



New Priorities for Disability Research in Europe

Report of the European Disability Forum
Consultation Survey 'European Research Agendas
for Disability Equality'

Executive Summary & Recommendations

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About this report

This report is intended to inform European researchers, research policy makers and research funders about the perspectives of disabled people's organisations and their priorities and needs for research on disability equality and non-discrimination. It should not be construed as a comprehensive or definitive list of research themes but provides a basis for mainstreaming disability in the research funding agenda and proposals for relevant areas of project development.

The views expressed in this report are those of respondents to the consultation and do not necessarily represent those of the wider community of disabled people's organisations, or of the European Disability Forum.

The consultation was co-ordinated by the European Disability Forum, in collaboration with the University of Leeds and Maastricht University.

Acknowledgements

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Acronyms

DPOs – Disabled People's Organisations

EDF – European Disability Forum

EU – European Union

FP7 - Seventh Framework Programme for Research and Technological Development

UNCRPD - United Nations Convention on the Rights of People with Disabilities



Executive summary

In Europe, substantial research investment has been made in the field of 'disability', including through European research funding programmes. While still predominantly medical, therapeutic and rehabilitation-oriented, there has been a growth in research that focuses on disability equality, non-discrimination and accessibility. Yet, for the most part, disabled people and their organisations have not been involved in research as active participants or researchers, nor have their perspectives, priorities and needs been considered and incorporated in research agendas. Two reasons for this are that most disabled people and disabled people's organisations have at their disposal but a fraction of the resources available to universities and that they may lack the knowledge capacity to engage in research as full and equal partners.

In light of these concerns, the project European Research Agendas for Disability Equality (EuRADE) aims to identify and increase awareness among academic researchers and funders about the research priorities of European disabled people's organisations; to enable disabled people's organisations to gain knowledge and skills about existing research methods and approaches to investigating disability issues; and to identify funding and collaboration opportunities for future research projects of benefit to disabled people.

The consultation presented here formed part of this larger project and was designed to address two complementary objectives, to:

- Determine the research priorities of disabled people's organisations and establish the basis for a new European research agenda defined by civil society; and
- Identify the existing research capacity and experience of disabled people's organisations in different European countries, and target capacity building support for the future research participation of those organisations.

This report summarises the methods, key findings and recommendations emerging from the consultation. The responses indicate that disabled people's organisations (DPOs) are not well resourced to conduct their own research but that they see positive value in collaborating with Universities. However, there is equally strong concern that academic researchers do not always



understand the research priorities and needs of disabled people in civil society, and that more could be done to mainstream disability equality in research projects and programmes.

Principal findings: research priority areas

Disabled People's Organisations (DPOs) rated their priorities for research that is needed in the next five years, and provided more than one hundred ideas for potential research themes. These are described in more detail in the various sections of the report. The summary sections below highlight the potential for diverse lines of research.

Mainstreaming disability in policies

- Evidence-based research on the practical impact of existing mainstream social policies and the relative effectiveness of disability-specific policies versus mainstream policies.
- Research to understand, evaluate and improve the involvement of disabled people's organisations in policy making processes.
- Evidence-based research on the practical impact of existing mainstream social policies and the relative effectiveness of disability-specific policies versus mainstream policies.
- Analysis of the appropriateness and adequacy of different disability mainstreaming approaches, including sector specific research.

Education

- Research based on best practices, both in policies and practice at the international level, on how to best integrate or improve integration of disabled people into the mainstream educational system without creating social and attitudinal barriers.
- Research on the type of support that would be needed, including adequate teaching and learning processes/methods or information technologies adapted to different specific impairments, to ensure an inclusive education system at all levels.



- Research on the levels of educational attainment of the disabled population.
- Country-specific data about disabled children in schools, e.g. representativeness with respect to type of disability, sex and age.
- Research on the levels of education accessible to disabled people and how this impacts on their participation in the labour market.
- Analysis of the implications of citizenship education in schools, e.g. teaching disability awareness.
- Research on adult lifelong learning opportunities for people with disabilities in accordance with their interests and needs, and the demands of the labour market.
- Research on the resources, processes and tools needed to provide lifelong learning opportunities for the adult disabled population.

