



New Priorities for Disability Research in Europe

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

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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.

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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.



Background

A great deal of academic research is carried out in the field of 'disability', and substantial research investment has been targeted in this area through European funding programmes. However, this investment has been dominated by investments in medical and rehabilitation research (e.g. towards developments in treatment and physical care, framed by the priorities of professionals in those disciplines). More recently, there has been a substantial growth in social science research, from a variety of disciplines, concerning the social, legal, economic and political aspects of disability and the lives of disabled people (although very little of this work has yet been funded by European Framework programmes). Here too, there are concerns that research has not always involved disabled people and their civil society organisations in a meaningful way, more often reflecting the priorities of academic researchers and the bodies that fund them. In light of these concerns, the overall goal of the European Research Agendas for Disability Equality (EuRADE) project is to increase the participation of European disabled people's organisations in future research.

The EuRADE project is based on a partnership between the European Disability Forum (EDF), the University of Leeds, and Maastricht University, funded by the Science in Society initiative of the Seventh Research Framework Programme of the European Community (FP7). The project aims to:

- map the research priorities of disabled people's organisations' in Europe;
- enable disabled people's organisations in Europe to gain knowledge and skills about the existing research methods and approaches so they may elaborate their own research proposals and engage in research as equal partners;
- increase awareness among academic researchers and funders of the research priorities of disabled people's organisations in Europe, and identify funding and collaborative opportunities for future research.

The project is focused on the development of capacity and the identification of research priorities in the broadly defined area of disability equality (embracing research carried out in all related disciplines).

The first phase of the project sought to map the research priorities of disabled people's organisations in Europe and involved review and consultation



activities¹, including a survey questionnaire for civil society organisations about their experiences and priorities for future European disability research. This report summarises the findings of that work. The primary objective of the survey was to identify the research priorities of disabled people's organisations, and to establish the basis for a new European research agenda defined by civil society. A secondary objective was to identify the existing research capacity and experience of disabled people's organisations in different European countries, and to target capacity building support for the future research participation of those organisations.

This paper provides an overview and an analysis of the responses received, and provides an important tool in communicating to academic researchers and funders the research priorities of European disabled people's organisations.

Methodology

The consultation was undertaken through a questionnaire which was made available (in English and French)² for online completion in a web-based format or for completion in print by downloading a PDF document. A text-only version was also produced on request. A presentation was made to delegates at the European Disability Forum Annual General Assembly (Slovenia, May 2008) and a printed copy of the questionnaire was distributed, for publicity purposes. In June 2008 details of the survey with access instructions were also distributed in a periodic mailing from EDF to all of its member organisations. The questions and prompts in the survey sought information about each organisation, its past experiences of research, its priorities for future research, and its interest in research participation. The survey included both closed and open questions (a copy is available on the project website³). Responses from 68 organisations in 25 countries were received. Of these, the majority were national or European level organisations controlled by disabled people.

¹ The partners reviewed recent key policy documents of the European Disability Forum to identify the policy priorities of this organisation. In addition, documents issued by Disabled People International, as well as the European Community Disability Action Plan, the Council of Europe Disability Action Plan, and the United Nations Convention on the Rights of Persons with Disabilities were reviewed with a view to identifying possible related research priorities.

² In addition to English and French, respondents could complete the questionnaire in German, Spanish, Italian, Dutch and Portuguese.

³ www.eurade.eu

Response to the survey

Overall, responses from 70 organisations were received. After consolidating duplicate entries and removing two ineligible responses (one from outside Europe and one from a University research centre) valid responses were recorded from 68 civil society organisations in 25 countries.

The majority of respondents represented national level organisations. In addition, two organisations that did not identify themselves as national organisations could be regarded as such (bringing the total to 44 out of 68).

Type of organisation		
Answer Options	Response Percent	Response Count
Local organisation	20.6%	14
National organisation	61.8%	42
European organisation	17.6%	12
<i>answered question</i>		68
<i>skipped question</i>		0

Organisational control

For the purposes of the project it was important to differentiate disabled people's organisations from other types of organisations. For this reason, the questionnaire asked about the structure of control within each organisation.

Who controls your organisation? (actual response)		
Answer Options	Response Percent	Response Count
Disabled people	75.0%	42
Parents and families	12.5%	7
Service providers	12.5%	7
Other (please specify)		21
<i>answered question</i>		56
<i>skipped question</i>		12

Three quarters of those who answered this question identified themselves as organisations controlled by disabled people. Some respondents provided a structured response with additional explanation. Twelve organisations (17.6%) did not answer the question directly but provided an alternative explanation. The following list illustrates the kind of responses they provided.



Examples of alternative responses: Who controls your organisation?

- *Public enterprise, regional office of the International organization, led by specialists.*
- *The Board of Management have service user and staff representation*
- *People with aphasia helped by professionals*
- *Board of Trustees and paid officers, some of whom are blind or partially sighted*
- *Parents and families. Disabled people part of board*
- *Both disabled and non-disabled people*
- *Both disabled people and parents and families (e.g. for categories of disabled people that cannot represent themselves)*
- *80% Persons with Disability & Parents / 20% Service Providers*
- *Organisation advocating for and promoting disabled people working with disabled people*
- *Service providers. Participation of disabled users*
- *Regional Government*
- *Employees and volunteers on the management board*

Allowing for some interpretation of this diversity, it was clear that most of the responses came from organisations that were either controlled by disabled people or in which disabled people were influential at a high level. On the basis of the information provided, around two thirds had a significant level of control, with a number of others demonstrating shared control between disabled people and other groups. In 8 or 9 cases the responses suggested organisations in which disabled people or their close advocates did not exercise significant control. This interpreted result is shown below.

Who controls your organisation? (interpreted results)		
Answer Options	Interpreted Response	Response Count
Disabled people	64.7%	44
Shared control	13.2%	9
Parents and families	10.3%	7
No evidence of control	11.8%	8
Total	100.0%	68

Using this interpretation of the data, and cross-tabulating with the type of organisation, the data suggests that most of the respondents represented national or European level organisations controlled by disabled people. More than half of the 'local' organisations were also controlled by disabled people.

