



New Priorities for Disability Research in Europe

European Disability Forum Briefing Seminar on the Consultation Survey 'European Research Agendas for Disability Equality' Briefing Seminar Report

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European Disability Forum – Forum européen des personnes handicapées
rue du Commerce 39-41 — B-1000 Brussels
T : +32 (0)2 282 46 00 - F : +32 (0)2 282 46 09 - W : www.edf-feph.org
Contact : Sandra Tavares Moreira - sandra.tavares-moreira@edf-feph.org





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About EuRADE

Recent years have witnessed a growth in research that focuses on disability equality, non-discrimination and accessibility. Key to this development has been the growing demand by disabled people's organisations for a more holistic approach to research which addresses the underlying causes of social exclusion. Disabled people's organisations have also demonstrated a sustained interest in engaging in research, arguing that their voice, needs and priorities should be better represented in shaping research agendas.

Yet, for the most part, research on disability has been and is still dominated by professional academics, researchers and industry. The participation of disabled people and disabled people's organisations as equal and active partners in research remains a challenge. A reason for that is their lack of research knowledge and capacity as well as their limited access to research funding opportunities.

In light of these concerns, the European Research Agendas for Disability Equality (EuRADE) project seeks to increase and enhance the full participation of disabled people's organisations as equal and active partners in future research initiatives promoting disability equality and non-discrimination in Europe. Funded under the Seventh Framework Programme for Research and Technological Development (FP7), the project is led by the European Disability Forum (EDF), in partnership with the University of Leeds (United Kingdom) and Maastricht University (The Netherlands).

For further information, please visit: www.eurade.eu.



Introduction

This report covers the proceedings of the briefing seminar on the 'Consultation Survey 'European Research Agendas for Disability Equality': New Priorities for Disability Research in Europe', held at the European Parliament, in Brussels, on 21 January 2009. Organised by the European Disability Forum, the briefing seminar was hosted and chaired by Ms Catherine Trautmann, MEP & Vice-Chairwoman of the Committee on Industry, Research and Energy.

The primary purpose of the seminar was to present the principal findings and recommendations of a consultation recently conducted by the European Disability Forum, in partnership with the University of Leeds and Maastricht University, with disabled people's organisations in European countries. The consultation, which ran from May to July 2008, aimed at giving disabled people's organisations in Europe the opportunity to share information about their past research experiences, their priorities for future research and their interest in research participation. It gathered responses from 68 organisations in 25 countries, the majority of which work at the national or European levels, and are controlled by disabled people.

The briefing seminar brought together representatives of the European Parliament and the European Commission, as well as stakeholders of the disability, academic and research communities from around 15 European countries. Participants discussed and exchanged views on the perspective of future research in Europe highlighting the barriers to, as well as the potential benefits of, ensuring the equal and full participation of disabled people in research and building research partnerships between disabled people's organisations and researchers. Current opportunities for the participation of disabled people's organisations in the European Commission's Seventh Framework Programme for Research and Technological Development (FP7) and concrete proposals on how the voice of disabled people may best be represented in shaping European research agendas that will support disability equality and non-discrimination in European societies were also presented.



Seminar opening

Ensuring equal and active participation of disabled people's in research: the fundamental role of policymakers

Britta Thomsen, MEP & Member of the Committee on Industry, Research and Energy and the Committee on Women's Rights and Gender Equality - Denmark

Opening the briefing seminar, Ms Britta Thomsen MEP referred to the results of the EuRADE consultation survey noting that although disability is a growing field of research, disabled people and their organisations have not been involved in research as active participants or researchers, nor have their needs been incorporated in research agendas. Ms Britta Thomsen MEP highlighted the lack of resources in disabled people's organisations as one of the reasons hampering their full participation in research, and recognised that it is the responsibility of policy-makers to take action to address and help change this situation. She also acknowledged that there is a need for the European Parliament and the European Commission to pay greater attention to and gain a better understanding of the importance of including disabled people and their organisations in the construction of the FP7, and to facilitate research collaboration among researchers and civil society organisations. Finally, Ms Britta Thomsen highlighted the equal opportunities and non-discrimination directive adopted by the European Commission in July 2008 which she stated "will improve the rights of disabled people all over Europe" including with relation to the FP7.

