

Institution: University of Leeds
Unit of Assessment: 22 Social Work and Social Policy
Title of case study: Shaping disability policies in Europe
<p>1. Summary of the impact</p> <p>Research led by Professor Mark Priestley at Leeds increased the democratic participation of policy users in the disability field and shaped public policy, law and services across the European Union (EU). Collaborative research methods provided the knowledge and skills for disabled people's organisations to change the investment priorities of European funding programmes. A seven-year programme of comparative research provided the evidence and tools for the European Commission to develop disability policies and fulfil EU treaty obligations to the United Nations. The impact pathways are based on (a) strategic partnerships with research users, (b) policy relevance in the underpinning research, and, (c) direct inputs to EU policy process. These pathways are illustrated with reference to two EU-funded projects (value in excess of €4m).</p>
<p>2. Underpinning research</p> <p>Since the 1990s the disability policy agenda, and public understanding of disability, has shifted from a more medical view towards the greater recognition of disabled people's rights to full participation and equality. Much of the research supporting this shift was pioneered at Leeds (as evidenced in RAE2001 and 2008). A distinctive Leeds approach centred on a 'social model of disability' and on participatory research methods. This involved research on the barriers to disabled people's equal opportunities, rather than on their impairments, and engaged disabled people and their representative organisations as active participants in that research (particularly in the UK).</p> <p>The translation of this approach to a European level began in 2002 with a concern, expressed by disabled people's organisations (DPOs), about the lack of 'social model' research funded by the EU, or evidence of its policy impact at EU level. This case study shows how these two concerns were addressed. An assessment of the EU context was advanced through an ESRC Seminar Series at Leeds in 2004 and subsequent academic papers [1]. User partnerships were consolidated with seed corn investment from the University of Leeds Fund for International Research Collaboration, which led to a new research programme, illustrated here by two projects.</p> <p>i) European Research Agendas for Disability Equality (EuRADE, 2007-2009): the first project set out to engage DPOs as agents of change in shaping EU research funding agendas - to ensure that social model and rights-based approaches were more mainstreamed in European R&D programmes that impact on disabled people's lives.</p> <p>The project sought to understand more about the research experiences and priorities of European DPOs and to build their capacity to participate in research. The methods included a survey of research engagement amongst civil society organisations in 25 countries, critical analysis of EU research funding programmes, and the development of a ten-point plan for new research priorities [2]. Priestley designed the methodology in partnership with the European Disability Forum (the co-ordinating assembly representing Europe's 80 million disabled citizens) and Professor Lisa Waddington at Maastricht University.</p> <p>The findings showed that civil society organisations wanted to shape research agendas in Europe but lacked the expertise, capacity and opportunity to do so within the existing EU funding programmes, where there was a lack of disability mainstreaming. Capacity building and mentoring for DPO representatives (e.g. a summer school and online research methods training) were thus provided by Priestley and Waddington, to support them in their initiation of new user-led research initiatives and in advocacy interventions with the EU institutions [3].</p> <p>ii) Academic Network of European Disability experts (ANED, 2008-2014): the second project established, and maintained for seven years, a pan-European research evidence network to support implementation of the European Disability Strategy 2010-2020 and of the United Nations Convention on the Rights of Persons with Disabilities in Europe.</p> <p>The seven-year scientific programme was designed and directed by Priestley, with a core research team including Anna Lawson (Leeds), Professors Lisa Waddington (Maastricht</p>

University) and Stefanos Grammenos (CESEP, Brussels), co-ordinated by Human European Consultancy (Utrecht). The research focused on the situation of disabled people and on national disability laws and policies, as well as the extent to which disability issues have been mainstreamed in the EU's own policies (e.g. in EU law or the Open Methods of Co-ordination on employment and social inclusion). More than 300 reports were produced by researchers in 34 countries with synthesis reports from a range of experts, primarily from the core research team.

Amongst its key findings, ANED demonstrated a lack of coherence and consistency in European cross-national data on disability policies and their outcomes for disabled people, suggesting the need for a new framework of more systematic EU policy monitoring and exchange [4]. Proposals for a new EU framework of policy indicators and concurrent monitoring were thus conceptualised by Priestley and Lawson, with statistical input by Grammenos, and stakeholder consultation [5].

3. References to the research

One selected output from the conceptual phase, framing the policy problem.

1. Priestley, M. (2007) In search of European disability policy: between national and global, *Alter: Revue européenne de recherche sur le handicap*, 1(1): 61-74 [<http://dx.doi.org/10.1016/j.alter.2007.08.006>] (submitted to RAE2008)

Two outputs selected from the EuRADE project, funded by the FP7 Capacities, 'Science in Society' programme, SiS-2007-1.2.1.1 (€340k). Peer reviewed with a panel score of 14/15. Co-ordinated by the European Disability Forum.