Organisational type and control (interpreted results)						
Control		Disabled people	Shared control	Service providers	Parents and families	Total
Type	European organisation	7	1	2	2	12
	Local organisation	7	2	4	0	13
	National organisation	30	6	2	5	43
Total		44	9	8	7	68

Later in this report, the data is divided into responses for all organisations (68) and for a sub-set of representative national or European level organisations controlled by disabled people (34). It was these organisations in particular that were the target population of the consultation exercise.

Geographical response

Each respondent was asked to identify the location of their organisational head office. Responses were received from organisations based in 25 different European countries, including 21 EU member states, one candidate state (Croatia), two of the EFTA states (Iceland and Norway), plus Serbia. The largest numbers of respondents were based in Belgium (11),⁴ followed by Denmark (6), Finland (5), the United Kingdom (5) and Germany (4). Amongst the remaining 21 countries there were six with a single response. There was no response from six of the EU member states (Austria, Cyprus, Estonia, Poland, Slovenia and Sweden) or from Turkey. Disabled people's organisations from 23 countries were represented.

Country (where main office is located)	Response Count
Belgium	11
Bulgaria	2
Croatia	2
Czech Republic	2
Denmark	6
Finland	5
France	2
Germany	4
Greece	1
Hungary	3

⁴ This reflects the fact that many European level organisations are based in Brussels.

Iceland	1
Ireland	2
Italy	3
Latvia	1
Lithuania	1
Luxembourg	1
Malta	3
Netherlands	3
Norway	1
Portugal	2
Romania	3
Serbia	1
Slovakia	1
Spain	2
United Kingdom	5
answered question	68

Text responses to the open-ended questions were received in English, French, German, Spanish, Italian, Dutch and Portuguese. Where necessary, all responses were translated into English for the purposes of this analysis.

In the remainder of this report, identifying details have been removed from examples of individual responses in order to maintain the anonymity and confidentiality of the respondents (e.g. organisational, personal or country names etc.). Substitutions are indicated in the text using square brackets.

Research capacity for collaboration

Approximately one third (22) of respondents said that their organisation employed staff with responsibility for research activity, although a clear majority did not.

Do you employ research staff in your organisation?		
Answer Options	Response Percent	Response Count
Yes	36.1%	22
No	63.9%	39
answered question		61
skipped question		7

A quarter of the organisations in which disabled people had significant control employed their own research staff (11 out of 44). Those organisations not under the control of disabled people were more likely to employ research staff,

although the numbers were too small to generalise. In general terms, disabled people's organisations appeared less well resourced than other organisations to carry out their own research. However, the large majority of them (at least 30 out of 44) had been involved in some kind of recent research activity. Across all types of organisation, three quarters of those who answered the question said that their organisation had been involved in a recent research project. Almost all of the organisations controlled by service providers, in whole or part, had some recent research experience (15 out of 17) but only 2 out of 7 parent and family controlled organisations.

Has your organisation been actively involved in carrying out any research projects during the past five years?		
Answer Options	Response Percent	Response Count
Yes	74.6%	47
No	25.4%	16
Additional details of research topic or website provided		48
<i>answered question</i>		63
<i>skipped question</i>		5

Most of the respondents (48) were able to provide some additional information about the kinds of research they had previously been involved in.

There was also strong evidence of research collaborations with Universities or Institutes, with the majority of respondents identifying at least one such collaboration. Amongst disabled people's organisations at least half identified some experience of academic research collaboration and 34 provided examples.

Has any of this research been conducted in collaboration between a disabled people's organisation and a university or research institute?		
Answer Options	Response Percent	Response Count
Yes	64.9%	37
No	35.1%	20
Which one(s)? (optional comment)		34
<i>answered question</i>		57
<i>skipped question</i>		11

As noted earlier, we were particularly interested in national and European level organisations controlled by disabled people, and 34 organisations identified themselves in this way. Looking at this sub-group of organisations,



only one third employed their own research staff but four out of five had been involved in recent research projects. Around three quarters had some experience of collaboration with Universities or research institutes (18 examples were provided in more detail). So, although disabled people's organisations did not have extensive research resources of their own, even at the national level, they did have experience of research and of collaboration with academic institutions.

Views on academic collaboration

We asked all the respondents to rate the importance for disabled people's organisations of collaborating with academic researchers, using a four-point scale (from essential to undesirable). The responses were overwhelmingly positive and only 1 organisation out of 68 rated academic collaboration as 'not very useful'. None replied that it was 'undesirable' (or 'don't know'). Looking only at the national and European organisations controlled by disabled people, the response was equally positive (with 70% of those who replied rating academic collaboration as 'very useful' and 30% as 'essential'). It is clear that representatives of civil society organisations, including disabled people's organisations, believe that there is positive potential in academic research collaboration.

However, the responses also revealed more negative aspects. We asked the same organisations if they thought that Universities understood the research needs of disabled people's organisations. Overall, 62 organisations expressed a view and, of these, two thirds felt their needs were 'not very well' understood'. Looking at the 29 national and European disabled people's organisations who expressed a view on this question, only 8 thought that Universities 'mostly' understood their research needs while 21 (70%) thought that their needs were 'not very well' understood. These findings raise concerns. Civil society organisations perceive value in academic collaborations, and many of them have experience of doing this, but academics are still seen as lacking a real understanding of civil society's research needs.

We also asked for qualitative responses about the advantages or disadvantages of working with academic researchers, and for their suggestions about how academics in Universities could make their research more relevant to disabled people. We received 55 responses to this question; including 29 from national or European level organisations controlled by disabled people.



The positive values attached to academic collaboration highlighted the benefits of high quality research, methodological expertise and the credibility of research findings. The negative comments suggested that research agendas need to be more responsive to real needs, that researchers need greater knowledge about disability equality, and that disabled people wish to be engaged as equal partners (rather than the 'subjects' of research). The main qualitative arguments presented by disabled people's organisations can be summarised as follows.

