

Recommendations to promote better inclusion of people with chronic conditions in the workplace in the context of the European Pillar of Social Rights

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1. Introduction

Following EPF's position statement entitled "Equal treatment for patients in education and employment" that was published in January 2016 to highlight this issue and provide recommendations on how to tackle discrimination; in 2017, EPF set up a temporary task force on discrimination in the workplace and on the employment market.

The task force developed a set of materials, including this document, to promote better inclusion of people with chronic and long-term conditions in the workplace.

This work is directly relevant to EPF's strategic goal on non-discrimination, to promote the development of EU and national policies that tackle discrimination faced by people with chronic conditions in employment.

This task force, made up of volunteers from the EPF membership provided expert advice in order to develop the content and format of this set of materials.

This document is intended for policy makers from the health, employment, social and financial sectors.

Aside from these recommendations, the other materials that have been developed include: A compendium of patient organisation initiatives to promote patient-led actions and promote EPF member action on this topic and take-up of existing materials, and a factsheet for employers on the inclusion of people with chronic diseases in the workplace and how to foster inclusive work places.

2. Working with a chronic and/ or long-term condition

The burden of chronic diseases is well known. They account for up to 80% of healthcare costs in terms of premature deaths, healthy life years lost, and lost productivity.¹ In addition to the "big" chronic diseases linked to ageing, many diseases affect people of all ages, including the young, as well as families and society at large.² Multimorbidity is increasing at a significant rate and poses a particular burden on patients and families.³ The impact of chronic illness is multi-faceted and includes negative impact on quality of life, education and employment.⁴

According to Eurofound's Third European Quality of Life Survey 2001–2012, about **28% of Europeans** report having a chronic (longstanding) physical or mental health problem, illness or disability, though

¹ http://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/reflecti_on_process_cd_final_report_en.pdf; <http://www.oecd.org/health/health-at-a-glance-europe-23056088.htm>

² <http://www.eu-patient.eu/globalassets/policy/chronic-disease/epfchronic-diseases-consultation-response-2012.pdf>

³ http://biac.org/wp-content/uploads/2017/01/2017-01_Health_Vision-and-Priorities-Paper1.pdf; Rijken M, Struckmann V, et al. (2017) "How to improve care for people with multimorbidity in Europe?" Policy Brief 23, p. 9.

⁴ J-C Suris, P-A Michaud, R Viner (2004) "The adolescent with a chronic condition. Part I: developmental issues," *Arch Dis Child* 2004;89:938–942.; Eurofound (2014) "Employment opportunities for people with chronic diseases," available at <https://www.eurofound.europa.eu/sites/default/files/ef1459en.pdf>; OECD/EU (2016), p. 20, 26-27.

with much variation depending on member states.⁵ **1 in 4 people** of working age (15 to 64) are estimated to live with long standing health problems that restrict their daily activities. The majority of these health problems come directly from chronic diseases.⁶ Furthermore, about **350 million working days** are lost in the European Union each year due to work-related health problems.⁷ It is this interrelation that makes workplace health such an important element of modern public health policies.

Employment is fundamental to staying connected to the community, maintaining skills and continuing to develop professionally. Conversely, unemployment can contribute to further ill health for people with chronic conditions such as mental health conditions for example: the longer unemployment lasts, the more difficult it is for people with mental health conditions to go back to work.

While some people with chronic conditions cannot continue their professional activity due to their health condition, many can and do continue working or wish to do so, while for others this might have a beneficial impact on their recovery. With adequate support they can work, resulting in a hugely improved quality of life that minimises the negative financial impact of chronic ill health, the risk of social exclusion, poverty and positively contributes to their mental health. For people with chronic conditions, the value of staying at work also goes beyond providing financial stability - it contributes to social inclusion, well-being, and even to recovery in some diseases areas.

⁵ <https://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases>

⁶ https://ec.europa.eu/health/sites/health/files/social_determinants/docs/final_full_ecorys_web.pdf

⁷ http://www.enwhp.org/fileadmin/rs-dokumente/dateien/Hearts_Minds-Summary.pdf

In the workplace however, people with chronic conditions often face low levels of awareness from their employers on managing chronic conditions. Employers are often misinformed regarding the abilities of people with chronic conditions to continue working, resulting in stigma. Stigma and discriminatory attitudes faced by people with chronic conditions from employers or colleagues include inappropriate disclosure of their condition, lack of support when returning to work after sick leave, or even difficulties after a long-term absence as well as more difficulties obtaining training opportunities and promotion.

It goes without saying that the increase of public awareness and sensitivity will reduce discrimination in the workplace, open the way for increased employment, reduce social exclusion and add to the quality of life of people with chronic conditions.

Mental health: Work-related stress is the second most reported work-related health problem in Europe.