2. Priestley, M., Waddington, L. and Bessozi, C. (2010) New priorities for disability research in Europe: Towards a user-led agenda. *Alter: Revue européenne de recherche sur le handicap*, 4(4): 239-255 [<http://dx.doi.org/10.1016/j.alter.2010.07.001>] (included in REF2)
3. Priestley, M., Waddington, L. and Bessozi, C. (2010) Towards a User-led Agenda for Disability Research in Europe: learning from disabled people's organisations, *Disability & Society*, 25(6): 731-746 [<http://dx.doi.org/10.1080/09687599.2010.505749>]

Two outputs selected from the ANED project, funded by the PROGRESS initiative VT/2007/005 (€2m) and JUST/2011/PROG/PR/01/D3-30-CE-0450002/00-88 (€1.95m). Assessed by EU Commission staff in competitive tenders. Co-ordinated by Human European Consultancy.

4. Priestley, M. (2012) Disability policies and the Open Methods of Co-ordination, *European Yearbook of Disability Law*, 3: 7-34 (included in REF2)
5. Lawson, A. and Priestley, M. (2013) Potential, principle and pragmatism in concurrent multinational monitoring: disability rights in the European Union, *International Journal of Human Rights*, [<http://dx.doi.org/10.1080/13642987.2013.834494>] (included in REF2)

The above references are all peer reviewed research papers in international periodicals, of which *Disability & Society* is the pre-eminent journal in the field and *The European Yearbook* is the definitive periodical reference work on developments in EU disability law and policy.

4. Details of the impact

The EuRADE project enabled the European Disability Forum (EDF) to adopt a new policy position on disability research, to secure new commitments from industry actors and an investment of €2.5m for social model research in the FP7 Social Sciences and Humanities work programme.

The ANED project enabled the European Commission to make policy recommendations to the Council of Ministers for the reform of disability policies in EU Member States, to adopt new policy monitoring tools, to propose new legislation, and to fulfil the EU's obligations to the United Nations on disability and human rights.

i) EuRADE – <http://www.eurade.eu>

EDF (representing European DPOs) launched its involvement in the project at its General Assembly (Slovenia, 2008). The research findings were validated by the EDF Board, published on their website, and promoted to policy stakeholders at two briefings given by the EuRADE team and

participating DPOs. The first was hosted by the European Parliament (Brussels, 2009) with contributions from MEPs and European Commission representatives (responsible for FP7 Social Science, FP7 Science in Society themes and Eurostat).

Based on the research findings, EDF published a new policy statement, presenting recommendations to the European Commission for alignment of EU research and development funding with a social model and human rights based approach, and greater support for research participation by DPO's [A]. EDF was invited to present these recommendations at the 2009 European Health Forum and also arranged lobbying meetings with the EU Commission's Research Directorate (e.g. its Horizontal Aspects and Coordination Units). EDF exploited the research findings to lobby the European Technology Platforms, which provide a framework for industry stakeholders to define their research priorities (e.g. European Road Transport Research Advisory Council, European Rail Research Advisory Council, European Construction Technology Platform, the eMobility platform and the Networked and Electronic Media platform).

In 2009, the International Telecommunication Union and Global Initiative for Inclusive ICTs (G3ict) identified the EuRADE project as a civil society example of good practice in their e-Accessibility Policy Toolkit [B]. A notable outcome of the EuRADE project was EU commitment to a disability topic in the FP7 Social Science and Humanities roadmap for 2011-13 (resulting in a project call in the 2012 work programme, with a budget of €2.5m) plus two project calls in the Information and Communications Technology (ICT) work programme [C].

As corroborated by the EDF Director, 'As a consequence of the EuRADE project EDF adopted a strong policy statement and a guide on user-defined research priorities to assist the European Commission's Research Directorate General (EC DG RTD) in shaping disability related work programmes. The findings enabled us to lobby key stakeholders within the EU institutions and Technology Platforms for change in their research agendas and funding priorities.' [D].

ii) ANED - <http://www.disability-europe.net>

Collectively, the ANED network has published more than 300 policy-related reports, leading to diverse stakeholder utilization at national and European level. For example: the Federal state of North Rhine-Westphalia (Germany) and the Accessibility Directorate of Ontario (Canada) in revising their employment activation policies; the Estonian Statistical Office and the Flemish Minister for Mobility and Public Works (Belgium) in developing rights-based indicator methods; the European Parliamentary Disability Intergroup in requesting advice on disability benefits and entitlements; the European Parliament's Equality and Diversity Unit on proposals for transferable recognition of disability status in European Countries; the office of the Vice-President of the European Parliament on poverty and social inclusion; the European Network on Independent Living, utilizing country reports in advocacy campaigns; or the World Bank's Disability and Development Team, reproducing research material in a web-based toolkit.