- In many European countries there is a lack of academic research on disability equality, and traditional or medical model views of disability are held by academics and influence research agendas. Closer partnerships with disabled people's organisations could increase the knowledge and commitment of academic researchers to social and human rights models of disability.
- Mutual collaboration is useful for disabled people, but this involvement should be between equal partners. Disabled people and their civil society organisations must be involved from the beginning of the research process, particularly in shaping the research agenda and identifying research needs in the real world. This would also increase the social relevance of academic research.
- The high quality and credibility of disability research is important, and academic institutions can assist in achieving this through the provision of research skills, facilities and resources. Disabled people's organisations can also contribute to the quality of research data by facilitating access to disabled people's practical knowledge.
- Academic institutions have significant expertise and resources for generating research grants. Through effective collaboration these resources could be directed towards the funding of projects defined by civil society.
- The academic research process can be slow. Projects may take a long time to get started and to complete. Ongoing collaboration with disabled people's organisations can help Universities to be more responsive.
- Academic researchers may have narrow specialist interests but real world problems often require a wider range of academic disciplines. Collaboration with civil society organisations may help academics to develop interdisciplinary collaborations.
- Academic research projects often fail to disseminate their results and findings effectively. Partnership with disabled people's organisations



provides opportunities for advocacy to transfer research findings into policy and practice. Civil society partners can also help to translate academic research findings in more accessible ways.

- Disabled people are under-represented in Universities and there is a need to increase their participation as students, researchers and teachers. Disabled people's organisations can contribute to both research and teaching in Universities.

Research priorities

Given the apparent lack of understanding about disabled people's research needs, it was particularly important to identify the priorities of civil society organisations for future disability research. The survey included a grid of 21 themes (derived from our reviews of EDF and DPI policy documents during the first phase of the project) plus two free choice areas. Respondents were invited to choose up to five themes and to rank their importance as research topics for the coming five years.

The following table shows the choices made by the total number of respondents (61 out of 68 respondents answered this question). This shows that the most selected topic overall was 'education', with 36 votes, although only 8 first priority votes. The next most popular themes were 'Mainstreaming disability in policies' and 'Non-discrimination and human rights' (each with 32 votes) followed by 'employment', 'social exclusion and poverty' and 'support for independent living' (with 26-24 votes each). In terms of '1st priority' choices, 'Non-discrimination and human rights' achieved almost twice as many votes as education, followed by health care.

13. What are the most important topics for European disability research in the next five years? (all responses)						
	1st	2nd	3rd	4th	5th	Total
Education	8	7	6	9	6	36
Non-discrimination and human rights	15	8	4	1	4	32
Mainstreaming disability in policies	3	9	9	8	3	32
Employment	1	1	7	11	6	26
Social exclusion and poverty	1	7	4	4	9	25
Support for independent living	5	3	8	7	1	24
Information and communication	4	2	4	2	3	15
Health care	6	3	4	1	0	14
Transport, mobility or tourism	0	4	2	1	7	14
Organisations of disabled people	1	0	1	2	8	12
Bioethics and rights to life	5	1	0	2	1	9
Disabled children and youth	3	2	1	1	1	8
Housing	0	2	2	1	3	8
Parenting and family life	1	3	1	2	0	7



Urban and built environments	1	1	2	2	1	7
Residential institutions	2	2	0	2	0	6
Other [specify in Section 2b]	2	2	0	2	0	6
International development	1	0	1	0	3	5
Other [specify in Section 2b]	0	0	1	1	2	4
Disabled women and gender equality	1	2	0	0	0	3
Media, art and culture	0	2	1	0	0	3
Sexuality and reproductive rights	0	0	1	1	0	2
	answered question					61
	skipped question					7

A slightly different pattern is revealed by applying a weighted score to the rankings (i.e. giving a score of 5 to 1st choice; 4 to a 2nd choice; 3 to a 3rd choice; 2 to a 4th choice; and 1 for a 5th choice). This is shown in the table below. Overall, this list probably provides a more accurate interpretation of the results, when all types of organisation are included.

13. What are the most important topics for European disability research in the next five years? (all responses, weighted rankings)		
	Total votes	Weighted score
Non-discrimination and human rights	32	125
Education	36	110
Mainstreaming disability in policies	32	97
Support for independent living	24	76
Social exclusion and poverty	25	62
Employment	26	58
Health care	14	56
Information and communication	15	47
Bioethics and rights to life	9	34
Transport, mobility or tourism	14	31
Disabled children and youth	8	29
Parenting and family life	7	24
Residential institutions	6	22
Other [specified]	6	22
Organisations of disabled people	12	20
Urban and built environments	7	20
Housing	8	19
Disabled women and gender equality	3	13
International development	5	11
Media, art and culture	3	11
Other [specified]	4	7
Sexuality and reproductive rights	2	5

A similar pattern is evident when looking only at the 34 national and European level organisations controlled by disabled people. The topics chosen by national and European level disabled people's organisations as their '1st priority' were as follows:

13. What are the most important topics for European disability research in the next five years? (national and European level DPOs only)		
	1st priority	Total responses
Mainstreaming disability in policies	2	19
Education	3	17
Non-discrimination and human rights	8	15
Employment	0	13
Support for independent living	5	12
Information and communication	3	11
Social exclusion and poverty	0	11
Transport, mobility or tourism	0	10
Organisations of disabled people	1	7
Bioethics and rights to life	3	6
Health care	3	6
Urban and built environments	1	5
Housing	0	5
Disabled children and youth	0	3
Parenting and family life	1	2
Disabled women and gender equality	0	2
International development	0	2
Media, art and culture	0	2
Residential institutions	0	2
Sexuality and reproductive rights	0	1
Other [specify in Section 2b]	0	1
Other [specify in Section 2b]	0	0
	answered question	31
	skipped question	3

Based on total votes, the three most popular choices were 'Mainstreaming disability in policies', 'Education' and 'Non-discrimination and human rights' (the same top three choices indicated in the overall data, although in different order). Five other topics also received 10 or more votes (i.e. votes from a third or more of the respondents). They were Employment; Support for independent living; Information and communication; Social exclusion and poverty; and Transport, mobility or tourism. It is relevant to note that only 10 out of the 21 topic areas received any '1st priority' vote from national or European level disabled people's organisations. This data then provides an initial framework for developing a civil society agenda or priorities for European disability research. These responses were examined in more detail.

Agendas for research

Respondents were invited to describe their priorities for future research in more detail. Taking into account all of the optional responses, the 34 organisations in this sub-set of the data provided a total of 115 priorities or examples of possible future research themes (217 suggestions were received



in the overall dataset from 68 organisations). This qualitative data was not always easy to interpret, revealing some of the obstacles to effective research collaboration between academic institutions and civil society organisations. For example, several organisations were able to strongly identify their policy objectives or advocacy priorities, but did not necessarily express these in terms of ‘research’ projects. Such examples support the need, identified previously, for early stage involvement in academic collaborations to translate real world problems into research questions. However, other respondents were adept at framing such questions and articulated clearly their need for specific kinds of studies or data.