Musculoskeletal disorders: Over 40 million EU workers have musculoskeletal disorders caused by their work, representing almost 50% of all absences from work of three days or more.

Diabetes: A person living with diabetes is 4 times more likely to be excluded from their working environment due to their condition and ignorance induced discrimination is the principal obstacle for the employment of people with diabetes.

Epilepsy: People with epilepsy are more than twice as likely to be unemployed as the general population, but this varies considerably between countries: in Poland, 49% of people with epilepsy are employed, compared with 77% in Germany.

Multiple Sclerosis: The [multiple sclerosis cost of illness study](#) provides information on the burden of multiple sclerosis to both society and MS patients. Mean costs are found to be € 22,800 for mild disease condition, € 37,100 for moderate and € 57,500 for the severe type.

3. Raising awareness – Highlighting issues of importance to people with chronic conditions

People with chronic conditions and the EU Equal Treatment Legislation

A key question for patients is whether or not they are in the **scope of the EU legislation on discrimination**, as people with chronic conditions are not currently protected on the ground of **health status**. This currently depends on the definition used by their Member State's law for disability, as the concept of disability does not have a common definition at EU level. These vary from very restrictive definitions to broader definitions in which people with chronic conditions are always included. Inclusion or exclusion within this concept also depends on the person's type of disease. A **key shortcoming** of the [Council Directive 2000/78/EC](#) of 27 November 2000 establishing a general framework for equal treatment in employment and occupation is that it does not harmonize definitions of disability. This creates ambiguity as to whether the Directive applies to people with chronic conditions. Furthermore, a European Court of Justice case law *Chacon Navas v Eures*

Colectividades SA, dating from 2006⁸ specified that people with sickness are not covered by the Directive. Nevertheless, if the chronic condition is considered as disability by the Member State, people with chronic conditions may have the right to accommodation and adjustments. For this reason, EPF strongly believes that **people with chronic and/or long-term conditions should be protected from discrimination on the ground of health status**. Such provisions already exist in the legislation of some Member States and need to be replicated in all Member States and at EU level.⁹

Unclear rights of people with chronic conditions at work

The lack of clear structure and rights encountered by people with chronic conditions in various situations could be considered an indirect structural form of discrimination. For example, it is unclear whether people with chronic conditions are protected when they risk losing their job due to repeated or long-term absence.

The rights of people with chronic conditions regarding the workplace are not always clear, do not respond to the needs of people with chronic conditions, and are not always well-implemented across the European Union. Adapted systems and protective legislation are not always in place to allow people with chronic diseases to remain in the workplace under acceptable conditions. When these systems and laws do exist, they are usually under-used; employers and the population at large tend not to be aware of their existence.

Actions to raise awareness within companies or trade unions and for the general public could contribute significantly to tackling this problem.

A critical situation is when patients are diagnosed as being terminally ill. A recent campaign in the UK called “Dying to work” uncovered that terminally ill patients are inadequately protected by legislation in this situation. As a result, patients have to undergo stressful human resource procedures, financial difficulties, and anxiety resulting from the loss of employment.¹⁰

Invisible disability

We all know about disability and the support measures that are very correctly taken by the pertinent authorities in most countries, in order to ensure that everyone is socially included.

However, if we look around us carefully, we will witness many people who live with chronic diseases, e.g. cardiovascular, respiratory, diabetes, inflammatory bowel diseases, cancer, multiple sclerosis and many others, which in their severe form also cause a lot of physical pain, psychological stress and social seclusion, as well as unemployment and discrimination, yet the barriers some people face might not be seen, as their disability is usually invisible.

It is high time governments look into this problem and implement such measures in collaboration with patients and civil society organisations that will make the lives of people with chronic conditions easier

⁸ <http://curia.europa.eu/juris/liste.jsf?language=en&num=C-13/05>

⁹ http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper_equal-treatment-in-education-and-employment.pdf

¹⁰ <https://www.dyingtowork.co.uk/>

and more comfortable through financial and psychological support, as well as offer opportunities to employment and support.

It is accepted that it is more difficult to identify and fairly evaluate such cases, but the identification of people's support needs can provide a just and valid evaluation.

An encouraging example is that some countries have made the first step and have adopted employment schemes for qualified people with invisible disability in some sectors. In the teaching sector in Greece and Cyprus for example, the employment of teachers with disability is backed up by a plan for supply teachers to cover in case these persons are absent from work for medical reasons.

A very brief research showed that there is relevant legislation in some European countries, but it is not actually applied as one would expect to happen.

Youth, education and employment

Discrimination in education directly affects young people's employability. For example, due to various discriminating practices young people with chronic conditions may not be able to pursue or finish the studies of their choice. Accessibility of buildings, classrooms, toilets etc. do not necessarily require complicated or costly adjustments to be adapted for young people with visible but also invisible disabilities. However, this unfortunately still remains a challenge in educational settings.

