ASSESSMENT HORIZON 2020 WORK PROGRAMMES 2014 - 2015

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Introduction

The **European Disability Forum (EDF)** is the European umbrella organisation representing the interests of 80 million persons with disabilities in Europe. EDF's mission is to ensure persons with disabilities full access to fundamental and human rights through their active involvement in policy development and implementation in Europe. EDF is a member of the Social Platform and works closely with the institutions of the European Union (EU), the Council of Europe and the United Nations.

EDF has closely followed the adoption and implementation of the new EU Research & Innovation framework **Horizon 2020** (2014-2020)[1]. The programme provides 80 billion euros of funding to support the most innovative EU research areas. Thus, the goal of EDF with regard to this crucial flagship of the EU is to **ensure that Horizon 2020 is fully in compliance with the UN Convention on the Rights of Persons with Disabilities[2]** which explicitly obliges the State Parties to "undertake or promote research and development of universally designed goods, services, equipment and facilities", including "information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost" (Article 4(1)). The Convention also requires the States Parties to facilitate "cooperation in research and access to scientific and technical knowledge" among them for the accomplishment of the objectives enshrined in the Convention (Article 32).

EDF believes that even though the EU has funded research projects in the field of disability, with an increasing number of projects focusing on equality, non-discrimination and accessibility, **there is still a predominant medical, therapeutic and rehabilitation-**

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[1] Regulation (EU) No 1291/2013 establishing Horizon 2020 is available at
http://ec.europa.eu/research/participants/portal/desktop/en/funding/reference_docs.html#h2020-legal-basis-fp)
[2] The UN Convention on the Rights of Persons with Disabilities is available at:
http://www.un.org/disabilities/convention/conventionfull.shtml

oriented approach in the EU research priorities that has been pointed out by some studies in the past[3]. Hence, EDF regrets that **Horizon 2020 does not address disability from a human rights perspective and the accessibility and universal design perspective is not mainstreamed in the work programmes**. Furthermore, there is not a specific requirement for projects to use **accessible means of information and communication**, and the gender dimension of the Regulation does not take into consideration the **situation of women and girls with disabilities**.

The multiannual **work programmes**[4] which are prepared by the European Commission are the basis for the funding of projects under Horizon 2020. The work programmes indicate the different research areas identified as priorities, as well as the main objectives and the project award criteria for the different calls for proposals.

In order to provide evidence of the absence of a disability perspective in the work programmes, and to encourage the European Commission to mainstream disability from a Human Rights perspective in the forthcoming work programmes of 2016-2017, EDF has requested Professor Lisa Waddington, of Maastricht University, to undertake a series of in depth reviews of the main work programmes that might more directly affect persons with disabilities.

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[3] See "New Priorities for Disability Research in Europe", Report of the European Disability Forum Consultation Survey "European Research Agendas for Disability Equality", Prepared by Prof. Mark Priestley and Prof. Lisa Waddington for the European Disability Forum, December 2008, available at: http://www.eurade.eu/admin/wysiwyg/assets/Consultation%20Survey/EuRADE%20consultation%20report_FINAL.pdf;

[4] All work programmes can be found at: http://ec.europa.eu/research/participants/portal/desktop/en/funding/reference_docs.html#h2020-work-programmes-2014-15

About Professor Lisa Waddington

Professor Waddington completed her studies in Law and Politics (first class honours / cum laude) at the University of Birmingham (1989) and received her Doctorate of Law in 1993 from the European University Institute in Florence, Italy, for her dissertation: *'More Disabled Than Others. The Employment of Disabled People within the European Community: An Analysis of Existing Measures and Proposals for Reform'*.

Prof. Waddington also worked as a researcher at the University of Georgetown, Washington D.C. in 1992 and as an associate professor at the University of British Columbia, Vancouver, in 2000. Between 1993 and 2004 she was the editor of the Maastricht Journal of European and Comparative Law. In 2000, Prof. Waddington received an ASPASIA award from the NWO (Netherlands Organisation for Scientific Research) for the enhancement of the number of women in higher academic positions.