The following sections provide summary analysis and comment on the responses received with regard to the most popular headings and research priorities from national and European level disabled people’s organisations (DPOs).

Mainstreaming disability in policies

Disability is still not systematically and effectively mainstreamed into European, national, regional or local policies. There is a general consensus among disabled people’s organisations that there needs to be effective participation of disabled people and their civil society organisations in all stages and areas of policy making and implementation. Yet there is a lack of knowledge about the methodology and effectiveness of disability mainstreaming.

A variety of research priorities were identified in this area, including the need for evidence to support mainstreaming; ways in which mainstreaming could be more effectively carried out; the impact of mainstream policies; how disabled people’s organisations could participate in policy making and implementation; and how to distinguish between fields which require a disability specific approach, and fields where mainstreaming is appropriate. A number of respondents called for comparative research within the EU.

Many of the respondents referred to the problems policy makers have with mainstreaming disability into general policies, and called for research that would facilitate this. One respondent wrote:

‘The local, national and European policy makers have difficulty to mainstream disability issues in all areas. ... It is necessary to promote research in this area, such as appropriate statistics on discriminatory



conditions, methodologies and services which can promote inclusion in education, employment, sport etc...'

Adopting a similar perspective, a second respondent wrote:

'Disability issues are not taken into account in the design of policies that address the general population. Evidence needed: a) results from the monitoring of the existing social policies, b) data on the percentage of people with disabilities that benefit from public services and goods'.

The same respondent also focused on the attitudes of policy makers, and called for 'research on the perceptions of decision makers and policy officers with regard to people with disabilities and their needs...'

A further prominent theme was the need for research to facilitate the involvement of disabled people's organisations. One respondent called for research that would consider:

'what tools can be developed to qualitatively and effectively improve the participation of disabled people's organisations in the reflection on and implementation of disability policies, whilst another called for research to identify what should be done to ensure partnerships and dialogue between people with disabilities and policy makers?'

A further theme identified was the need for research to distinguish between those fields where mainstreaming was appropriate and beneficial, and those areas where a disability specific approach should be maintained. One respondent called for research to: 'determine the importance given to disability in policies: should it be a specific or horizontal theme, or both?'. Disability specific policies were also the focus of another respondent who called for research to identify 'what kinds of problems the use of specific laws etc. creates in society?' A third respondent identified the need for research to distinguish between different fields or sectors, and felt research should consider if 'there is a best way of dealing with the mainstreaming of disability in different sectors of society? i.e. would it be possible to develop a framework for that process, so that it is not necessary to start from scratch in each sector?'

A number of respondents called for comparative research, to reveal how different countries and regions addressed mainstreaming. One respondent believed: 'understanding and analysing the mechanisms for putting [mainstreaming] into place in some countries of the European Union should help us to be engaged in politics in a more effective way.' Whilst another



called for a 'comparative study on the mainstreaming of disabled people's interests in national, regional and local level'.

The key priorities for research identified by the respondents can be summarized as follows:

- 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
- Analysis of the appropriateness and adequacy of different disability mainstreaming approaches, including sector specific research

Education

Education is a universal right, recognized in the United Nations Convention on the Rights of People with Disabilities (UNCRPD). However, there is still a persistent gap between disabled people and non-disabled people's access to education and lifelong learning. This emerged as a major concern among respondents, particularly due to the profound impact of education on disabled people's full social inclusion and labour market participation. Education, in its broadest context, was also seen as playing a key role in empowering disabled people to, as noted by one of the respondents, 'assert their fundamental rights more effectively'.

The lack of education experienced by disabled people in certain European countries was a matter of concern. In some countries there is also a perceived lack of data about disabled children in schools. Research was seen as means to spread good practice, for example: 'Many Countries have resistance to transforming the educational system in the direction of an inclusive system. Promoting research and spreading best practices can be very useful.'

Education was viewed as an extremely important topic for research because of its profound impact on future social inclusion and labour market participation. Education was seen to improve competence and empower positive roles. As one respondent noted: 'Persons with disabilities who receive a more comprehensive education are able to participate more fully in society and assert their fundamental rights more effectively'. In addition, it was relevant to consider the implications of 'citizenship in school'.

Several respondents made a strong case for new research, for example, arguing that research could identify 'new combinations of effective policies



and examples of international practice' (e.g. in identifying a 'way out from special schools'). Such research could help to identify:

'What works? And what does not? And how are pupils and students included in the mainstream educational system with the needed support without creating social and attitudinal barriers, i.e. how is the development of strong and participating individuals supported while at the same time ensuring that special needs are catered for?'

'What are the obstacles for better education of disabled people? How could they be overcome? What type of support would be needed to provide inclusive education for disabled people?'

There were suggestions for research on specific good practice in learning processes and information technologies to support inclusion of pupils with specific impairments. For example:

'How do the educational institutes take hard of hearing students into consideration (educational inclusion)? Are all levels of education accessible for hard of hearing youth? If education is not accessible for the hard of hearing student, what kind of impacts does this have on the employment issues in the future? Do the language knowledge requirements in education take into consideration hard of hearing youth?'

It is important to acknowledge the importance of education beyond school and youth, so that there is 'education for life' and: 'Opportunities of life long learning for people with disabilities according their interest, needs and demand of labour market'. In this wider context, it is therefore relevant to ask: 'What is the educational structure of disabled population? What is needed to provide on-going education for the adult disabled population?'

Research needs identified as a priority in this area were:

- 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 and how this impacts on their participation in the labour market
- Country-specific data about disabled children in schools, e.g. representativeness with respect to type of disability, sex and age.
- Analysis of the implications of citizenship education in schools, e.g. teaching disability awareness

Special attention was also drawn to the need for acknowledging the critical importance of lifelong learning in supporting the integration of adult people with disabilities into the labour market. Research priorities mentioned in this specific area include:

- 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

In recent years, there has been a significant increase in the prominence given to disability non-discrimination and equality, as a human rights issue, in the EU and its member states. Overall, however, legislation remains scattered and inadequate both at European and country level. It may therefore come as no surprise to find that non-discrimination and human rights was one of the priorities where much emphasis was placed on legal research by DPOs.