Presentations

EuRADE: building the capacity of disabled people organisations for research participation

Erzsebet Szollosi, Member of the Executive Committee, European Disability Forum - Hungary

Ms Erzsebet Szollosi provided an overview of the of the European Research Agendas Disability Equality (EuRADE) project outlining its goals and key activities. Developed and led by the European Disability Forum in partnership with the University of Leeds and Maastricht University, the project focuses on building the capacity of disabled people's organisations to participate as equal and active partners in future research initiatives that will promote disability equality and non-discrimination in Europe. This is being achieved, thanks to the support of the FP7, by engaging representatives of European disabled people's organisations in activities involving the definition of research policies and

priorities, research knowledge and capacity development - including participation in a research summer school, in an online research training and in research conferences -, and through mapping opportunities for funding and research collaboration between disabled people's organisations and academics. Recognising that research is a fundamental tool for policy making, Ms Erzsebet Szollosi also underlined that disability research should be grounded in the social model of disability "where the disability is [...] the result of the interaction between [an individual's] impairment and the barriers that are built by society".

The top 10 research priorities of disabled people's organisations

Mark Priestley, Professor of Disability Policy, University of Leeds - United Kingdom

Whilst there is a need for increased research capacity in disabled people's organisations, Professor Mark Priestley from University of Leeds also stressed that disabled people and their organisations clearly have a strong contribution to make to future research and a strong motivation to be involved in research as active and equal partners. After providing a clear insight into the EuRADE consultation survey design and implementation, Professor Mark Priestley summarised its key findings and presented the top ten priorities for disability equality research as identified by the disabled people's organisations which responded to the consultation survey: 1) Non-discrimination and human rights; 2) Support for independent living; 3) Education; 4) Information and communication; 5) Bioethics and rights to life; 6) Health care; 7) Mainstreaming disability in policies; 8) Organisations of disabled people; 9) Urban and built environments; 10) Parenting and family life. In his closing comments, Professor Priestley presented some thoughts on possible ways in which disabled people could be involved in research. Building on the general principle of equal and full participation, where disabled people become research 'subjects' as opposed to research 'objects', roles for disabled people could range from acting as a project reference group, consultants or peer interviewers to co-researchers, academics or project coordinators.

An executive summary of and the full analysis report on the results of the consultation survey are available from the EuRADE website: www.eurade.eu.

Panel and open floor discussion

The briefing seminar also saw a high-level panel discussion, chaired by Ms Catherine Trautmann MEP, followed by an open floor discussion on ways to facilitate and ensure the



equal and active participation of disabled people and their organisations in shaping European research agendas as well as in formulating, designing and implementing future research initiatives.

Overcoming the barriers to participatory action research

Lisa Waddington, Professor & EDF Chair in European Disability Law, Maastricht University - The Netherlands

Focusing on the barriers to participatory research as these can be perceived by academics, Professor Lisa Waddington highlighted the challenges of developing fruitful partnerships between academics and disabled people's organisations - notably the lack of research capacity and knowledge among disabled people's organisations, the inexperience of academics, as well as a general lack of appropriate funding schemes that facilitate participatory research between academics and disabled people's organisations. Whilst these barriers may seem difficult to overcome, Professor Lisa Waddington also noted that "there is potential for [participatory] research and for disability to be taken into account in all areas of research". In this context, she put forward some proposals on the possible strategies to overcome these barriers, including providing training and support to both academics and disabled people's organisations (e.g. through a research summer school) as well as developing adapted funding schemes that would cover training costs and research activities of disabled people's organisations at 100% and provide incentives for partnerships between civil society organisations and researchers that are based on the principles of equality and full participation.

'Nothing about us without us': the equal and active participation of disabled people in research as a matter of human rights and democracy

Yannis Vardakastanis, President, European Disability Forum - Greece

Echoing the needs highlighted by Professor Waddington, Mr Yannis Vardakastanis referred to Article 16 of the European Council's regulation 1083/2006 on Structural Funds General Regulation and called for non-discrimination and equal access for disabled people to be set as criterion for the definition and implementation of research funding programmes. Mr Vardakastanis also argued that "the issue of making research accessible to disabled people – as students, researchers, teachers or through their representative organisations – is a matter of paramount importance", adding that ensuring the involvement of disabled people in the research agendas planning, setting and implementation process clearly is a political issue that needs to be addressed by decision- and policy-makers both at the European and the national levels. Emphasising



that the equal and active participation of disabled people and their organisations in research is fundamentally a matter of human rights and democracy and that strong decisions should be made to open up research to disabled people, Mr Vardakastanis also acknowledged that “the disability movement itself has the great responsibility for putting research issues high in their agendas”.