Equally important is the flexibility of teachers (possible adjustments: class attendance flexibility, alternative exam dates and exam formats etc.) but also the support of classmates who due to lack of awareness on chronic diseases might discriminate their classmates. Such discrimination might lead to isolation, psychological distress and loss of motivation of young people with chronic diseases which in turn will have an impact on their desire to work and employability. Raising awareness about these issues is of crucial importance. Member States and more specifically, local administrations need to play a stronger role in making education and educational facilities accessible to all, as well as raising awareness among school staff and students.

Poverty and social exclusion

Disability and ill-health are both a cause and consequence of poverty. On average the incomes of people with disabilities are 12% lower than the rest of the population. In some countries, the incomes can be as much as 30% less¹¹. The costs are not only incurred by the individual; OECD countries have been spending 1.2% of GDP (up to 2% when including sickness benefits) on disability benefits¹². The cost of systemically excluding people with partial capacity from the workforce has a serious impact on the public expenditure. In some countries the public spend on disability benefits is more than 2.5 times what is spent on unemployment benefits¹³.

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.oecd.org/els/emp/42699911.pdf>

¹³ <https://www.oecd.org/els/emp/42699911.pdf>

Being without work and a sufficient income means individuals incur further costs on their health. People with disabilities, excluded from the workforce are at greater risk of poverty which, in and of itself, is a sustained deprivation of resources, choices, security and life choices¹⁴.

Attitudes to people with partial work capacity continue to be an issue when combined with *entrenched disability benefit* culture. The same systems that support people at times of need, are, when rigidly applied, maintaining the status quo so that anyone with a disability is viewed as **incapacitated** and excluded from the workforce. People with disabilities that have partial work capacity are forced to stay on benefits, close to the poverty line and without any options due to inflexible benefits systems.

It is vital that people with partial work capacity are supported to stay in or return to work through clearly defined programmes run by professionals experienced in providing vocational rehabilitation. An appreciation of the intersectionality of disability, exclusion and poverty would also be useful to moving this issue to a point where the focus is on an individual's ability, first and foremost.

4. Recommendations to promote better inclusion of people with chronic conditions in the workplace in the context of the European Pillar of Social Rights

In November 2017, the European Pillar of Social Rights¹⁵ was proclaimed and signed by the Council of the EU, the European Parliament and the Commission. The European Pillar of Social Rights sets out 20 key principles and rights to support fair and well-functioning labour markets and welfare systems.

This Pillar is an important opportunity to provide rights on equal opportunities and access to the labour market, fair working conditions, social protection, include the right to health coverage and inclusion.

Delivering on the principles and rights defined in the European Pillar of Social Rights is a joint responsibility of Member States, EU institutions social partners and other stakeholders.

Establishing appropriate rights and legislation for people with chronic conditions

1. EPF recommends that **EU and Member States' legislation on equal treatment in workplaces** should prohibit discrimination based on health status/chronic conditions.
2. The EU and Member States should provide for clear **rights to adjustments and accommodations** in education and at work and encourage implementation of these rights.
3. **People with chronic conditions facing discrimination** should have access to mediation, complaint and redress mechanisms at national level, and independent support structure to seek compensation.

¹⁴ Human rights, Health and Poverty Reduction Strategies: Health and Human Rights Publications Series, Issue No 5, December 2008

¹⁵ <http://data.consilium.europa.eu/doc/document/ST-13129-2017-INIT/en/pdf>

4. Member States should ensure that **terminally ill patients** are adequately protected by legislation and ensure that employers provide reasonable adjustments to these patients.
5. Appropriate legislation is needed to support **informal / family carers** and ensure they benefit from their right to work. Appropriate respite should be granted, as well as flexible solutions for carers' leave.

Information, Training and Awareness raising

1. National governments have the responsibility of **raising awareness of chronic and long-term conditions and challenges faced by people with chronic conditions** to the general public, through an organised plan of action, including campaigns and other activities. Such awareness raising initiated by national governments together with patient associations should be encouraged and implemented with the aim of promoting better inclusion of people with chronic conditions in society at large. Such actions to contribute significantly to tackling stigma faced by people with chronic diseases in the workplace and in society.
2. **Trainings to inform** workers, employers, and human resources managers about existing rules and rights as well as existing policies to support both employees and employers should be provided by Member States with the support of trade unions.
3. Member States should provide **one-stop-shop websites** to inform employers and employees about the rights of people with chronic conditions at work and information about reasonable adjustments. Employers need more information regarding the types of reasonable adjustments that can be made to support people with chronic conditions to stay in work. This will help reduce the number of people with chronic conditions leaving employment as a result of functional limitations and to help overcome any discrimination that may be experienced in the workplace.
4. The EU should encourage **exchange of best practices** of the above-mentioned initiatives among member states.