The research priorities identified by DPOs revealed the need for a better understanding of the nature of disability discrimination and the way in which disability non-discrimination law operates, as well as a desire for more research on the implications of the United Nations Convention on the Rights of Persons with Disabilities in this context. With regard to gaining a better understanding of disability discrimination, one respondent noted:

‘Evidence needed; a) proof (statistical data etc.) of all types of discriminatory behaviour (direct, indirect etc.) in all areas of life, b) proof of multiple discrimination, especially against the most vulnerable groups of disabled people like women with disabilities, immigrants with disabilities etc. ...’

whilst another wrote:



‘How do discrimination, obstacles and inequality manifest themselves in the lives of hard of hearing people? What different forms of discrimination are there? How to recognize institutional discrimination? And what kinds of institutional discrimination are there?’

Respondents also felt that research was needed to enable a better understanding of how disability non-discrimination law worked in practice, and what changes are needed to improve its efficiency. One respondent wrote:

‘Analyse why instruments such as reasonable accommodation have not worked as well as expected and the main barriers preventing its effective use. ... If strategic litigation is the way to go, how can this be most efficiently done. The success rate before courts has been low – how can this be improved?’

whilst another concisely notes: ‘How are people empowered to use these otherwise rather abstract principles?’ and another suggested: ‘a study on the formulation of a new legislative framework that can promote the principle of equal treatment’.

The responses also revealed the need for, and value attributed to, comparative legal research in this area. One respondent advocated:

‘A research on the type of policies being implemented by Member States would, in our opinion, highlight, or maybe not, the non-integration of a human-rights approach national policies’. Whilst another, writing about the situation in a particular Member State, concluded by asking: ‘What is the existing legislation and its enforcement in comparison with other European countries?’

A number of respondents emphasized the need to integrate work on the United Nations Convention into research in this area.

Given the prominence given to disability non-discrimination within the EU and its member states, it is perhaps not surprising to find that this was one of the priorities where much emphasis was placed on legal research by DPOs. The key goal for all respondents was for research to contribute to a better understanding of the nature of disability discrimination, and the creation of a legal framework which would serve to combat such discrimination and guarantee the rights of persons with disabilities.

The opportunities for research arising from the respondents’ contributions can be summarized as follows:



- 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

Employment is a key issue for disabled people in the EU. A recent communication published by the Commission⁵ highlighted how 'disabled people continue to be disproportionately excluded from the labour market and that the situation of women with disabilities is worse than that of disabled men. Moreover, people with learning or intellectual disabilities are even less likely to be in work than those with physical disabilities'. The responses suggest that employment is an area where some DPOs feel research needs to focus on the diverse experiences and capabilities of people with different impairments. However, themes common to the wider group of disabled people and, in particular, unemployment, were also identified.

⁵ Situation of disabled people in the European Union: the European Action Plan 2008-2009



A number of respondents called for impairment specific research in the area of employment. For example:

'The main focus of disability and employment is on (physical) accessibility... We think that we need to focus more on invisible accessibility, such as cognitive problems at the work place. Therefore more research is needed on how people with problems of e.g. memory, attention, learning etc. can benefit from special cognitive methods and information technology in order to handle a job.'

'What is the unemployment rate in the hard of hearing group? Are there any obstacles for hard of hearing people in transition from education to employment? Is the work environment accessible for hard of hearing people?'

'How can the labour market participation of people with visual impairment be increased? What mixture of measures work?'

One respondent referred to national legislation adopted in their Member State which they felt had had a negative impact of disabled workers, leading to an increased chance of dismissal and reduction of employment rights. In light of this, and the general increase in unemployment rates, the respondent called for research on 'the impact of unemployment on persons with disabilities'. Lastly, a respondent called for research on 'disabled persons as employers (particularly re: personal assistance schemes) and self-employment'.

The opportunities for research arising from the respondents' contributions can be summarized as follows:

- 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 vs. residential institutions

In Europe, thousands of disabled people, of all ages, are forced to live in closed residential institutions deprived of their fundamental human rights, such as their rights to freedom of movement and to live in the community. Independent living was a prominent priority for future research, viewed by the respondents as central to the achievement of wider social inclusion goals.

A key concern was to examine how independent living rights can be assured and supported for disabled people with different impairments, different ethnicities and ages in different countries. While the main focus was on understanding what works and identifying best practice in support for independent living (e.g. in enabling living environments, direct payments, personal assistance, provision of enabling technologies), it was also seen as important to develop robust 'benchmarks that will allow for monitoring the numbers of people still living in institutions'.

It was seen as important to:

'Allocate more funds to research on support for independent living (with support from governments and the private, industrial, pharmaceutical, high-tech sectors, etc.)'

The main focus was on understanding what works and best practice in support for independent living (e.g. in enabling living environments, direct payments, personal assistance, provision of enabling technologies). For example:

'Research into how living environments in the best way contribute to the quality of life of persons with disabilities. How can it be organised to ensure the highest degree of own control over the life of the person with a disability according to different kinds of disabilities. In relation to this, experimentation with ways of basing living environments in the community is essential.'

'It would be beneficial to have information on how to develop supports for community living that will inform policy development and be accessible to service providers and disabled people's organisations. This research should include quality criteria, to ensure that services developed do support disabled people to live included in society.'

'More information on how the different models actually work for disabled people, do they deliver?'



In order to do this it would be useful to develop 'EU best practise examples' and to highlight the enabling outcomes of independent living, such as 'quality of life and personal achievements'.

Independent living was viewed as a human right (asserted in the UN Convention) and so a key concern for research is to examine how this can be assured for disabled people with different impairments, of different ethnicities, ages and in different countries – in particular, 'the portability to be able to retain this [support] when moving around EU Member States'. It would also be important to understand the 'costs and benefit for the whole society if IL will be provided comparative analysis of situation in different countries'.

In order to provide more equitable provision of support for independent living, there is a need for new research data.

'We do not know the composition of severely disabled persons who are not able to live and independent life. We do not know their circumstances and have no information whether they are able to live independent life under given conditions. With the above information we could define the conditions, equipment necessary for them to live independent life.'

In this context, particular attention should be paid to the needs of different groups of disabled people in an ageing society:

'Overcoming the policies and practices of institutionalisation is possible only by promoting independent living for all people with disabilities, taking account of the dishomogeneous nature of disability. Research in this field is rare and not available in any country.'