Linking research with democracy: an innovative perspective to research

Britta Thomsen, MEP & Member of the Committee on Industry, Research and Energy and the Committee on Women's Rights and Gender Equality - Denmark

Having joined the panel discussion, Ms Britta Thomsen MEP pointed to the innovative nature of the EuRADE project which, by linking research with democracy, brings a new perspective to the way politicians perceive research. She recalled the first meeting held by the Disability Intergroup of the European Parliament on how to promote disability research within the Seventh Framework Programme (FP7), and recognised that such a link had not been made or raised as an issue, perhaps due to disability research still being understood from the traditional medical perspective. With discussions continuously under way, including as regards the proposed Article 13 EC non-discrimination directive, Ms Britta Thomsen MEP encouraged the disability movement to pursue its collaboration with the European Parliament and strongly recommended that disabled people increase their lobbying efforts to influence the early stages of the research agenda setting of the European Framework Research Programme. Referring to the principles of equality and non-discrimination promoted by EuRADE, Ms Britta Thomsen MEP also highlighted the need for women with disabilities and their specific concerns to be recognised and included in the research agendas setting and implementation process.

The European Commission: slowly, but surely moving towards a greater involvement of civil society in research

Jean-Michel Baer, Director, Directorate of Science, Economy and Society - Directorate-General for Research, European Commission - Belgium

The European Commission is currently reflecting on the implementation of the European research area (ERA), so as to better coordinate research activities whilst ensuring cooperation in addressing challenges. According to Mr Jean-Michel Baer efforts are also being made to ensure that civil society organisations are actively involved in debating, setting and also implementing the European research agenda as partners. Although the process may seem to be evolving slowly and despite the limitations, “European institutions are listening to the voices of civil society” he said, highlighting EuRADE as an



example that should inspire future cooperative actions between disabled people's organisations and research institutions.

Recalling Professor Waddington's proposal for new funding approaches, Mr Jean-Michel Baer noted that the European Union's funding programmes must comply with Community regulations which do not currently permit research projects to be funded at 100%, and stressed that resources should also be mobilised at the national level. However, it is the Commission's intention to continue to foster civil society participation in research. In recent years, instruments have been developed and designed specifically to allow civil society organisations to submit proposals for research, notably the "Research for the Benefit of Specific Groups – Civil Society Organisations (BSG-CSO)" funding scheme. Another step in that direction is a new type of funding scheme which is expected to be introduced next year. It will aim at funding transnational programmes over a period of up to 3 or 5 years. The new funding scheme will provide a new approach to participatory research. Indeed, it will fund the establishment of consortiums that will bring together municipalities, parliamentarians, research centres and civil society organisations to discuss and define strategies on topics that will address the needs of civil society.

In response to specific concerns raised by representatives of disabled people's organisations about the lack of European research into, and resources for, disability equality, Mr Baer argued that "disability is not being addressed as a minority [issue] by the European Commission", adding that the Commission shall seek to facilitate the mainstreaming of disability research in other areas of the FP7, e.g. to hold meetings between the EuRADE Coordination Team and Directorates of relevance to the research topics identified through the consultation survey. In response to concerns raised about the lack of knowledge, human and financial resources of disabled people's organisations to be able to effectively participate in research, Ms Viviane Willis-Mazzichi (Policy Officer & EuRADE Project Officer, Directorate-General for Research, European Commission) advised that the new funding scheme would also provide support for research training/studies.

Disability research in support of the United Nations Convention on the Rights of Persons with Disabilities (CRPD)

Gyorgy Konczei, Professor of Disability Studies at the Eotvos Lorand University & Member of the Committee on the Rights of Persons with Disabilities for the UN Convention on the Rights of Persons with Disabilities – Hungary

With the Committee on the Rights of Persons with Disabilities now established, Professor Gyorgy Konczei considered how emancipatory research could support the Committee. First calling for the disability movement and disabled people to pursue the fight for their

rights, Professor Konczei highlighted the importance of the perspective of disabled people in challenging, introducing, shaping, and implementing policies. Recognising the importance of research to support the effective monitoring by the Committee of the implementation of the Convention, Professor Konczei also encouraged disabled people's organisations to collaborate with academics in order to produce high-level research results. He also stressed the importance of the full and equal accessibility of disabled people to research results, suggesting that this could be achieved by developing an online research knowledge resource centre intended which would take into account the needs of persons with different impairments. A similar website could be developed to support their participation in decision-making processes. As regards research needs, Professor Konczei asserted that the Committee would benefit from research into some of the topics emerging from the EuRADE consultation survey, notably in the areas of litigation and independent living. Professor Konczei also suggested that evidence-based research is undertaken on the exclusion of persons living with intellectual and psychosocial disabilities in relation to the current political system, as well as research into self-advocacy empowerment.

