Work Package is developing the CHRODIS+ Toolbox, which comprises a training tool for employers and the employment sector, as well as a toolkit for adaptation of the workplace for prevention and maintenance of chronic diseases.

Work Package 8 will also produce policy recommendations, with the ultimate goal of helping decision-makers develop policies that will support persons with chronic conditions access, reintegrate and stay in the labour market.

²⁷ <https://www.path-ways.eu/>

²⁸ <http://chrodis.eu/>

3.8 EPF YOUTH GROUP SURVEY ON EMPLOYMENT-RELATED CHALLENGES FACED BY YOUNG EMPLOYEES WITH CHRONIC DISEASES

Andreas Christodoulou and Borislava Ananieva, EPF Youth Group



Borislava Ananieva and Andreas Christodoulou presented the results of the European survey conducted within the EPF Work and Youth Strategy (WAYS) project²⁹ and pointed out that all members of the Youth Group³⁰ had experienced some form of discrimination throughout their experiences in looking for a stable work environment. However, they had never actually discussed these experiences because they thought they were something quite

“normal”. Furthermore, close to half of the WAYS survey respondents reported having experienced discrimination in the employment field, and 35% of the persons who completed the survey stated that they would not disclose their condition before a job interview.

Andreas Christodoulou then clarified the methodology of the survey, stating that it was completed by persons from over 23 countries in Europe, out of whom 15% had received treatment abroad.

The next steps for the WAYS project include developing a factsheet with major recommendations to employers and employees with chronic diseases based on the survey results, as well as producing a video about patients’ rights in employment settings.

“One of the leading suggested measures for better inclusion is flexible working time with the option of working from home.”

3.9 HOW DOES EMPLOYMENT STATUS IMPACT ACCESS TO HEALTHCARE?

Katarzyna Ptak Bufkens, Policy Officer, Performance of national health systems Unit, DG for Health and Food Safety, European Commission



Katarzyna Ptak Bufkens opened her presentation by discussing the vast human and economic cost of mental health problems and chronic diseases, and the under-investment in these. She referred to evidence showing the impact of behavioural determinants of health on the labour market status of working age population, stressing the case for prevention. She also referred to evidence showing the huge costs of ill health of working age population for social protection systems.

Ms Ptak Bufkens explained how the European Semester³¹ can benefit people living with chronic conditions, through helping improve the

²⁹ <http://www.eu-patient.eu/News/News/epf-youth-group-ways-project-conclusions-and-upcoming-projects/>

³⁰ <http://www.eu-patient.eu/About-EPF/whoware/Youth-Strategy/>

³¹ https://ec.europa.eu/info/business-economy-euro/economic-and-fiscal-policy-coordination/eu-economic-governance-monitoring-prevention-correction/european-semester_en

accessibility, effectiveness and resilience of healthcare systems. In what concerns access to healthcare, she noted that “access” in itself is a multi-dimensional issue and closely interconnected with effectiveness and resilience.³² She talked briefly about the Commission’s ongoing work to improve the data on gaps in access to healthcare, which aims at getting a better picture of personal and clinical characteristics of persons who face particular problems with access to healthcare.

She also referred to the Commission’s initiative on social protection, explaining the rationale behind it and challenges with access to healthcare which this initiative could address. One of these challenges is healthcare coverage, which today is not guaranteed for people working in some new types of work arrangements. Another is under-insurance, which may be linked to affordability reasons, and which is particularly a challenge for some categories of self-employed in systems where health insurance is voluntary or even mandatory. Furthermore, many citizens are unaware of their rights and are therefore not covered.

Policy responses to these issues include the European Semester and the work done under this framework to encourage health and other reforms in various Member States. Ms Ptak Bufkens explained the knowledge building activities which feed into this work, referring to the State of Health in the EU cycle and other activities which put accessibility in focus. She also highlighted the commitment to improve social standards in Europe through the European Pillar of Social Rights and one of the linked initiatives – a Council Recommendation on access to social protection for workers and the self-employed proposed in December 2018.³³ Finally, she referred to the Health Policy Platform³⁴ and stressed the importance of this tool in disseminating good examples.