The opportunities for research arising from the respondents' contributions can be summarized as follows:

- 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 and Communication

Given the important role played by information and communication technologies and mass media in all aspects of life, it is perhaps unsurprising that several respondents prioritised this theme. Their concerns addressed the need for research to promote access for people with (particular kinds of) impairments, as well as for research into how the general public perceive disability.

Respondents addressed both the need for research to promote access of people with (particular kinds of) impairments to information and communication technologies, including the internet and other forms of electronic media, as well as for research into how members of the general public perceived disability and how the public could receive and accept positive images of disability.

In the context of the information needs of disabled people, a number of respondents called for research on promoting the accessibility of electronic media and equipment. One respondent called for: 'inclusive accessibility of internet and information and communication systems, resources and products', another mentioned the need for 'special devices for different people with different kinds of disabilities to use computers, telephones etc', whilst another, focusing more closely on a research agenda, argued in favour of 'data about the number of disabled people using new technologies and study on the cost of accessibility within the mass media'.



A second theme relating to the information needs of people with disabilities was the need for impairment specific research. Specifically, research into the needs of people with visual impairments and people with hearing impairments was called for.

Respondents also addressed the need for research on how information and communication could help to improve the perception the general population has of people with disabilities. One respondent wrote:

‘We would like to learn more about how we can eliminate psychological barriers, barriers in the minds of “healthy population” and our policy makers. We also feel an absence of awareness and information about disability issues within the general public. That is why we are interested in what are the most effective ways for disseminating information and raising awareness. How to make people understand and accept the demands of people with disabilities?’

A second respondent referred to the ‘preservation of negative stereotypes and called for research on the portrayal of disabled people in the mass media, research on the perceptions of the mass media managers towards the new disability approach,⁶ and public opinion research on perceptions and how disabled people are portrayed’. One goal of the research should be the ‘elaboration of a European study on the correct portrayal of people with disabilities (and a guide also).’

One can conclude that DPOs feel there is a need for research on how to improve access of disabled people to the many services and products which fall within ‘new media’, as well as a need for further research addressing the information and communication needs and experiences of people with particular kinds of impairments. However, research addressing the portrayal of disability to the general public, and the perception of disability which the public has, were also seen as important.

The priorities identified highlight the need for research on accessibility and new technologies; the information/communication needs of people with specific impairments; the public media portrayal of disabled people and disability awareness. The opportunities for research arising from the respondents’ contributions can be summarized as follows:

- Research to promote the development of information and communication systems, resources and products inclusive and accessible to disabled people

⁶ Presumably, a reference to the social model of disability.



- 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

In every country, disabled people are amongst the poorest of the poor and the most threatened and excluded members of society in all areas of life. Social exclusion and poverty often follow the onset of impairment or chronic illness, and those in poverty are more likely to experience disability. Understanding the causes of poverty and relative disadvantage experienced by disabled people was therefore recognised as an important issue. Priorities ranged from comparative analysis of disabled people's living/social conditions to help determine the specifics of poverty and social exclusion for people with disabilities across Europe in general and low-income European countries in particular, to research to understand the financial costs that derive from the disability condition. It was felt that, with greater knowledge, NGOs would be able to act more assertively in advocating social rights and solutions.

Addressing the widespread poverty and relative social disadvantage experienced by disabled people was recognised as an important issue. For example, respondents noted that, 'Disabled people still belong to the most poor and the most excluded inhabitants. We would like to find effective ways for what can be done to improve the situation'.

It is important to understand the current situation and its causes in a comprehensive way. Thus, 'Social exclusion and poverty often follow chronic illness and disabilities. It is important to make comparative studies of living conditions focusing on income, employment, quality of life, obstacles, social life etc.' More specifically:

'What are the costs of disability, what are the specifics of poverty and social exclusion for people with disabilities, what measures would help to decrease level of poverty of disabled people?'

'Evidence needed: a) proof (statistical data etc) of the low income of people with disabilities and their families, b) data for the high financial needs that derive from disability condition, c) study on the welfare



system and its effectiveness d) research on the employment status of people with disabilities and the existing legislation that promotes it, e) research on the educational, training and life long learning conditions that lead people with disabilities in low rate employment positions and jobs Kind of research: a) collection of statistical data, b) review of the welfare, educational system, employment conditions and legislation'

Importantly, there is a need for 'research that will inform policy development' and social action.

'Persons with disabilities are certainly disproportionately represented among the poor. However, specific data on the social situation of persons with disabilities does not exist, or is not publicly available. A comprehensive research on poverty among persons with disabilities should be undertaken urgently across Europe, in particular in low-income European countries. Thanks to this knowledge, NGOs would be able to act in a much more assertive way in order to reverse the trend towards an improved situation for persons with disabilities'.

In addressing policy development, research could assist in formulating an effective welfare benefits system tailored to individual need. Including attention to: 'compensatory benefits (disability allowances); reintegration into social employment life in order to prevent social exclusion and poverty'; and, the 'importance of development and implementing of programmes for social and economic re-integration'.

The research priorities identified include: comparative data on living conditions and poverty; Understanding the financial costs of impairment and disability; and, research to inform policy development in social protection and employment. The opportunities for research arising from the respondents' contributions can be summarized as follows:

- 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 for 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

This sub-section discusses responses received under the heading of transport, mobility or tourism and the heading of urban and built environments. This is because both sets of responses focused, in particular, on the need for research to contribute to promoting accessibility for disabled people.

In the context of transport, mobility or tourism, respondents emphasized that ‘architectural, urban and transport barriers represent an actual and daily damage which isolates, causes physical, social and economic harm’ and referred to the need to provide access and independent use of public transport and tourist facilities through the various accommodations and accessibility options which are already known about. In addition there were calls for research on tools that could easily be put in place and which could provide different solutions to make transport accessible, and research on technical specifications for audio support to facilitate orientation and mobility, with the goal of ensuring that different systems are compatible with each other. There was also a more general call for ‘research to promote accessibility and universal design’.

Accessibility was also a prominent characteristic of the priorities identified with regard to the urban and built environment. One respondent called for research on tools which could be developed ‘to qualitatively and effectively improve the knowledge of “technicians” to create infrastructures that are accessible for all’. The respondent called for multi-disciplinary research to be carried out involving fields such as ‘architecture, design, and medicine – ergonomic’ and for ‘technical studies (e.g. industrial engineers)’ to incorporate a disability perspective ‘at the medical / social level’.

