

Date: 01 November 2016

Title: Consultation on the European Pillar of Social Rights

The Commission has launched a broad **public consultation** to gather views and feedback from national authorities, social partners and citizens. The goal is to:

- make an assessment of existing rights
- reflect on new trends in work patterns due to the impact of new technologies, demographic trends or other factors
- reflect on the particular needs of the euro area
- help Member States outside the euro area to determine whether to participate in this initiative.

The online questionnaire can be found [here](#).

Below, please find EMSP's replies on the questions raised in the consultation:

1. What do you see as most pressing employment and social priorities?

The European Multiple Sclerosis Platform (EMSP) represents the interests of more than 700.000 people with multiple sclerosis (MS) around Europe, a disease that is often diagnosed between 20 – 40 years old, an age that is crucial in the professional life of most people, especially the young ones who are just starting off their careers.

Improving access to employment for people with multiple sclerosis and other chronic conditions is a very important issue, not only for the patient but also for the employer and for Europe's economy as a whole.

One of the most pressing issues for people with disabilities in the employment field is the need to access work and to remain in workplace, to benefit from the support they need in order to live their life to the fullest and have a societal contribution. Although all European countries have protective social legislation, in practice people with multiple sclerosis and other potentially disabling neurodegenerative conditions are disadvantaged in the current job market, experiencing inequality and lack of opportunities. Their right to work, as described by the Universal Declaration of Human Rights, is in many cases overlooked, thus diminishing their independence and scope for participating in and contributing to society.

In a recent survey undertaken by our organisation, we have identified that the most common barriers to accessing work are the symptoms of their condition, attitudes of employers to people with MS and discrimination. These can be overcome by implementing flexible working hours and arrangements, together with policy and support for planned 'return to work'.

A better alignment of health, labour and social policies and practice to keep people with MS as healthy and productive as possible will ultimately lead to significant public health and economic benefits for society.

Some of the most pressing issues regarding employment and social priorities are:

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1. **Discrimination:**

- a. We strongly need to tackle inequalities and make the necessary changes to make sure EU legislation is being applied at national level in order to put an end to discrimination.
- b. EMSP pledges for the empowerment of people with disabilities, they need to have access to the right tools and information in order to stand up for their rights. It is very often that employers take advantage of their vulnerability and do not give them the same opportunities thus not allowing them to live their life at the fullest potential and have an active contribution to society.

2. **Financial support:**

- a. We need to speak the same language when defining disability. Because there is no common definition of disability, accepted and implemented in all member states, determining eligibility for income maintenance is still difficult. This leads to employers finding gaps in the law and patients are being discriminated in the end.
- b. We also need to ensure this Social Pillar will enforce a minimum income scheme for people with disabilities, to ensure their rights will be respected, as recommended by the United Nations Committee on the Rights of Persons with Disabilities.

3. **Education:**

- a. We need to provide increased support at an early stage to enable the young generation to continue their studies and be prepared to access the job market according to their capabilities.
With the launch of the Youth Guarantee by the European Commission, the Social Pillar could be used to complement and reinforce the measures of it and to provide access to high-quality education, traineeships and jobs to all young people. Young persons with disabilities need to be taken into account and benefit from adapted services and policies, such as some we already outlined in the Practical Toolkit from Employers developed by EMSP.

2. **How can we account for different employment and social situations across Europe?**

High-equal employment opportunities lead to an active social participation as well as a higher contribution to the economy as a whole. However, people with disabilities still face discrimination and are excluded from the labour market: they are either unemployed, underpaid, or simply the employer makes it more difficult for them to retain employment. Very often they work below their capabilities and are unable to make the best use of their skills and experience.

The existing social protection schemes are insufficient to meet the needs of people with disabilities and implicitly multiple sclerosis to enable them to be fully integrative and have an active role in their workplace. The EU should work closer with patient representatives and Return to Work/Disability Management professionals and take into account also the invisible facets of certain disabilities, like multiple sclerosis (e.g. fatigue). A minimum set of core standards needs to be applied in all EU member states in relation to access to employment for people with disabilities.

EMSP also recommends more cooperation between member states, sharing examples of good practices and implementing them regional / European wide is crucial in order to guarantee assistance to accessing employment to all categories of people, including those with disabilities. In this context, as there was nothing existent for people with neurodegenerative conditions and

implicitly multiple sclerosis, EMSP has developed a Practical Toolkit for Employers, a toolkit that makes recommendations and also offers practical solutions on the best means to accommodate a person with MS in the workplace.

The guidelines for employers that are made in the toolkit can be replicated for other diseases as well, this is a very good example of how we can learn from each other and improve cooperation among patient organisations in the disability field. For example, in Ireland, the MS Society localized the Toolkit and made the necessary changes so that the national legislation in the field of disability and employment was included. They launched a set of practical employment resources to support people with MS and their employers, resources that hopefully will lead to better support and working conditions for all people with disabilities in Ireland.

3. Is the EU "acquis" up to date and do you see scope for further EU action?

EMSP advocates for a better implementation of European legislation at national level. Basic human rights principles are still not applied in all states and people with disabilities face not only discrimination in the workplace but cannot access goods and services. All these represent important factors and have a negative impact on the quality their lives.

