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Young people with MS, the floor is yours!



Interview by Anna Zaghi.

In the following interview Jacobo Santamarta Barral, who has Multiple Sclerosis (MS), takes up the challenge of explaining how his mental wellbeing was affected by the way his employer treated him.

In the context of the European Youth Event that took place in Strasbourg on 20th-21st May, the European Multiple Sclerosis Platform (EMSP) and the European Patients' Forum (EPF) co-organized a workshop entitled: 'Young Patients: Ready, Brilliant and Able to work!'.

Main objectives of the workshop were firstly to raise awareness on the importance of employment among young patients as it provides self-esteem and financial independence; secondly, to promote the needs of young people with chronic conditions among employers and the adjustments that need to be done in the workplace.

After the presentation of some initiatives implemented by the EMSP to support young people with MS all around Europe to access the labour market - e.g. [the Believe & Achieve training programme](#) as well as the release of the [Practical Toolkit for Employers of People with MS](#) the discussion has moved to the delicate relationship between mental health and employment.

In this regard, a young person from Spain, Jacobo Santamarta Barral, who has MS, shared his experience of when was first hired at his company presenting a disability certificate and then moved to a different position without being asked in the first place.



Q. What is your story?



When I first was interviewed by the Company, they already knew about my disability. They were looking for someone with a Disability Certificate so they can meet their legal requirement with the quota system.

Once I was hired, I completely disclosed about my MS even though at that time I did not have any major symptoms. After six months doing the job I was hired for, without consulting me, they decided to change my role into an administrative position which required no special knowledge or skills.

During the past four years, I qualified to be an Intellectual Property (IP) lawyer in Spain, I completed a course on copyright law and a Masters on IP law. I am currently completing my PhD on the same topic. At the same time, I have started a blog on IP issues and I have been studying Russian.

Q2. How you did you feel knowing the company recruited you because of the Disability Certificate?



At the beginning it felt like a relief knowing that I had an opportunity to access the job market. However, knowing that the only ability that is required for the candidate is having a disability is disappointing, even if you know it from the beginning. I am glad to have a job, but I did not want to get it like this.

Q3. Changing your position: was it done in consultation with you? If yes, how is it important? How did you emotionally, psychologically react to this change?



Even though I was informed in advance that my position would be changed, no one asked for my opinion. The decision was already taken by my Employer.

Since the very beginning, I told my boss that this change would impact negatively on my performance as it was a less challenging position and therefore less motivating professionally. Seeing the decision go through, despite the fact that I expressed my concerns, was a huge disappointment and my speaking up then seemed like a failure. I had to accept the changes because I had no other option.

Q4. Disability/mental health: people are suffering from discrimination even when it is done “for your own good”. We even call it “positive discrimination”. How do you personally view this? Is it a good thing? Does it make it even worse? E.g. the legal quota system for employers to recruit people with disabilities.



I personally believe that this type of initiative puts people with any kind of disability in a difficult situation. This is because, unlike other recruitment procedures, access to the job does not take into account the knowledge and skills of the candidate. There is reason to believe that people are being considered for a position only for the reason of having a medical condition. This is translated into mixed feelings in the candidate given that, even though having a job is definitely a good thing, knowing how they have accessed it has a negative slant to it. This is especially relevant when this path seems to be the only option they may have. Things like the quota system are used to make people aware of the issues that people with different specific conditions have to face in the workplace and to normalise their situation as another part of the workplace population. But when the normalisation never comes and these opportunities are still seen by everyone else as a privilege or special treatment rather than a necessary help, the worker is forced into difficult situations that can be a huge strain on them mentally and emotionally. This is not something their work colleagues would expect to deal with yet it is something people with chronic illness or disabilities are almost forced to accept while being grateful for the ‘special treatment’.



Jacobo’s experience has taught us that a lot still needs to be done in terms of access to employment and non-discrimination in the workplace for young patients who face stigma and labelling every day. In particular, further action should be taken to support employers to adopt a new perspective on hiring someone with chronic conditions. As often happens, some employers do not focus on the abilities of the candidate/employee but rather see the difficulties that their business might experience by employing someone who needs small adjustments or specific care requirements. This attitude is based on lack of information. For information on employing people from diverse groups, particularly people with disabilities, the International Labour Organisation has profiled successful global leaders here:

http://www.businessanddisability.org/images/pdf/disability_workplace.pdf.