“Social protection systems must answer to the requirements of modern world of work. Furthermore, the promotion of prevention needs to continue – more than 790.000 people die prematurely every year due to behavioural risk factors.”

3.10 LE CLUB DES ENTREPRISES, CANCER AND WORK: A PROMISING INITIATIVE

Emmanuel Collin, Director of Communications and Information, French National Institute of Cancer



Emmanuel Collin said that cancer in the corporate world is a growing phenomenon, as the population ages. Thanks to improved treatment methods, survival rates are better, and more patients can stay at work during treatment or return to work afterwards. He then went on to introduce “Club des entreprises – Cancer et emploi”.³⁵ This initiative by the French National Cancer Institute comprises a network of companies committed to improving the retention and return to work of their employees suffering from cancer. Currently, 41 companies with 1.3 million employees are involved. The network is developing workshops to support its members and has also produced an online “toolbox” and other support materials. Further, the network members have implemented inspiring

³² https://ec.europa.eu/health/sites/health/files/state/docs/2018_healthatglance_rep_en.pdf

³³ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2018:0132:FIN>

³⁴ <https://webgate.ec.europa.eu/hpf/>

³⁵ <https://www.e-cancer.fr/Institut-national-du-cancer/Cancer-et-Emploi/Club-des-entreprises>

projects around the theme of retention and return that could serve as a model to several other organisations.

Mr Collin noted that this while the network is currently better suited for larger companies, its future prospects include adapting its services for small businesses and the self-employed. He also hopes that more organisations in the public sector will participate in the initiative.

“Maintaining a professional activity during treatments is a gain for both employees and employers; it can positively contribute to the employee’s overall quality of life, as well as help the companies maintain their level of performance by retaining a competent and trained workforce.”

4. Conclusions

The EPF Multi Stakeholder Roundtable brought forward many important views on how to improve access of persons with chronic conditions in the labour market and work against discrimination. An issue that was repeatedly brought up was that strategies for persons with disabilities **miss the target** when it comes to the needs of patients with chronic diseases and mental health problems. As a result, the legal definition of disability at EU level and in a number of Member States needs urgent reconsideration, as it currently excludes persons living with a chronic condition from social protection in the labour market in many of them. This work needs more commitment from national authorities to help change the situation.

Another key issue raised was that employers as well as trade unions need to **address the discrimination** of persons with chronic conditions in the labour market in a more robust manner. A number of factors can contribute to their access, including relations between employers and employees, and the attitudes and culture in the workplace and wider society. As one participant noted: Disability is defined by the health condition and the environment surrounding the patient, and it can be reduced by acting on the environment. This calls for work against conscious and unconscious biases through **awareness-raising and education**. Furthermore, the importance of clearly defined, professionally run **rehabilitation programmes** assisting employees with chronic conditions to return to employment cannot be underestimated. To this end, EPF is pleased to see promising and successful work being carried out in this area, as demonstrated by the speakers from France and the UK.

In what concerns social protection in the labour market, participants raised the need for **social protection systems** to be adjusted and updated to answer to the requirements of the modern world of work, where an increasing number of people are working in non-traditional forms of employment.

Some participants also highlighted the **significant role many patients themselves have** in returning to and staying in employment: it is important to understand one’s abilities, skills and transferable skills, retrain if necessary, and communicate to employers about the ways they can get return for their investment. To this end, “return” does not only translate to direct economic benefit. For example, recognition of diversity and fair treatment can also help boost employee morale and commitment.

The event also underscored the importance of **collaboration between stakeholders** from the health, education, employment, and justice and finance sectors. Forming alliances and sharing information and inspiring practices is the way to move forward in promoting the inclusion of persons with chronic conditions. Furthermore, it is important that stakeholders think even more outside their own perspective and work together to promote the “mindset change”. Together, we can contribute to help normalising the view that discrimination in the labour market is not a patient’s problem but a societal

problem: with the right kind of support, many persons with chronic conditions can stay active in the world of work.

As a next step, EPF will disseminate these important messages to the new European Commission and the European Parliament for their consideration, as well as to our pan-European network of 74 patient organisations and to stakeholders across the spectrum of employment and social protection.