Between 2004 and 2007, in collaboration with universities and international institutions in Belgium and Ireland she is coordinated, with colleagues, a large EU research and education project with regard to European non-discrimination law and is currently coordinating Maastricht University's involvement in the Marie Curie Initial Training network DREAM (Disability Rights Enabling Accessible Markets). Prof. Waddington is also the disability coordinator of the EU Network of Legal Experts in the Non-Discrimination Field and a member of the core research team of the Academic Network of European Disability experts (ANED).

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Assessment Horizon 2020 Work Programmes 2014-2015 (I)

Health, demographic change and wellbeing

The work programme[5] includes 34 topics on "personalising health and care", 16 "coordination activities" and 8 other actions.

The decision to focus on "personalising health and care" is stated to be "informed by the ageing of the European population, an increasing communicable and non-communicable disease burden and the fall-out from the economic crisis" (p. 5).

The "personalising health and care" call "aims to create opportunities for real breakthrough research and radical innovation in response to these challenges, by supporting the translation of findings into clinic and other health and care settings to improve health outcomes, reduce health inequalities and to promote active and healthy ageing" (p. 5).

The research funded under this work programme will "improve our understanding of the causes and mechanisms underlying health, healthy ageing and disease; improve our ability to monitor health and to prevent, detect, treat and manage disease; support older persons to remain active and healthy; and test and demonstrate new models and tools for health care and delivery" (p. 5).

This is a good **summary of the goals of the work programme, reflecting both its strengths and weakness from a disability perspective**.

Disabled people, just as all other members of the population, benefit from the prevention of illness and poor health and the efficient and appropriate delivery of good health care. However, **the work programme pays more or less no attention to the health needs of people with disabilities as a specific group**. The work programme rarely mentions

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[5] The work programme "*Health, demographic change and wellbeing*" is available at:
http://ec.europa.eu/research/participants/data/ref/h2020/wp/2014_2015/main/h2020-wp1415-health_en.pdf

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disability explicitly[6], and seems to perceive disability as a negative consequence related to a health condition that should be prevented or treated and **regards disability in the same way as disease**. Other than this perspective, it is difficult to find a disability-dimension to the work programme.

A key point is that there is no recognition in the calls that persons with disabilities may have particular needs in term of healthcare – whether that be in terms of medication or treatment – and, whilst, many calls require the research to have a gender dimension and, occasionally an age dimension, meaning that research projects should take these elements into account, **there is no mention whatsoever of the need to include a disability dimension**. By a "disability dimension" I mean the need to consider how medication, treatment or tools for health and care impact particularly on persons with disabilities, or persons with particular kinds of disabilities, and can be made accessible to persons with disabilities. In contrast many calls require assessment or the taking account of "age and gender aspects"[7] or sex and gender aspects / differences / balance[8]. **This represents a significant missed opportunity**.

An example of a call which could have usefully mainstreamed disability is *PHC 23 – 2014: Developing and comparing new models for safe and efficient, prevention oriented health and care systems*. Proposals under this call should "develop new, or improve existing, models for health systems, in order to make these systems more patient-centred, prevention oriented, efficient, resilient to crises, safe and sustainable" (p. 33). Given that people with disabilities may have particular needs in terms of accessing and using health systems, **the call could have usefully called for researchers to take account of the disability dimension, as well as the gender dimension**. The call also requires that "views of relevant stakeholders such as policy makers and citizens should be taken into account in the design and evaluation of these models" (p. 34), but there is no specific requirement to involve people with disabilities or their representative organisations.

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[6] A rare reference is under the call PHC1 where a reference is made to "the identification of health trends and determinants, their validation, and the validation of risk factors for disease and disability" – disease and disability are thus regarded in the same way here.

