

# Work-life balance Directive

## - The factsheet -

On 13<sup>th</sup> June 2019, the Council [adopted](#) the Work-life balance Directive, a piece of legislation that will help working parents and carers to reconcile work and family responsibilities, setting new or higher minimum standards across EU countries. EURORDIS-Rare Diseases Europe warmly welcomes the Directive, since the latter has the potential to bring concrete and long-awaited changes to the life of people with a rare disease (PLWRD) and their carers. However, it also notices that many aspects of the legislation are left to the appreciation of the Member States and that therefore, there is the need to wait and see how every country will deal with them.

### What?

The **Directive on work-life balance for parents and carers** (hereinafter "WLB Directive") is one of the deliverables of the [European Pillar of Social Rights](#), an initiative launched by the President of the European Commission J.C Juncker in 2015 which expresses 20 principles and rights essential for fair and well-functioning labour markets and welfare systems in the 21<sup>st</sup> century in Europe.

The WLB Directive aims to address the **work-life balance challenges faced by working parents and carers**, encouraging a better sharing of caring responsibilities between **women and men**.

In particular, the Directive provides for individual rights related to:

- a) paternity leave, parental leave, carers' leave;
  - b) flexible working arrangements for working parents and carers.
- What the legislation does in these areas is to set minimum standards in the EU. Member States may obviously introduce provisions that are more favourable to workers, if they wish so.

### Why?

One of the main reasons behind the WLB Directive is that **women remain considerably underrepresented in the labour market and management**.

Currently, the employment rate in Europe is 11.5% lower for women; 31.1% of women work part-time, especially when they have children, compared to 8.2% of men; and **caring responsibilities are the reasons for inactivity for almost 31% of inactive women**, far from the 4.5% of men.

### When?

- **26<sup>th</sup> April 2017**: the Commission presents the [legislative proposal](#)  
[Ordinary legislative procedure](#): the Council and the Parliament have both a deciding vote and can amend the proposal
- 15<sup>th</sup> May 2017: Committee referral announced in Parliament
- 8<sup>th</sup> December 2017: [Debate](#) in Council
- 11<sup>th</sup> July 2018: [Vote](#) in European Parliament Employment Committee
- **September 2018**: Negotiations among the Commission, the Council and the Parliament start
- **24<sup>th</sup> January 2019**: A [provisional agreement](#) between the Council and the Parliament is reached
- **4<sup>th</sup> April 2019**: The Parliament [adopts](#) the text
- **13<sup>th</sup> June 2019**: The Council [adopts](#) the WLB Directive as a final step
- **June/July 2019** – tbd: Publication of the Directive in the [Official Journal of the EU](#)\*
- **July 2019** (the twentieth day following the publication) - tbd: Entry into force of the Directive
- **2022** (3 years after the date of entry into force): each Member States must have transposed the Directive into national law
- 2027: Member States have to communicate to the Commission all information concerning the implementation of the Directive that is necessary for the Commission to draw up a report

\*Here, it will be possible to access the official version of the text of the Directive

## Why is the WLB Directive relevant for PLWRD and their carers?

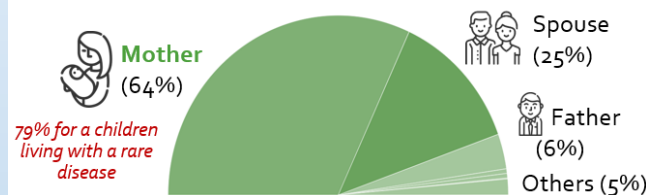
The **WLB Directive** will contribute to address the situation of PLWRD and their carers especially with regards to their **autonomy, integration and participation in the labour market and in the society**.

In fact, as demonstrated by RareBarometer survey '[Juggling care and daily life: The balancing act of the rare disease community](#)', rare diseases generate **severe consequences on employment** of PLWRD and their carers, as well as **important economic burden**:

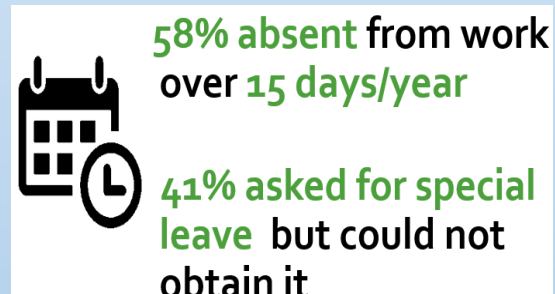
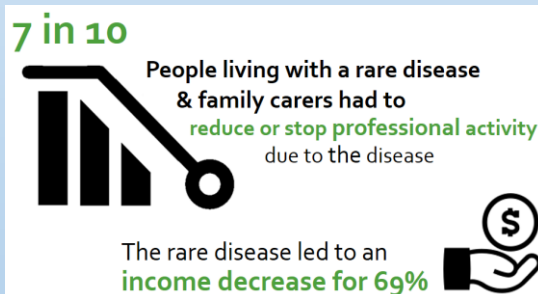
- the **time and care burden is substantial** for the majority of PLWRD and their carers;

**42%** of people living with a rare disease & family carers spend **more than 2h/day** on **illness-related tasks**

The role of the primary carer for people living with a rare disease is primarily assumed by women



- rare diseases have a **strong impact on work-life balance**, leading to absence from work, hampered professional activity, and economic burden;



- rare diseases have significant **repercussions on the mental health** of PLWRD and their carers.