Conclusion

Disability equality research is in the general interest of all

The briefing seminar was characterised by an open, frank and transparent dialogue between all parties concerned, reflecting the growing interest in research into disability equality and non-discrimination both at the national and European level. This view is reinforced by the closing comments made by Ms Catherine Trautmann MEP who, acknowledging and supporting the concerns raised by representatives of disabled people's organisations in attendance, stated: "We will all become disabled in time, either due to an accident, or disease, or ageing [...]. Disability equality research should therefore take into account 100% of the population and be treated as a first priority in the general interest of all."



Annex I - List of Participants

Title	Last Name	First Name	Organisation	E-mail	Country
Ms	Bourgon	Roselyne	Mental Health Europe	Roselyne.bourgon@mhe-sme.org	Belgium
Ms	Brünger	Karin	European Dislexia Association	ka.battip@web.de	Germany
Mr	Campbell	Bill	Inclusion Scotland	bill@inclusionscotland.org	United Kingdom
Mr	Cattani	Rodolfo	European Blind Union	inter@uiciechi.it	Italy
Ms	Chupina	Karina	International Federation of Hard of Hearing Young People	karina.chupina@gmail.com	Germany
Ms	Dekkers	Jantien	Maastricht University	Jantien.Dekkers@ASSISTENTFDR.unimaas.nl	The Netherlands
Dr	Duindam	Simon	Personal Assistant to Prof Waddington	lisa.waddington@facburfdr.unimaas.nl	The Netherlands
Mr	Griffo	Giampiero	Italian Disability Forum	giampeer@tin.it	Italy

European Disability Forum – Forum européen des personnes handicapées
rue du Commerce 39-41 — B-1000 Brussels
T : +32 (0)2 282 46 00 - F : +32 (0)2 282 46 09 - W : www.edf-feph.org
Contact : Sandra Tavares Moreira - sandra.tavares-moreira@edf-feph.org



Mr	Huntjens	Sebastiaan	Maastricht University	Sebastiaan.Huntjens@BU.unimaas.nl	The Netherlands
Ms	Jolly	Debbie	European Network on Independent Living (ENIL)	Debbie.jolly@enil.eu	United Kingdom
Ms	Kett	Maria	Leonard Cheshire Disability and Inclusive Development Centre, University College London	m.kett@ucl.ac.uk	United Kingdom
Ms	Kiiski	Pia	Finnish Disability Forum	piakiiski@hotmail.com	Finland
Ms	Lavikainen	Anniina	Finnish Federation of Hard of Hearing	anniina.lavikainen@kuulonhuoltoliitto.fi	Finland
Ms	Lidon-Heras	Leonor	Fundosa Grupo (Fundacion ONCE)	llidon.fundosa@fundaciononce.es	Spain
Mr	Logaras	Dimitrios	National Confederation of Disabled People	communication@esaea.gr	Greece
Ms	Mahlamäki	Pirkko	Finnish Disability Forum	pirkko.mahlamaki@nkl.fi	Finland
Ms	Marshall	Angela	Inclusion Scotland	angelam@inclusionScotland.org	United Kingdom
Mr	Miet	Philippe	Conseil Français des Personnes Handicapées pour les Questions Européennes	Philippe.miet@apf.asso.fr	France
Mr	Olsen	Erik	European Network of (ex-)Users and	fap@kontor.dk	Denmark