[7] E.g. PC4, PC5, PC26

[8] E. g. PC1, PC2, PC3, PC6, PC7, PC13, PC 17, PC19, PC20, PC21, PC23, PC24, PC25

Further calls which could have mainstreamed disability in the same way are *PHC 24 – 2015: Piloting personalised medicine in health and care systems, PHC 25 – 2015: Advanced ICT systems and services for Integrated Care, PHC 26 – 2014: Self-management of health and disease: citizen engagement and mHealth, PHC 27 – 2015: Self-management of health and disease and patient empowerment supported by ICT, PHC 28- 2015: Self-management of health and disease and decision support systems based on predictive computer modelling used by the patient him or herself*, and *PHC 29 – 2015: Public procurement of innovative eHealth services*.

In addition to a failure to "mainstream" disability in the various calls, **there are also no calls which specifically address the health needs of persons with disabilities, or a sub-group of persons with disabilities**. In contrast, a call which focuses on the needs of a particular group is *PHC 18 -2015: Establishing effectiveness of health care interventions in the paediatric population*. It is possible to envisage a call focusing on the health needs of a particular section of the population of disabled people, such as people with learning disabilities.

There are also a number of calls which focus on healthcare for the "elderly". Call *PHC 17 – 2014: Comparing the effectiveness of existing healthcare interventions in the elderly* could potentially provide a model for a similar call relating to healthcare interventions for particular groups of persons with disabilities.

A number of calls under the sub-heading "Advancing active and healthy ageing", could have usefully included the needs of younger people with (severe) disabilities as well as older people. Examples include *PHC 19 – 2014: Advancing active and healthy ageing with ICT: Service robotics within assisted living environments, PHC 20 – 2014: Advancing active and healthy ageing with ICT: ICT solutions for independent living with cognitive impairment* and *PHC 21 – 2015: Advancing active and healthy ageing with ICT: Early risk detection and intervention*.

Amongst the calls for coordination activities is *HCO – 2014: Global Alliance for Chronic Diseases: prevention and treatment of type 2 diabetes*. This call for proposals focuses *inter*

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alia on the prevention and treatment of type 2 diabetes for "vulnerable population in high income countries" (p. 67). *HCO 6 – 2015* includes a similar call with regard to prevention and treatment of lung disease. Whilst I do not regard people with disabilities as vulnerable *per se*, they may be rendered vulnerable in particular situations, e.g. through a lack of accessible health care facilities or a lack of medicine or advice which takes account of their specific impairment or situation. **The concept of "vulnerability" could at times be an appropriate means to integrate a disability dimension to research under this work programme – although any call should make clear that the goal of the research is to reveal ways of reducing and eliminating vulnerability**.

Science with and for Society. Revised

The *Science with and for Society* Work Programme[9] should "help build effective cooperation between science and society, to recruit new talent for science and to pair scientific excellence with social awareness and responsibility" (p. 4). The Introduction to the Work Programme notes that "important ethical, legal and social issues that affect the relationship between science and society" are on the rise and there is a need "to enable the development of policies more relevant to citizens" (p. 4).

Science with and for Society should allow "all societal actors (researchers, citizens, policy makers, business, third sector organisations etc.) to work together during the whole research and innovation process in order to better align both the process and its outcomes with the values, needs and expectations of European society" (p. 4). This approach to research and innovation is called **Responsible Research and Innovation**, and it consists of designing research and innovation policy that will meet five goals:

- Engaging society more broadly in its research and innovation activities;

- Increasing the access to scientific results;

- Ensuring gender equality in both the research process and research content;

- Taking account of the ethics dimension; and

- Promoting formal and informal science education.

The Work Programme consists of calls for proposals focusing on four broad areas: "Making science education and careers attractive for young people"; "Promoting gender equality in

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[9] The Work Programme "*Science with and for Society. Revised*" is available at:
http://ec.europa.eu/research/participants/data/ref/h2020/wp/2014_2015/main/h2020-wp1415-swfs_en.pdf

research and innovation"; "Integrating society in science and innovation"; and "Developing governance for the advancement of responsible research and innovation". Each call consists of between four and nine topics. The Work Programme also contains calls for fifteen other actions.