Another respondent provided more detail about the kind of research that was needed to promote accessibility:

- ‘a) registration of the existing situation, b) registration of legislation that promotes accessibility, but which is not applied in practice, c) registration of potential areas that are not covered by existing legislation, d)



registration of accessibility technical standards for every field, covering national, European and international standards.

Kind of research: a) statistical data, b) overview of all legislation, c) collection of available accessibility standards (national, European and international).'

Lastly, three responses called for research into the accessibility of the urban and built environment for people with visual impairments. One called for a 'comprehensive survey of all European tactile walking surface indicators and their application', whilst another called for research on the best kind of material which can be used to make 'public information material/stands which provide information in Braille'. The third called for accessibility relating to electronic banking technologies.

The priority areas for research include: accessibility and universal design; compatibility of different systems providing accessibility; reviews of existing legislation and standards designed to promote accessibility; accessibility for people with specific impairments. The opportunities for research arising from the respondents' contributions can be summarized as follows:

- 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

In the last three decades, disabled people around the world have increasingly developed their own organisations to campaign for their full inclusion and active participation in society on the basis of human rights. Often united under the principle 'nothing about us without us', disabled people's organisations are particularly valued for playing a key role in disseminating information and promoting the rights of disabled people. They are also seen as having a



significant role to play in implementing the UNCRPD and influencing national disability policy.

Having recognised the influence that research may have in disability policy development and needs for research in key policy areas, disabled people's organisations have also challenged traditional approaches to disability research, arguing that they should be actively involved and their voice and priorities better represented in shaping research funding opportunities and practice. There is potential for new research to build the research capacity of such organisations (as demonstrated throughout the EuRADE project). Having said that, disabled people's organisations also recognise a need to understand more about civil society itself – particularly the self-organisation of disabled people's as an important social movement in Europe. In this context, respondents were particularly keen on:

Not only have civil society organisations recognised needs for research in key policy areas, but also a need to understand more about civil society itself – particularly the self-organisation of disabled people's as an important social movement in Europe. According to the respondents, such organisations are important because:

'Organisations of and for persons with disabilities play a key role in disseminating information and promoting the rights of persons with disabilities.'

'The communication between handicap organisations, disabled persons and the "normal" world is very important. In this way you can show the importance of building good buildings for disabled persons, of making good schools for disabled children and so on. Also the communication between the people of the helping offices, towns and state, etc. and the disabled persons and their organisation is important to find out, what you must do, and pay, for making a good life for disabled persons and their families.'

Disabled people's organisations (DPOs) have a significant role to play in implementing the UN Convention and influencing national disability policy. There is potential for new research to build the capacity of such organisations (as demonstrated throughout the EuRADE project). In this context, respondents were particularly keen to understand the structure, funding, role and strategies of disabled people's organisations in different countries.

'What are the existing capacities of organization of disabled people, what is the focus of their activities, whom they are controlled by, how are they



financed, how much do they influence policy? Recommendation on how to become better advocate for disabled people's rights.'

'What should they look like? What is their role and what are their competencies in a modern society? How does a profile or a structure of an ideal PWD organization look?'

'Is there a best way of obtaining influence for DPOs? Is obtaining power different when you are disabled?'

The priority areas for research include: the roles and strategies of disabled people's organisations, and their organisational structure, capacity, funding and sustainability. The opportunities for research arising from the respondents' contributions can be summarized as follows:

- 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 the most effective advocacy strategies for disabled people's rights.

Bioethics and rights to life

Bioethics and rights to life have featured more prominently in the priorities of disabled people' organisations than in the policy and research agenda. Among the respondents' concerns is that the human rights perspective is not well incorporated and that disabled people are frequently discriminated against in the development of biomedicine (i.e. genetics, new technologies, euthanasia among others). In terms of specific research agendas, it was also felt that interdisciplinary research, with a disability perspective is needed to address such a complicated area. In this area also, research on how to challenge negative perceptions of disability in society was again viewed as critical, particularly given the impact these may have on parents or prospective parents in pre- and postnatal life-or-death decisions. For example, as one respondent wrote:

'The development of biomedicine (genetics, new technologies, euthanasia, etc.) is not aware about the human rights perspective and



frequently discriminates against persons with disabilities. It is necessary to build a bioethics model of disability.'

In terms of specific research agendas, 'multiscience' (interdisciplinary) research, with a 'disability perspective' is needed to address such a complicated area. Research needs are wide ranging, including research on 'the perception of disabilities in this changing society', which informs life and death decisions.

'Pre and postnatal elimination of children with disabilities is the result of the image disability in the general population and this selection has again an impact on the image of disability.'

'How are pregnant mothers counselled, what information is given, what determines their decision? What information tools are doctors using to inform about disability? How are disabilities described in medical publications? A literature study of the image of disabilities in medical literature towards gynaecologist would be useful.'

The priority areas for research include: a disability and human rights perspective in bioethics research; challenging cultural images of disabled people; providing appropriate information to prospective parents. The opportunities for research arising from the respondents' contributions can be summarized as follows:

- 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

The research paradigm within which the consultation was conducted (a social and human rights perspective) is concerned with disability equality rather than



with specific treatments, cures or therapies targeted towards people with impairments. However, it was clear that there are pressing issues of equality of access to health care for disabled people, which must be considered as an issue of rights and barriers. For example:

‘The right treatment is key for disabled people with a chronic illness. Many problems of social exclusion, employment and education can be reduced if everybody gets the best and right treatment.’

‘Why are people with mental health problems treated differently by the health care system? Forced treatment etc.’

Other respondents pointed to the need for greater knowledge about the inequities of specific health conditions affecting disabled people, including responding to the ‘depression that many disabled people have’, or the loss of independence experienced by the ageing ‘survivors of post-polio syndrome’.

‘User involvement’ in service provision was highlighted and there were calls to investigate the role of ‘holistic’ and ‘complex’ systems of health care and rehabilitation, and the social return of investing in such models. With massive investments and rapid changes in health technologies there is also a need to consider the potential outcomes for disabled people. As one respondent put it:

‘The last few decades I’ve seen medicine in the North evolving to an overactive high technology and this new knowledge has to be translated urgently into real help and efficient care.’