Non-discrimination and human rights

- Evidence-based research (e.g. statistical data) on all types of discriminatory behaviour - direct, indirect, multiple discrimination, among others - in all areas of life, in particular but not limited to the most vulnerable groups of disabled people such as women, immigrants, among others.
- Research on how discrimination and inequality manifest themselves based on the type of impairment.
- Analysis of the different forms of discrimination in the disability context, including institutional discrimination, and how these can be recognised.
- Research on how to empower disabled people to exercise fully and effectively the rather abstract principles of non-discrimination and human rights.
- Examine how disability non-discrimination law works in practice, including identifying the main barriers to the effective enforcement of each of its provisions (e.g. reasonable accommodation).
- Investigation to find the determinants and impediments to successful litigation.
- Research in support of the formulation of a new legislative framework to promote the principle of equality.



- Comparative research on the existing national legislation and policies, their level of enforcement and the extent to which they may or may not integrate a human rights approach across different European countries.

Employment

- Research on accessibility barriers to and solutions for labour market participation that encompasses all forms of visible and invisible disabilities.
- Comparative research on the employment status and conditions of disabled people to redress deficiencies in existing datasets, including statistical data on the employment situation of people with different types of impairment.
- Analysis of the impact of existing employment legislation on disabled workers' rights and their maintenance in employment.
- Research on the impact of unemployment on disabled people.
- Research on disabled people as employers (of personal assistants).

Support for independent living

- Research on community-based living environments and how they can be organised to ensure the highest degree of choice and control in the lives of disabled people.
- Research on the delivery of community-based services that can inform policy development and be accessible to service providers and disabled people's organisations. Such research should include the development of quality criteria to ensure that services effectively support inclusion in society.
- Comparative research, based on the identification of best practises, on the different models of support in different countries and on how these actually work for disabled people (in terms of quality of life and personal achievements).
- Research on the transferability and mobility of support systems for independent living between EU Member States.
- Analysis of the costs and benefits, for the wider society, of support systems for independent living.
- Research on the composition and living circumstances of severely disabled people to define the necessary conditions and equipment for them to be able to live an independent life.



- Research to develop policies and practices of de-institutionalisation, taking into account the diverse needs of different groups of disabled people.
- Research on the combined social challenges of ageing and disability.

Information, Communication and Media

- Research to promote the development of information and communication systems, resources and products inclusive and accessible to disabled people.
- Data about disabled people's use of ICT and new media technologies.
- Research on the costs associated with accessibility within the mass media.
- Research on the effectiveness of awareness raising about disability and the communication of claims made by disabled people's organizations to policy makers and the general public.
- Research on how disability is portrayed in the mass media and on the perceptions of public audiences on how disabled people are portrayed.

Social exclusion and poverty

- Comparative studies of disabled people's living conditions, focusing on income, employment, quality of life, obstacles, social life, education, training and life long learning, etc.
- Studies on European welfare systems and their effectiveness in satisfying the diverse needs of disabled people.
- Analysis of the specifics of poverty and social exclusion for people with disabilities and identification of measures to help to decrease their level of poverty, including data on the personal and household financial costs of living with impairment and disability.
- Research on the relationship between educational exclusion, qualification, employment and poverty with regard to disabled people.
- Research to assist in formulating effective welfare benefits systems tailored to individual needs.
- Research to support the development and implementation of social and economic reintegration programmes and policies.

Accessibility in built environments and transport



- Reviews of existing legislation and technical standards promoting accessibility and evaluation of the extent to which they are put into practice, including identification of areas not covered by national, European or international legislation
- Multi-disciplinary research involving fields such as architecture, design, medicine, and ergonomics with a view to achieving the incorporation of a disability perspective (both medical and social) into technical and industrial education.
- Research on the accessibility to disabled people of existing and future transport systems.
- Research to promote accessibility and universal design in diverse product and system areas.

Organisations of disabled people

- Research on the organisational structures, roles, capacities, funding sources and sustainability of disabled people's organisations in different countries.
- Research on the relationship and communication between service providers and disabled people and their organisations, and its impact on planning and the social inclusion of disabled people.
- Research on the extent to which disabled people's organisations influence policy, and evaluation of effective advocacy strategies for disabled people's rights.

Bioethics and rights to life

- Research that incorporates a disability and human rights perspective on bioethical technologies and debates, including the involvement of disabled people's organisations.
- Analysis of the ways in which public and biomedical perceptions of impairment and disability affect parents or prospective parents of disabled children.
- Analysis of life-or-death decisions concerning disabled people and their impacts on professional and public perceptions.
- Research on the information tools used by doctors to inform and counsel prospective parents about disability.



- Research on the representation of impairment and disability in medical literature intended for gynaecologists and other relevant practitioners.