Regarding the social pillar, we need to make sure the legal instruments will be integrated in the final text. There should be clear recommendations on the implementation, with measures in place, as well as a system that will monitor and account for the Member States' actions.

Furthermore, we do recommend to take into account and start enforcing sanctions for employers who do not fill in the number of job positions for people with disabilities. The charge should be strict and large enough as these funds could be used for people with disabilities for the following purposes:

- conducting training for people with disabilities
- technical equipment and adaptation for all job positions (including transport) for people with disabilities
- rehabilitation services, consultations and support for severely disabled workers
- individual professional integration of people with severe disabilities in social companies
- Institutional support

Such a practice, called "benefit sanctions" already exists in many countries, such as Germany, and acts as an effective tool to increase employment. We consider that this should be implemented at European level so each legislation to be adapted with such a requirement for employers.

4. What trends would you see as most transformative? [Please select at most three from the list below]

- ✓ New ways of work
- ✓ Inequalities
- ✓ Technological change

5. What would be the main risks and opportunities linked to such trends?

In addition to the already existing barriers and high levels of discrimination in some EU countries, one of the primary risks is higher rates of unemployment. Technological change can lead to lowered social standards and labour rights for those with disabilities and others in the general population. With the emergence of new technologies, we need to make sure everybody can access the right training in order to understand and include this in their way of working, where it is the case. Unless we don't this, the situation will only worsen as we are already witnessing an alarming number of young people who are NEETs (more than 15% of those between 15 – 29).

In the same time inequalities could be overcome by new ways of work, for example flexible working arrangements would allow people with multiple sclerosis and other chronic conditions to be fully operational when in good health but also to allow a break when their condition requires it. This will not lead to lower productivity and would also mean the employer is communicating with his employees and understands their needs.

Any individual can be sick or affected by long-term conditions, currently 23% of the working age population and 19% of employed persons have a long-term condition. Therefore, being sick or having special needs does not mean you are “not normal”. In order to change that mind-set, the employer will ensure information and policies are shared as part of the daily business. This will have two advantages: it will encourage dialogue between the employer and the employee but also positively change the work environment for everyone and take away the pressure disability puts away the society.

6. Are there policies, institutions or firm practices – existing or emerging – which you would recommend as references?

As a response to the needs of people with neurodegenerative conditions to find and stay in the workplace and as a result of active consultation with our member societies (currently 40 from 35 European countries), EMSP has developed a Practical Toolkit for Employers. We want to transform how businesses manage the staff members who are affected by MS or other chronic diseases. By providing practical support and guidance to businesses, people with MS can continue in work while the business benefits by holding onto experienced staff and being prepared for other incidents where health issues impact staff members.

Developing a good workplace environment and a healthy workforce is a long-term process that incorporates different work functions and people. Business leadership, management teams, human resources and general staff are all involved.

The Practical toolkit will help both people with MS and other neurological conditions to open the dialogue with employers about their needs. These may include making adaptations in the workplace. This also has the effect of motivating employers to build policies on recruitment, attendance management and return-to-work procedures. This activity ensures the business is as prepared as possible and mitigates against risk for the current and future workforce.

Implementation measures of returning to work as part of the business measures include:

- ✓ Adhering to legislation as part of good business practice
- ✓ Supporting reintegration into the workplace
- ✓ Accommodating potential changes in employee circumstances

- ✓ Reducing recruitment, training and insurance costs

More details on the toolkit can be found [here](#).

The toolkit is directly linked to the Believe and Achieve training programme, a programme developed and coordinated by EMSP. For people to gain a foothold into the world beyond the MS walls they need to have the chance to be employed. This is where EMSP's "Believe and Achieve" project comes in providing young people with paid internship opportunities across Europe. Young people across Europe are being left out of employment, they don't have opportunities to use their education and skills and Europe is wasting the human capital worth billions.

EMSP developed the Believe and Achieve project to provide a practical solution, a bright light that highlights the potential of these young people in this economic and social environment. The effects of an MS diagnosis, the impact on a young person's confidence and discrimination, combined with the difficult job market, mean the barriers for some are great.

It our role to help break down those barriers through lobbying and influencing politicians and policy makers. But there is the more immediate issue of boosting young people's employability. While culture slowly changes, EMSP is working with corporate partners to give young people the opportunity to gain valuable professional experience that will enhance their employability. To work, to live, be independent and lives full lives in spite of having an MS diagnosis.

Another example of good practice is the Patient Empowerment Campaign of the European Patients Forum (EPF) that was launched in 2015. EPF officially launched a major one-year campaign on Patient Empowerment to concert with the health community to promote understanding of what patient empowerment means from the patient perspective among political decision-makers and health stakeholders. As part of the campaign deliverables, they released a Charter of Patient Empowerment and a multi-stakeholder Roadmap for Action.