In 2009, presentations of ANED findings on employment and social inclusion were invited to the official European Day of Persons with Disabilities and as oral evidence to the European Economic and Social Committee, referenced in the Committee's written Opinion [E]. These findings were used in European Commission staff input to the European Council's Joint Employment Report for 2009/2010 [F] and referenced in EU Vice-President Vivian Reding's address to the ministerial conference of the Hungarian EU Presidency on European Disability Strategy (2011). The Commission again drew on ANED findings in 2012 to make country-specific recommendations for changes to employment and welfare policies for disabled people in Denmark, Estonia and the Netherlands and, in 2013, to make the legislative and business case for a new European Accessibility Act.

Impact on EU policy monitoring and co-ordination is also evident. In 2010, the European Commission requested ANED's advice to inform preparation of its Disability Strategy 2010-2020. The Strategy then made a commitment to improve EU-level monitoring on disability rights, including the development of a new online tool to map and monitor progress on disability policies across the 34 EU Member States, Candidate and Associate countries [G]. This tool, designed by **Priestley** and piloted within ANED, was launched in 2012 as the 'Disability Online Tool of the Commission' (DOTCOM) [H]. In combination with statistical indicator development, DOTCOM

provides public access to data on more than 1,500 national policies and programmes relevant to the implementation of the European Disability Strategy and provides a new model of concurrent multinational rights monitoring [5].

In 2010, the EU ratified, for the first time, an international human rights Treaty – the United Nations Convention on the Rights of Persons with Disabilities. The European Agency for Fundamental Rights (FRA) was tasked with independently monitoring the EU's progress on implementation and the Commission invited FRA to develop its monitoring activity with reference to the framework of indicators developed by ANED [1].

In parallel, an expert team was engaged to provide the Commission with evidence and advice to help draft the EU's first official Treaty report to the UN. Professors **Priestley** and Gerard Quinn (Galway) were the principal advisors and, on the basis of their teams' input, the EU's initial report was prepared for the EU Council of Ministers and submission to the UN in 2013.

As corroborated by the Head of the EU Commission's Disability Unit, 'The Centre for Disability Studies at the University of Leeds has provided the academic leadership for ANED and I am happy to confirm that the research outputs of Mark **Priestley** and Anna Lawson have resulted in the impact on our policies described. ...In particular, ANED work on data collection and dissemination as well as the development of relevant indicators has strengthened our approach to disability rights monitoring, e.g. through the Disability Online Tool of the Commission launched in June 2012.' [J].

5. Sources to corroborate the impact

- A. European Disability Forum (EDF) Policy Statement - <http://www.edf-feph.org/Page.asp?docid=18048&langue=EN>
- B. *e-Accessibility Policy Toolkit for Persons with Disabilities: A Joint ITU/G3ict Toolkit for Policy Makers Implementing the Convention on the Rights of Persons with Disabilities*, (see, Section 3, Policy development, examples of good practice) [http://www.e-accessibilitytoolkit.org/print/developing_policy/Step 3: policy_development/policy%20development](http://www.e-accessibilitytoolkit.org/print/developing_policy/Step_3:_policy_development/policy%20development)
- C. Commitments to disability research priorities were included in the FP7 Socio-economic Sciences and Humanities Indicative Strategic Research Roadmap 2011-2013 (see, Activity 3) - http://ec.europa.eu/research/social-sciences/pdf/roadmap-2011-2013-final_en.pdf ; the FP7 ICT Work Programme 2011-12 (see, Challenge 7, Objective 7.2) - ftp://ftp.cordis.europa.eu/pub/fp7/ict/docs/ict-wp-2011-12_en.pdf ; and the FP7 SSH Work Programme 2011-12 (see, SSH.2012.3.2-2) - ftp://ftp.cordis.europa.eu/pub/fp7/docs/wp/cooperation/ssh/h-wp-201201_en.pdf
- D. Letter received from the Director of the European Disability Forum (26 February 2013)
- E. *Opinion of the European Economic and Social Committee on People with disabilities: employment and accessibility by stages for people with disabilities in the EU. Post-2010 Lisbon Strategy* (see, footnote 79) - <http://www.eesc.europa.eu/?i=portal.en.soc-opinions.14185>
- F. COM(2009) 674 final, *Draft report from the Commission to the Council: Draft Joint Employment Report (JER) 2009/2010* - <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2009:0674:FIN:EN:PDF>
- G. SEC (2010)1323 final, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, (29 references to ANED's work on pp. 9, 14, 18, 29, 36, 40, and specifically Annex 2) - http://www.ipex.eu/ipex/cms/home/Documents/doc_SEC20101323FIN
- H. *The Disability Online Tool of the Commission (DOTCOM)* <http://www.disability-europe.net/dotcom>
- I. Letter received from the Head of the Equality and Citizens' Rights Department of the European Union Agency for Fundamental Rights (31 January 2013)
- J. Letter received from the Head of the European Commission's Disability Unit (7 February 2013)