Health care

- Research on inequalities in the type, appropriateness and quality of health care and treatment available to disabled people, including the consequences for disabled people (e.g. loss of independence).
- Research on policies and practices for user involvement in health care provision.
- Analysis of holistic approaches to health care and rehabilitation.
- Analysis of rapid change in medical technologies and their potential outcomes for disabled people.

Housing

- Improved statistical data on the housing situation of disabled people living in private households and residential institutions, including physical, geographic and tenure characteristics.
- Research on the housing and community support needs disabled people have in rural and urban environments.
- Comparative research on the different housing design and accessibility options, and methods of financing, available to disabled people in different European countries.

Sexuality, parenting and family life

- Analysis of the barriers to parenthood for disabled women and men.
- Research into the reasons for disabled people's longer-term dependency on their parents, and the support required to help them become more independent in an earlier phase of life.
- Research on disabled people's barriers to and experiences of living in close personal relationships.



- Research into the barriers or the types of support and assistance to disabled people's full enjoyment of their rights to an emotional and sexual life on equal basis with others

Disabled children and youth

- Statistical data on the number and characteristics of young disabled persons.
- Analysis of the barriers experienced by disabled children and young people in everyday life.
- Research to facilitate early identification and support for the social inclusion of disabled children.

Disabled women and gender equality

- Research on the gendered dynamics and outcomes of disability discrimination.
- Research on employment and equal pay for disabled women.
- Research on the issue of mothering and family responsibilities.



Conclusions

The findings from the consultation show that civil society organisations, and particularly disabled people's organisations, have a high level of motivation and readiness to participate in research that will have a positive effect on disabled people's lives in European countries.

Such organisations, controlled by disabled people, are often lacking in funding and capacity to conduct their own large scale research projects according to their needs (when compared with more well-resourced voluntary organisations and professional associations). However, many disabled people's organisations have experience of being involved in University research projects and perceive a potential for great value in this kind of collaboration.

The main barriers to effective collaboration with academics, as perceived by disabled people's organisations, are (a) a lack of understanding in Universities about the research needs and priorities of civil society; and, (b) a history of unequal power relationships in which disabled people have been engaged primarily as 'subjects' or 'objects' of research rather than as equal partners. In order to develop effective research partnerships it is therefore important to build capacity for change.

First, it is important to communicate the real research priorities of disabled people's organisations so that they can shape the research agenda of academics and, importantly, research funding bodies (including the EU Seventh Framework Programme, the European Research Council and national funding councils).

Second, it is important to build new research collaborations between Universities and disabled people's organisations founded in equal partnership to design, implement and disseminate research within this user-led agenda. To do this it will also be necessary to build the research knowledge and capacity of disabled people's organisations, and to facilitate the full participation of disabled people in research processes.

This results reported here provide sufficient evidence and detailed examples, from a wide range of different organisations and countries, to facilitate further analysis and dissemination. They also provide evidence of sufficient commitment and engagement from disabled people's organisations to justify capacity and partnership building for future research projects of benefit to disabled people in Europe. The evidence from widespread consultation offer



concrete evidence and real world examples that provide the basis for a new user-led research agenda in Europe.

A detailed summary of results and qualitative responses can be viewed online using the following web link:

http://www.surveymonkey.com/sr.aspx?sm=ojSNX3n0zzqcrVaWWgIHXR3bDval6cNhTij54J7Bl_3d

Recommendations

Provide support for active participation of disabled people and disabled people's organisations in research as full and equal partners: as highlighted above, capacity building and equal access to funding are essential if disabled people's organisations are to be able to actively, qualitatively and effectively engage in research. Only with this goal being achieved will research effectively contribute to the elimination of all the barriers preventing the full social inclusion of disabled people.

Develop a user-led research agenda to promote disability equality in all areas and at all levels of society: to achieve this it is important that the research priorities and needs of disabled people's organisations are widely communicated and fully incorporated in the research agenda of academics and research funding bodies (including the EU Seventh Framework Programme, the European Research Council and national funding councils).

Create opportunities and build new research collaborations between universities, policy-makers and disabled people's organisations: collaborations must be founded in equal partnership and dialogue to design, implement, disseminate and evaluate research. The objective is to promote mutually-beneficial cooperation based on research priorities identified by disabled people's organisations.

Ensure disability equality is addressed in all areas of research undertaken at the European level: with the exception of medical research and research in the area of information and communication technologies and new technologies, the EU calls for research projects rarely mention disability or research relevant to people with disabilities. It is therefore critical that disability is addressed in all sectoral and thematic research programmes of the EU.