7. Do you agree with the approach outlined here for the establishment of a European Pillar of Social Rights?

Agree

Please specify:

EMSP welcomes the actions of the European Union that are designed to reinforce and strengthen the implementation of the social rights across the countries in the EU. In this context, we welcome the establishment of a European Pillar of Social Rights.

In the field of disability, we agree that:

"People with disabilities are at much higher risk of poverty and social exclusion than the general population. They face a lack of adequate accessibility in the work-place, discrimination and tax-benefit disincentives."

- a. Persons with disabilities shall be ensured enabling services and basic income security that allows them a decent standard of living. The conditions of benefit receipt shall not create barriers to employment.

However, EMSP is concerned this will not actually have a meaningful impact on improving the lives of people with disabilities. When the Social Pillar will be established, as it is mentioned in the draft version “the Pillar should become a reference framework to screen the employment and social performance of participating Member States, to drive reforms at national level.” However, it is up to the Member States to decide if they decide to follow the recommendations, as it is always the case with all policy documents. In this context, we need an accountability mechanism to make sure the legal status of the Social Pillar will be taken into consideration by all member states. Furthermore, clear policy instruments and recommendations should be made to the Member States, addressing the specific needs each country has, especially in the field of disability.

Detailed comments by domain

1. Skills, education and life-long learning

In June 2016 the European Commission launched a new Skills Agenda for Europe - Working together to strengthen human capital, employability and competitiveness. Some of the actions proposed by the Commission refer to making Vocational Education and Training (VET) a first choice by enhancing opportunities for VET learners to undertake a work based learning experience.

The new skills agenda is encouraging business and social partners to get more involved in designing and delivering VET at all levels. VET should include a strong work-based dimension, whenever possible coupled with an international experience.

EMSP agrees on the view of the Commission that the quality of work placements is vitally important, and the need of people with disabilities, be them visible or “invisible” (as in the case of many people affected by multiple sclerosis). Funding must go hand in hand with national policies and measures that encourage and value the learning acquired, and ensure the relevance and quality of the training.

The social pillar states that:

“All persons shall have access to quality education and training throughout the life course to acquire an adequate level of basic skills and key competences for active participation in society and employment. Low skilled young people and working age adults shall be encouraged to up-grade their skills”

We would like to draw attention on the fact that currently 15% of young people in the EU are not in education, employment or training (NEET) and the numbers are growing at an alarming rate. Young people with disabilities need support to continue their studies and to find employment adapted to their needs and capabilities. Also, at the EU level, 58,5% of persons with disabilities participate on the labour market (employed or unemployed) compared to 80,5% of persons without disabilities (source: EDF). Out of these 58.5 %, 75% of the people living with MS (currently more than 70.000 in Europe) have declared that their condition has

impacted their employment and career aspirations (source: National Institute of Disability Management and Research).

2. Flexible and secure labour contracts

EMSP supports “flexibility in the conditions of employment” as we have also stated in the Practical Toolkit that was recently launched. For people with multiple sclerosis and other chronic conditions more flexibility would mean they would be allowed to access and retain employment and perform to the best of their capabilities. Some diseases are unpredictable and have invisible facets for the eyes of those surrounding them, like the way fatigue affects MS patients. Flexible and secure working contracts would mean business around Europe would transform the way they manage staff members and this will ultimately lead to effective and cost-saving policies for the businesses and the EU economy as a whole.

6. Active support for employment

“All people under the age of 25 years shall receive a good-quality offer of employment, continued education, an apprenticeship or a traineeship within a period of four months of becoming unemployed or leaving formal education.”

As we already mentioned, young people with disabilities need active support to continue their education, to enter the job market by accessing meaningful internships and traineeships, adapted to their skills and capabilities. It is very often that after being diagnosed with a chronic condition, young people will not continue their studies and they fail to enter the employment field. The European Union needs to better address the barriers people with disabilities face in accessing and retaining employment, we recommend awareness raising campaigns in all Member States and clear measures and tools to measure the impact the EU Social Pillar will have. We are extremely concerned about the situation of people with multiple sclerosis, at the moment more than 80% of those diagnosed will stop working in less than 15 years after diagnosis. We express our commitment to providing the EC our expertise and knowledge, if requested, to make sure the challenges of people with disabilities in the field of employment and social rights are addressed in the Pillar of Social Rights.

16. Disability benefits

The EU should look into defining clearly the concept of disability. Because there is no common definition of disability, accepted and implemented in all member states, determining eligibility for income maintenance is still difficult.

For people with multiple sclerosis, unemployment is common and is associated with substantial socioeconomic burden. Several MS-related factors have been found to be associated with employment status, including fatigue and depression. The relationship between MS and unemployment has been well documented, with the rate of unemployment

in MS falling between 22% and 80%, as we already mentioned before. Unfortunately, once an individual becomes unemployed, he or she may struggle to regain full-time employment for fear of losing the disability benefits.

Therefore, the EU through this Social Pillar needs to look into enforcing a minimum income scheme for people with disabilities, to ensure their rights will be respected and a decent standard of living is accessible to everybody.

The EU has the obligation to make sure “The conditions of benefit receipt shall not create barriers to employment”, as it is stated in the Pillar of Social Rights.