Creating supportive working environments for people with chronic conditions

1. Appropriate support and policies for **prevention, workplace adjustment, accommodations, and return to work** need to be implemented, building on existing good practices. More research in this area is needed in the EU and good practices should be evaluated with the participation of relevant stakeholders, including people with chronic conditions.
2. Employers should consider making **workplace and working hours adjustments** when the working arrangements put a person with a chronic disease at a disadvantage compared to other employees. Adjustments need to be discussed between the employer and the employee having a chronic disease and will depend on what is identified as a necessary, reasonable and feasible adjustment.
3. Employers should encourage **work-life balance** and highlight flexible working hours as part of workplace accommodations.
4. If people with chronic conditions cannot continue to work in their current job because of their health status but are willing to have a **professional reorientation**, policies and structure aiming at supporting them should be put in place at national level.

5. EU and Member States' **occupational health and safety at work strategies** should widen their scope to support people with chronic conditions at work (whether the condition is caused by work or not).
6. Workplace environments should provide employees with a **safe and open environment** where they can disclose their chronic condition, if they wish to. This requires reassurance for the employee that disclosing a health condition will not lead to discrimination or denial of employment. It also requires a functional absence-management procedure, audit and evaluation of absence management policies, and staff properly trained to support colleagues who have a health condition.
7. Employers, whether from the public or private sectors, have a key role to play in implementing measures towards making the **workplace accessible and inclusive** and raising awareness of the benefits of these actions for employers and employees.

According to the UN Convention on the Rights of People with Disabilities (UN CRPD), which has been ratified by the EU and 27 MSs, "**Reasonable accommodation**" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms

Examples of such adjustments could include:

- ✓ shorter or flexible working hours
- ✓ ensuring easy access to the building and/or office
- ✓ working from home
- ✓ allowing time for medical appointments
- ✓ offering another position within the company (accompanied by training for the new position)
- ✓ unlimited toilet breaks
- ✓ desk next to the toilet

Cooperation across policy areas: Health, Education, Employment and Finance

1. To effectively raise awareness and tackle stigma and discrimination in education and at work, the **involvement of stakeholders, including people with chronic conditions and civil society organisations, from the health, education and employment sectors is needed.**
2. **Active inclusion and youth employment policies and programmes** at EU and national level should explicitly target the unmet needs of young people with chronic and long-term conditions.
3. The **EU OSHA** and similar agencies in Member States should collaborate with patient organisations to develop information and resources for persons with chronic and long-term conditions regarding health and safety at work.
4. More **cooperation between EU Member States** is needed to exchange **information on good practices** in the area of education and employment of people with chronic diseases.
5. **Healthcare professionals** have a key role to play in taking into account health outcomes that are important for patients, such as school attendance or ability to work, into their dialogue with patients. Similarly, researchers should take into account these aspects in clinical trials, and ability to work should be accepted as a valid quality of life / patient-reported outcome.

6. Policies aiming at ensuring equal treatment in education and in employment should **involve people with chronic conditions and their organisations** in order to ensure they meet patients' needs. Patient organisations are actively promoting equal treatment at school and at work and combating stigma. But to do so effectively, they need appropriate resources to support their project, including funding, and willingness of decision makers and institutions to involve them. With appropriate support, successful initiatives put in place by patient organisations could be replicated and scaled up.
7. The **economic burden of ill health and unemployment on people with chronic conditions** and their families and resulting poverty, precarity and social exclusion should be seriously considered.
8. Policies and legislation protecting people with chronic or long-term conditions in the workplace should be encouraged.
9. Practices to enable the **collection of data** which supports the patient workplace experience should be promoted in order to further inform finance decision-makers to make progress in this direction.

5. Conclusion

A cultural shift is needed to address the barriers that people with chronic conditions face in education and in the workplace. To reach the goals of Europe 2020, both educational institutions and workplaces need to become **more supportive environments**. This is essential to improving quality of life for people with chronic conditions, who are an important share of the population - 1 in 4 people of working age (15 to 64) are estimated to live with long standing health problems, the majority of which are directly attributable to chronic diseases. Furthermore, about 350 million working days are lost in the European Union each year due to work-related health problems alone. With adequate support, people with chronic conditions who choose to work, can work, resulting in a hugely improved quality of life for patients that minimises the negative financial impact of chronic ill health, the risk of social exclusion and positively contributes to their mental health.

With a concerted action from a variety of stakeholders from differing sectors, driven by political incentives at EU and national level, we strongly believe it is possible to put in place measures to ensure people with chronic conditions are better supported and are encouraged to seek support when they need it, in education and in the workplace.



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