European disability network meeting
University of Leeds (UK), 7-9 September 2007

DISABILITY RESEARCH in FRANCE
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INSERM, IFRH, CERMES

Structuring of French Research
French specificity, heritage of history : coexistence of two main systems of public research

National Research Institutes
- EPST : Publicly-owned establishments in Scientific and Technological matter (45 000)
- CNRS : National Center for Scientific Research (26 600)
- INSERM : National Institute for Health and Medical Research (5 200)
- INRETS : Transportation and safety
- INED : Demographical Studies
- EPIC : Publicly-owned establishments in Industrial and Commercial matter (19 000)
- CEA : Atomic energy
- CNRS : National Center for Space Studies

Universities
- EPSCP : Publicly-owned establishments in Scientific, Cultural and Professional matter (131 000)
- Universities
- Great establishments
- CNAM : National Academy of Arts and Trades
- College of France
- EHESS : School of the High Studies in Social Sciences
- IEP : Institute of Political Studies of Paris (Sciences Po Paris)

French specificity, heritage of history :
- coexistence of two main systems of public research

Different directions
- Biomedical research including rehabilitation sciences
- Human and Social Sciences including disability studies
- Engineering and technological Research including assistive technology

A French tradition : very few dedicated research units
- Only one University Chair on disability : Pr E Sampaio (CNAM)
- CTNERHI : Centre Technique National d’Études et de Recherche sur les Handicaps et les Inadaptations

Disability research
- Main characteristic : scattering
- A priority : to federate dispersed forces

A structuring initiative : the Network IFRH
- The Federative Research Institute on Disability
Federative Research Institutes

- Partnership research structures inter-organizations
- The Agreement Protocol on IFRs institutes the « Program of IFR »
  - signed by Departments of Research, Higher Education and Health, Universities, and the main national research Institutes
  - in charge of a typical IFR agreement that settles the organization and functioning modalities of an IFR;
    - regulates the partnership terms between institutions and organisms of which depend research teams and
      determines the modalities of creation and evaluation of IFRs
- Multianual program of IFRs managed by the Department of Research
  - Strategy
  - Multiannual program of IFRs initiated by the Department of Research
    - Policy research unit aimed under various institutional partners around a common scientific strategy
    - Scientific policy formulated on a synergy between the units of research,
      -總統高科学計画における研究機関間の協同
    - Visibility of the activity of research, scientific animation, formation
  - Federator scientific projects
  - Social and economic partnerships
  - Call for projects of IFR: creation and renewing for 4 years
- About 100 IFRs in France (typically on-site)
- IFR on Disability: the unique network IFR

IFRH: multidisciplinary Network IFR

- Thematic federation
- Multiple locations
- Founded in 1995
- Renewed for 2007-2010
- 26 research teams
- 29 partner institutions
- 14 towns of establishment
- 9 administrative regions

PARTNER INSTITUTIONS of IFRH
TEAMS and PARTNER INSTITUTIONS

<table>
<thead>
<tr>
<th>Type of Institution</th>
<th>Nb Partner Institutions (Number of Teams)</th>
</tr>
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<tbody>
<tr>
<td>National Research Institutes</td>
<td>4 (INSERM (9), CNRS (5), INED (1), INRETS (1))</td>
</tr>
<tr>
<td>Higher Education Great Institutes</td>
<td>2 (CNAM (1), IHESS (1))</td>
</tr>
<tr>
<td>Public Health Institutions</td>
<td>1 (AP-HP (2))</td>
</tr>
<tr>
<td>Research Institutes</td>
<td>18 (Bordeaux II (1), Bourgogne (1), Bretagne-Occ. (1), Lille I (1), Lille II (2), Lille III (2), Lyon I (1), Montpellier I (1), Nancy I (1), Paris V (2), Paris VI (3), Paris VII (1), Paris XI (1), Rennes II (1), St-Etienne (1), Toulouse B (1), Valenciennes (1))</td>
</tr>
<tr>
<td>Non Profit Associations</td>
<td>3 (CTNERHI (1), RHEOP (1), CIT-Garches (1))</td>
</tr>
<tr>
<td>Research Foundation</td>
<td>1 (Fondation Garches (1))</td>
</tr>
<tr>
<td>Number of Partner Institutions</td>
<td>29</td>
</tr>
</tbody>
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Scientific orientations of IFRH

- Public Health and Human and Social Sciences
- Clinical Research and Rehabilitation Sciences
- Sensori-motor functioning, Technology and Compensation Systems

General Organisation

- Network Council
  - General Assembly of the Teams
    - 10 Teams
  - Area A: Researches in Public Health and Human and Social Sciences
    - 10 Teams
  - Area B: Researches in Clinical Research and Rehabilitation Sciences
    - 7 Teams
  - Area C: Sensori-motor functioning, Technology and Compensation Systems
    - 9 Teams (incl 1GIS)
Relationship with Disabled people’s organisations

- **CNCPH National Consultative Council of Disabled People**
  - composition
    - Associations of disabled persons and their families
    - Associations and organisations working in the field of disability
    - Organisations for social protection, Unions, professional organisations for employers, a French MP, a senator, and people representing local authorities, representations of Minister
  - Objective
    - to ensure that disabled persons participate in developing and implementing policies that concern them
    - to assess the situation of disabled people and to come up with recommendations for improving their living conditions and the environment to ensure effective participation

- **ONFRH National Observatory on Training, Research, Innovation on Disability (2007)**
  - composition
    - Associations of disabled persons and their families, nominated by CNCPH
    - Research institutes and Universities
    - Experts
  - objective
    - to evaluate how Disability is taken into account in research programs
    - Recommendations about research programs

SOME RECENT COLLECTIVE BOOKS of IFRH

Editorial Activity

- **HANDICAP**
  - Revue de Sciences Humaines et Sociales
  - in French
  - Published by CTNERHI
  - last issue 2005
- **Creation of ALTER**
  - European Journal of Disability Research
  - First issue November 2007
  - New peer-reviewed journal, English/French
  - ALTER and IFRH
  - Publisher : Elsevier
French Disability Research
In Social Sciences: 3 general orientations

• Social epidemiology: social inequalities, life conditions
  → Quantitative methods: National Surveys

• Historical and socio-political analysis
  → Qualitative methods: analysis of legal texts, specialised literature...

• Representations and meaning of disability experiences
  → Qualitative methods: narrative analysis, ethnographic observations