Given the overall aims of the *Science with and for Society* Work Programme to engage society more broadly in research it is somewhat surprising that **there is no mention whatsoever of involving persons with disabilities** in the Work Programme. This is important because, in order to involve disabled people in science, it will be necessary to take account of the **need to provide accessibility** to people with disabilities. For example, under the "Call for Making Science Education and Careers Attractive for young People", there is n**o mention of the need to provide accessibility or reasonable accommodation** for young people with disabilities, or to reach out to this group. Such references – albeit in a single sentence – could have usefully been included in *SEAC.1.2014.2015 – Innovative ways to make science education and scientific careers attractive to young people*, which refers to "formal and informal teaching and learning" without mentioning the need to make that accessible to young people with disabilities (p. 7); *SEAC.2.2014 – Responsible Research and Innovation in Higher Education Curricula,* which refers to "the design, production and dissemination of education material and curricula for use by Higher Education Institutions" and aims to assist the development of "openly available curricula", without referring to the need to make such curricula available in accessible formats (p. 8); and *SEAC.3.2014 – Trans-national operation of the EURAXESS Service network*, which will contribute to "the career development of mainly young researchers in Europe", without referring to the need to provide career development that takes account of the needs of disabled researchers (p. 9).

As noted, **such references could have been included in a single sentence in the topics**, and could have also reached out to other potentially disadvantaged groups such as ethnic minorities. This is also true of the first topic listed under the Call for promoting Gender Equality in Research and Innovation (*GERI.1.2014 – Innovative approach to communication encouraging girls to study science*). In this respect **it would have been appropriate for all**

calls and topics to have included a reference to implementation in accordance with the principle of non-discrimination, as elaborated in the TFEU, the EU Charter of Fundamental Rights and the UN Convention on the Rights of Persons with Disabilities. Non-discrimination would then be required with regard to the provision of services, training, teaching and support when implementing the project.

The "Call for promoting Gender Equality in Research and Innovation" includes various topics focusing on gender diversity / gender equality, including the topic *GERI.4.2014-2015 – Support to research organisations to implement gender equality plans*. The gender equality plans shall consist of a number of elements, including conducting impact assessments and auditing of procedures and practices; implementing innovative strategies to address gender bias, including providing training on gender equality; and setting targets and monitoring progress (p. 17). **These same approaches could usefully be applied in the context of disability equality**.

It is also worth noting that the various topics under this call addressing **gender equality / gender diversity make no mention of any characteristic of women other than their gender** – meaning that there is a risk that successful policies will focus on white non-disabled European women, and not benefit other women, including women with disabilities.

The "Call for Integrating Society in Science and Innovation" notes that "citizens' interests and values need to be better integrated into science, technology, research and innovations issues, policies and activities" and this will "increase the quality, relevance, social acceptability and sustainability of research and innovation outcomes" (p. 21). A number of the topics refer to the involvement of particular groups in society. *ISSI.1.2014.2015 – Pan-European public outreach: exhibitions and science cafes engaging citizens in science*, refers to drawing on the experience and capacity of various organisations, including Non-Governmental Organisations (NGOs) and civil society organisations. The funded projects are to "employ inclusive participatory techniques to engage with multiple publics (children, youth, women, adults, and other relevant stakeholders)" (p. 22). Projects funded under *ISSI.2.2014 – Citizens and multi-actor engagement for scenario building* are to "develop and implement methodologies for

pan-European and multi-lingual face-to-face participatory and inclusive workshops with citizens (including youth, women) and other stakeholders, to devise scenarios, visions and storylines in relation to desirable sustainable European research and innovation futures" (p. 23). **Whilst this part of the Work Programme refers to specific groups within the population, no mention is made of persons with disabilities** who may have particular visions on certain kinds of research. As a consequence, no mention is made of the need to ensure communication, or the sharing of knowledge and establishing online mechanisms, which are accessible to people with disabilities.

Under the Call for developing governance for the advancement of Responsible Research and innovation, which includes a number of topics focusing on ethics, topic *GARRI.9.2015 – Estimating the costs of research misconduct and the socio-economic benefit of research integrity*, refers to the consequences of research misconduct, which include harming people "(including patients and other vulnerable populations)" (p. 39). **This dimension is not explored further, even though disabled people could be particularly vulnerable to such abuse**.