**3 times more people** living with a rare disease and carers report being **unhappy and depressed** than the general population\*

\* Rare Barometer Voices sample compared to International Social Survey Programme, 2011

However, PLWRD are eager to work and often have the capacity to do so, **provided the workplace and work schedules are adapted to the challenges** generated by their specific condition and treatment pathway. Equally, their carers need **tailored support** to allow them to fulfill their caring role whilst remaining in employment.

## What will change for PLWRD and their carers?

- Fathers/equivalent second parents have the right to take **10 working days of paternity leave**, compensated at least at the level of sick pay.
- Each worker has an individual right to **parental leave of 4 months** that is to be taken before the child reaches a specified age, up to the age of eight, to be specified by Member States and compensated at a level to be set by Member States. 2 out of the 4 months are non-transferable from a parent to another.

Members States shall assess the need for the conditions of access to/application of parental leave, to be adapted to the needs of parents with a disability and parents with children with a disability or a long-term illness.

- Each worker has the right to **carers' leave of 5 working days per year**. Member States may determine additional details regarding the scope and conditions of carers' leave. In particular, each Member State will decide whether to provide a payment or an allowance for carers' leave.
- Each worker has the right to **time off from work on grounds of force majeure** for urgent family reasons in the case of illness or accident making the immediate attendance of the worker indispensable.
- Workers with children up to at least 8 years old and carers have the right to request **flexible working arrangements for caring purposes**.
- Member States must take the necessary measure to **protect workers against discrimination or dismissal** on the ground that they have exercised the above-mentioned rights.

**Paternity leave:** leave from work for fathers or, where and is so far as recognised by national law, for equivalent to second parents, on the occasion of the birth of a child for the purposes of providing care.

**Parental leave:** leave from work for parents on the grounds of the birth or adoption of a child to take care of that child.

**Carers' leave:** leave from work for workers in order to provide personal care or support to a relative, or to a person who lives in the same household as the worker, who is in need of significant care or support for a serious medical reason, as defined by each Member State.

**Relative:** a worker's son, daughter, mother, father, spouse or, where such partnerships are recognised by national law, partner in civil partnership.

**Flexible working arrangements:** possibility for workers to adjust their working patterns, including through the use of remote working arrangements, flexible working schedules, or reduced working hours.

### To note:

- **The WLB Directive applies only to workers** who have employment contracts or other employment relationships.  
*This means that PLWRD/carers who do not work are excluded from the scope of the Directive.*
- **These are the minimum standards** EU Member States must have. **Nothing prevents EU countries to introduce higher ones.** For instance, Member States can decide to expand the right to carers' leave to relatives such as grandparents and siblings, and they can increase the days of carers' leave to more than 5. Moreover, **it can happen that in a country more favorable provisions are already in place.** In this case, the implementation of the Directive shall not constitute grounds for justifying a reduction in the general level of protection of workers.
- **Many aspects of the legislation are left to the appreciation of the Member States.** For example, each country will define what 'employment contracts and employment relationships' consist of to be considered 'worker' under the Directive, as well as what 'a serious medical reason' that allows for the carers' leave is.

## How did EURORDIS contribute to the discussion on the Directive?

With the support of EURORDIS Social Policy Advisory Group, EURORDIS has taken the following three key actions in the context of the debates on the work-life balance legislation.

In December 2016, EURORDIS [replied](#) to the **European Commission consultation on the European Pillar of Social Rights**. In that document, EURORDIS already presented how the Pillar could be translated into concrete measures for PLWRD and their carers, especially in the fields of employment and social policies.

EURORDIS also contributed to the European Parliament discussion on the Directive, explaining how the specificities of the challenges faced by PLWRD and their carers should have been taken into account in the text. **EURORDIS welcomed the WLB Directive proposal, but it also identified gaps and areas of improvement.** For this reason, EURORDIS submitted some amendments to the text, especially with regards to carer's leave and flexible working arrangements. EURORDIS underlined the need to have clear and comprehensive definitions in the Directive, so as to avoid wide room for interpretation.

Furthermore, EURORDIS has recently published the [position paper](#) '**Achieving Holistic Person-Centred Care to Leave No One Behind**', which, inter alia, argues for the creation of the conditions for PLWRD and their carers to access adapted and sustainable employment.

## Conclusion & next steps

**Member States retain significant decision-making power** in relation to the scope and the conditions of the rights introduced by the Directive. In other words, there is the need to wait and see how every country will deal with the aspects left to appreciation. In this regards, the **role played by each National Alliance in monitoring** the trasposition of the legislation will be fundamental.

Nonetheless, the WLB Directive already constitutes a **big step forward** in terms of enhancement of European workers' rights and definitely has the potential to bring **concrete and relevant improvements to the life of PLWRD and their carers**. Indeed, the Directive offers the opportunity to ensure PLWRD and their carers the flexibility and protection needed to allow them to combine their care needs and responsibilities with an active professional life.