			Survivors of Psychiatry		
Ms	Pinto	Anna-Lucia	Agenzia per la Promozione della Ricerca Europea	a-sia@libero.it	Belgium
Ms	Prete	Federica	Agenzia per la Promozione della Ricerca Europea	prete@apre.it	Italy
Mr	Rasmussen	Tonni	University College Lillebælt	tonni.rasmussen@ucl.dk	Denmark
Mr	Simon	Jean-Luc	Disabled Peoples' International	chairperson@dpi-europe.org	France
Ms	Sjöberg	Anne	The Swedish Disability Federation	anne.sjoberg@hso.se	Sweden
Ms	Skestere	Inga	The Latvian Umbrella Body for Disability Organisations SUSTENTO	Inga.skestere@sustento.lv	Latvia
Mr	Soteres	Xiouros	Cyprus Confederation of Organisations of the Disabled	smxiouros@cytanet.com.cy	Cyprus
Ms	Stewardson	Gail	European Guide Dog Federation / The Guide Dogs for the Blind Association	gail.stewardson@guidedogs.org.uk	United Kingdom
Ms	Tavares Moreira	Sandra	European Disability Forum	sandra.tavares-moreira@edf-feph.org	France



Ms	Tinyakova	Yulia	University College Lillebælt	letv@ucl.dk	Denmark
Mr	Tvilum	Leif	University College Lillebælt	letv@ucl.dk	Denmark
Ms	Van Haute	Eleonore	Mental Health Europe	eleonorevanhaute@gmail.com	Belgium
Mr	von Diest	Christoph	European Affairs Consulting Group	Christoph.vondiest@eacongroup.com	Germany
Ms	Vrana	Marilena	European Foundation Centre	MVrana@efc.be	Belgium
Ms	Walsh	Caroline-Ann	AMCAI/University of Kent	C.A.Walsh@btinternet.com	United Kingdom
Mr	Wheatley	Mark	European Union of the Deaf	mark.wheatley@eud.eu	Belgium
Mr	Wiederholt	Mogens	Disabled Peoples Organisations Denmark	dh@handicap.dk	Denmark

European Parliament

Title	Last Name	First Name	Organisation	E-mail	Country
Ms	Thomsen	Britta	European Parliament (Panelist)	britta.thomsen@europarl.europa.eu	Denmark
Ms	Trautmann	Catherine	European Parliament (Host)	catherine.trautmann@europarl.europa.eu	France



European Commission

Title	Last Name	First Name	Organisation	E-mail	Country
Mr	Baer	Jean-Michel	Directorate of Science, Economy and Society, Directorate-General for Research (Panelist)	Jean-Michel.BAER@ec.europa.eu	Belgium
Mr	Batey	Nick	Directorate-General Information Society and Media, H3 ICT for Inclusion	Nick.BATEY@ec.europa.eu	Belgium
Mr	Gonzalez Sancho-Bodero	Miguel	Directorate-General Information Society and Media, D5 Communication and Information Management	Miguel.Gonzalez-Sancho-Bodero@ec.europa.eu	Belgium
Ms	Placencia Porrero	Inmaculada	Directorate-General for Employment, Social Affairs and Equal Opportunities, G3 - Integration of People with Disabilities	Inmaculada.Placencia-Porrero@ec.europa.eu	Belgium



Ms	Willis-Mazzichi	Viviane	Directorate-General for Research and Technological Development, L3 - Governance and Ethics	Viviane.Willis-Mazzichi@ec.europa.eu	Belgium
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Panelists from the Disability and Academic Community

Title	Last Name	First Name	Organisation	E-mail	Country
Prof	Konczei	Gyorgy	Eotvos Lorand University	konczei@disabilityknowledge.org	Hungary
Ms	Szollosi	Erzsebet	Hungarian National Council/European Disability Forum	szollosi_foldesi@yahoo.com	Hungary
Mr	Vardakastanis	Ioannis	European Disability Forum	esaea@otenet.gr	Greece

EuRADE Project Coordination Team

Title	Last Name	First Name	Organisation	E-mail	Country
Ms	Besozzi	Carlotta	European Disability Forum	carlotta.besozzi@edf-feph.org	Belgium



Prof	Priestley	Mark	University of Leeds	M.A.Priestley@leeds.ac.uk	United Kingdom
Ms	Tavares Moreira	Sandra	European Disability Forum	sandra.tavares-moreira@edf-feph.org	Belgium
Prof	Waddington	Lisa	Maastricht University	lisa.waddington@facburfdr.unimaas.nl	The Netherlands

Interpreters

Title	Last Name	First Name	Organisation	E-mail	Country
Ms	De Wit	Maya	Interpreter, International Sign Language	president@efsli.org	The Netherlands
Ms	Dormant	Yannick	Interpreter	-	Belgium
Ms	Paridaens	Isabelle	Interpreter	-	Belgium
Mr	Tuijnman	Daniel	Palantypist	daniel@velotype.nl tuijnmd2@xs4all.nl	The Netherlands