Communication, Dissemination and Exploitation. Revised

This short Work Programme[10] addresses information dissemination activities and communication activities. These are to be an important part of Horizon 2020. The Work Programme covers "Dissemination and exploitation", and "Corporate communication".

With regard to "Dissemination and exploitation", the Commission will provide web-based access to information on funded projects, as well as their results. Amongst other things, this will respond to the Commission's commitment to open access to public service information. A Common Support Centre (CSC) is to develop a strategy for dissemination and exploitation aligned with "the principles of IT and Web rationalisation" by 2015 (p. 2). The Commission wishes to ensure that dissemination and exploitation policy *inter alia* makes available "relevant services in user-friendly way including content management, IT developments, maintenance, operational and supporting activities" (p. 2). **No reference is made to making information available in disability accessible formats**.

Three other actions are listed under the heading "Dissemination and exploitation" activities: "Experts and Public Procurement – Information and Communication Technologies for Analysing Results of EU Project Portfolios for Policymaking"; "Public Procurement – Assistance for Dissemination, Valorisation and Exploitation Activities of FP7 Research Projects"; and "Public Procurement – Assistance for Partner Search and Dissemination Activities on the Participant Portal". No reference is made to making information available in disability accessible formats under any of these actions.

With regard to "Corporate communication", the goal is to ensure that the communication needs of the Europe 2020 Strategy are met. "Corporate communication will serve to convey top level messages about the EU which will create a leverage effect in support of

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[10] The Work Programme "Communication, dissemination and exploitation. Revised" is available at:
http://ec.europa.eu/research/participants/data/ref/h2020/wp/2014_2015/main/h2020-wp1415-comm-diss_e

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communication actions dealing with specific Europe 2020 policy areas, including research and innovation" (p. 5). It is noted that Horizon 2020 will play a central role in the delivery of the Europe 2020 strategy and that "corporate communication actions that demonstrate to non-specialised audiences the EU's added value in growth and job creation as well as seek views from the public on the future of the European Union intrinsically support Horizon 2020's core added values" (p. 5). Results from corporate communication should include increased learning from experience, a boosted transferability of results, a better understanding of the EU by citizens and an enhanced image of the EU institutions and their activities. Corporate communication is to be implemented through an integrated communication campaign, promoting the EU's activities. "The overall aim will be to reach particular segments of society" and the campaign "will use multiple channels to deliver a clear and consistent message to a variety of audiences". **No indication is given of the specific segments of society or specific audiences which are to be targeted**. This also means that there are no references to targeting people with disabilities or, once again, to making information available in disability accessible formats.

The addition of a sentence in the Work Programme referring to the **need to develop information and communication strategies which make use of formats which are accessible** to persons with disabilities would have addressed the needs of the disability community, and been in line with the 2012 Commission proposal for a directive of the European Parliament and the Council on the accessibility of public sector bodies' websites[11], since much information is to be disseminated via ICT.

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[11] Brussels, 3.12.2012 COM(2012) 721 final 2012/0340 (COD) is available at: http://ec.europa.eu/digital-agenda/en/news/proposal-directive-european-parliament-and-council-accessibility-public-sector-bodies-websites

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Useful links:

- [Policy Statement - European Research Agenda's for Disability Equality (EuRADE project)](#)

- [EDF Position on Horizon 2020](#)

- [EDF Amendments on Amendments on Proposal for a Regulation establishing Horizon 2020 - The Framework Programme for Research and Innovation (2014-2_020) (COM(2011)809 final)](#)

- [Amendments on Proposal for a Regulation laying down the rules for participation and dissemination in "Horizon 2020 – the Framework Programme for Research and Innovation (2014-2020)" (COM(2011)810final)](#)

- [EDF Amendments on Proposal for a Council Decision establishing the Specific Programme implementing Horizon 2020- The Framework Programme for Research and Innovation (2014-2020) (COM(2011)811 final)](#)

- [Disability Law and Research Policy Unit, National University of Ireland, Galway](#)

- [Casebook on non-discrimination law](#)

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