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Our wish list to the European Commissioners

 Helena Dalli, Commissioner responsible for Equality was appointed to combat all kinds of discrimination. IF welcomes the appointment of Commissioner Dalli and the creation of the Task-Force on Equality. The European Union has finally a champion for equality.

However, we call on the Commissioner to:

- give further explanations on how the Equality Task-Force will work to mainstream equality in all EU policies.
- ensure the full implementation and respect of the UN Convention on the Rights of Persons with Disabilities (UN CRPD).
- mainstream disabilities in all EU policies not only related to employment and social inclusion. We also hope that the Commission will continue to raise awareness on the living conditions of persons with disabilities and especially persons with spina bifida and/or hydrocephalus (SBH) and the challenges they encounter in everyday life.
- unblock the Anti-Discrimination Directive and find a way forward. This
 directive is essential to protect people from all kinds of discriminations outside
 of the labour market.
- ensure the swift and full implementation of the Work-Life-Balance Directive at national level. The transposition of the directive should also be the opportunity to pay special attention to the fair distribution of care responsibilities in the society, with particular attention to the situation of carers of children and adults with disabilities and especially to persons living with SBH.
- o present an ambitious **European Gender Strategy** which will (1) address the issues of women with disabilities; the well-documented knowledge gap about sexual and reproductive health of women and girls and especially of women with disabilities and with SBH; (2) raise awareness on the need of accessible sexual and reproductive healthcare services for women and girls with various disabilities (with a special attention to women from migrant or low socioeconomic background); (3) and the importance to train medical professionals on health rights of girls and women with disabilities and improve the accessibility of medical facilities.

IF hopes that we can rely on Commissioner Dalli to strengthen the inclusion and participation of persons living with SBH in society and promote equality within the European Union.



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Nicolas Schmit, Commissioner responsible for Jobs and Social Rights. IF
welcomes the fact that social rights have been included in his portfolio. Jobs must go
hand in hand with social rights if we want to achieve the inclusion and participation of
people with disabilities.

We call on the Commissioner to:

- launch an ambitious and inclusive European Disability Strategy for the next decade. The current European Disability Strategy will come to an end in 2020, it is time for the Commission to work on the next European Disability Strategy.
- ensure that the European Social Fund+ (ESF+) will remain an important tool to foster social inclusion and promote employment for persons with disabilities. The ESF+ is the main fund to promote social cohesion, improve social fairness across Europe. It is essential that ESF+ respects the UN CRPD, and is aligned with the European Pillar of Social Rights (pillar), to ensure the use of the fund for transition from institutions to community-based care.
- continue the work of the previous Commission and translate the European Pillar of Social Rights into policies. IF is looking forward to see the European Action Plan for Social Economy to continue the implementation of the Pillar.
- link the Pillar with the European Semester process for 2020 and with the next European Disability Strategy.
- ensure a labour market inclusive for persons with disabilities and especially for persons living with SBH. Persons with disabilities are still facing several difficulties in finding and/or keeping a job. In the EU, only 47%¹ of persons with disabilities are employed compared to 72% of persons without disabilities. It is essential to guarantee the same access to employment and training to persons with disabilities, especially to young people and women with disabilities and ensure that they can live independently;

IF hopes that it can rely on Commissioner Schmit to strengthen the social dimension of the European Union and improve the inclusion of persons with disabilities in the labour market.

1 From the article "Employment" of the European Disability Forum http://www.edf-feph.org/employment



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 Commissioner Stella Kyriakides, responsible for Health. IF welcomes the appointment of Commissioner Kyriakides whose priority will be to protect and promote public health.

IF calls on the Commissioner to:

- ensure access to high-quality, affordable person-centred and multidisciplinary healthcare. Access to safe, effective, quality and affordable healthcare is vital for persons living with SBH throughout the lifespan.
- tackle inequalities to access medicines and healthcare services between and within the EU Member States through the European Reference Networks (ERNs), the Cross-Border Healthcare Directive and multidisciplinary healthcare².
- o continue to support ERNs and provide them with technical support. ERNs³ are essential virtual networks of healthcare providers across the Europe Union.
- monitor the implementation of the Cross-Border Healthcare Directive and support the National Contact Points by communicating better to patients on their rights.
- present a new, modernised and robust legislative framework for medical devices. Medical devices and products are also highly important for persons living with SBH (shunts, wheelchairs, continence management products, etc.).
- tackle the lack of disaggregated data on disabilities and especially on data on persons living with SBH. Data on people with disabilities is incomplete or lacking, and this can lead to the presumption that SBH is a rare condition.
- tackle the lack of knowledge and persisting stigma and misconceptions that persons with disabilities do not or should not have sex and address the subsequent well-documented knowledge gap about sexual and reproductive health of women and girls with disabilities. Women and girls with disabilities will be more exposed to discriminations. It is essential to tackle stereotypes and discriminations against persons with disabilities.

IF hopes that it rely on Commissioner Kyriakides, to ensure and promote access to quality and affordable healthcare services, medical products and devices. This is key for people with SBH and ensure their inclusion in society.

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² Children and adults with SBH need different specialists who can address their multiple medical and cognitive issues and promote a healthier lifestyle. This can include urologists, neurologists, orthopaedists, psychologists and others. Multidisciplinary healthcare is essential for persons living with SBH, who need an integrated healthcare system, persons-centred healthcare and an effective transition from paediatric to adult care.

³ Which improve diagnosis and care for complex or rare medical diseases or conditions



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Vice - President Dubravka Suica, responsible for Democracy and Demography.
 In the upcoming years, the European Union will have to face even more democratic and demographic challenges such as tackling poverty and social inequality and ensuring equality between genders and age groups.

IF calls on the Vice-President to:

o include in the Green Paper on ageing, persons with disabilities and especially persons living with SBH. Persons living with SBH are facing daily barriers - physical, financial and technical - which prevent them from being fully included in society. Ageing is increasing those barriers. While people with SBH are living longer than ever before, still little is known about the lived experience of older persons living with SBH. IF hopes that this paper will set priorities on what needs to be done to ensure that people with SBH will maintain their health and can live their lives equal to others as they age.

We hope that the new European Commission will take our recommendations into account and will improve the daily life of people living with SBH and ensure their inclusion and participation in society - not only related to employment. The European Union should continue to design and implement policies and programming for persons with disabilities and especially take into consideration the complex needs of people living with SBH and respecting the UN CRPD.

For more information:

<u>Composition of the new European Commission</u>

Commitments made at the hearings of the Commissioners-designate