The priority areas for research include: equal treatment and access to health care; user participation in health care provision; holistic approaches to health care and rehabilitation. The opportunities for research arising from the respondents’ contributions can be summarized as follows:

- 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

With demands on support for independent living (highlighted earlier) there are also challenges for housing research. Some respondents pointed to a lack of information on the current housing situation of disabled people, which makes it difficult for organisations to plan and offer appropriate forms of support for improved standard of living. Others highlighted the need for comparative research on different housing options and support services available in different European countries. For example:

‘We do not know the composition of disabled persons from housing point of view. We have not information about the number of disabled persons living in family, alone, residential homes or institutions.’

‘We do not know what are their housing problems in small villages, towns or big cities. We do not know what kind of social community services are provided for them. With the above knowledge we could identify their needs for housing, for services which could improve their housing problems.’

‘We are very interested in the issues of the different housing options in relation to support services available. What are the different options available, the design issues (universal access, design for all...), the methods of financing... always with a view to comparing different European countries.’

The priority areas for research include: statistical data on disabled people’s housing situation; rural and urban housing environments; design and accessibility of housing. The opportunities for research arising from the respondents’ contributions can be summarized as follows:

- 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 of disabled people 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

Rule 9 of the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities⁷ asserts that 'States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.' Access to family planning methods, information, education and counseling on sexual health in an accessible way and ability to protect themselves from sexually transmitted diseases are also asserted as rights in this rule.

Despite international and European human rights and non-discrimination instruments, many disabled people, in particular disabled women, are still denied these rights, a fact that was acknowledged by some respondents. Also seen as important was the dependent relationship within families for disabled people (particularly in some European countries) which may hinder access to such rights. Finally, the importance of close personal relationships was also highlighted in relation to sexuality and access to sexual relationships (including support and assistance to facilitate participation in such relationships).

Some specific priorities were also raised in relation to parenting and family life more generally (whilst recognising the gendered relations of this topic identified later). For example it is important for research to investigate concerns where, '...the right to be a mother and to have a family are questioned or refused'.

'Research is needed on what are the reasons that disabled people depend on their parents much longer than their non-disabled friends. What are the methods which could help them to become more independent in earlier phase of life?', and, conversely, 'What are the reasons that disabled people are living alone?'

The importance of close personal relationships was highlighted in relation to sexuality and access to sexual relationships (including support and assistance to facilitate participation in such relationships). As one respondent wrote:

⁷ 'Although not a legally binding instrument, the [Standard Rules](#) represent a strong moral and political commitment of Governments to take action to attain equalization of opportunities for persons with disabilities. The rules serve as an instrument for policy-making and as a basis for technical and economic cooperation'.



‘We would be interested in learning more about all that helps or hinders the rights of disabled people to enjoy an emotional and sexual life like everybody else. What happens with persons who are not able to explore their sexuality on their own - the issue of sexual assistants?’

The priority areas for research include: rights to parenthood for disabled people; independence, interdependency and the family; access to sexual relationships. The opportunities for research arising from the respondents’ contributions can be summarized as follows:

- 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

While there is limited research available on disabled children and young people, current research indicates that they are among the most vulnerable and excluded from social participation of all the world’s children. Constantly experiencing barriers to the enjoyment of their basic human rights, they are among the most stigmatised and marginalised and often find themselves at significantly increased risk of facing poverty, abuse, and neglect. Lack of appropriate social support, unequal access to education and limited opportunities for employment further contributes to their social exclusion.

In this consultation, the particular issue of disabled children and youth was prioritised by three respondents. Early access to services and rehabilitation was seen by one of them as critical for disabled children if they are to maximise their opportunities in adulthood. An observation was also made that there is lack of reliable and usable data about the situation of disabled children and young people in European countries. For example:

‘We do not have any statistical data on young disabled persons. We do not know their composition (ratio, degree and type of disability, etc.) For



future planning we do need information about the most important difficulties that our young generation with disability faces.’

‘If disabled children and youth get the best available treatment and if their special needs are met, while they are young, they will be able to live their lives more in normal conditions and the risk of stigmatization will be reduced. Too many adults with disabilities have been stigmatized to such an extent that their chances of rehabilitation are very slim.’

The priority areas for research include: statistical data concerning disabled children; and, early identification and access to services for children. The opportunities for research arising from the respondents’ contributions can be summarized as follows:

- 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

Worldwide, disabled women and girls are recognised to be subject to dual, or multiple discrimination. According to the United Nations⁸: ‘Women with disabilities face significantly more difficulties in both public and private spheres, such as barriers to access to adequate housing, health, education, vocational training and employment, and are more likely to be institutionalized (E/CN.4/2005/43, paragraph 64). Disabled women also experience inequality in hiring, promotion rates, equal pay, access to training, retraining, credit and other productive resources, and they rarely participate in economic decision-making⁹’.

Gender issues cut across all of the topics identified above as research priorities and should be mainstreamed in all disability equality research.

⁸ Secretary-General of the United Nations in his report ‘Fifth quinquennial review and appraisal of the World Programme of Action concerning Disabled Persons’

⁹ ‘Employment barriers for women with disabilities’, Arthur O’Reilly, The Right to Decent Work of Persons with Disabilities, Skills Working Paper No. 14 (Geneva, International Labour Organization, 2003).



However, some specific points were raised by respondents, who noted that 'women with disabilities face dual discrimination' and that 'gender issues are majority issues for disability movement'. Recognising gender inequalities amongst disabled people is important if research is to acknowledge 'intersectional discrimination'. In particular, there were calls for research to 'learn about employment and family opportunities', and to consider 'pay discrimination'. Particular attention was drawn to 'mothers and caring duties'.

The priority areas for research include: dual discrimination in disability and gender; employment and equal pay for disabled women; mothering and family responsibilities. The opportunities for research arising from the respondents' contributions can be summarized as follows:

- Research on the gendered dynamics and outcomes of disability discrimination
- Research on employment and equal pay for disabled women
- Research on the experience of mothering and family responsibilities and the barriers to its fulfilment

Note

An overview of priorities across all research topics can be found in the Executive Summary at the beginning of this report.



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=ojSNX3n0zzqcrVaWWglHXRA3bDva6cNhTij54J7Bl_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.