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Introducing social policies and services into National Plans : The French experience

2005 - 2013

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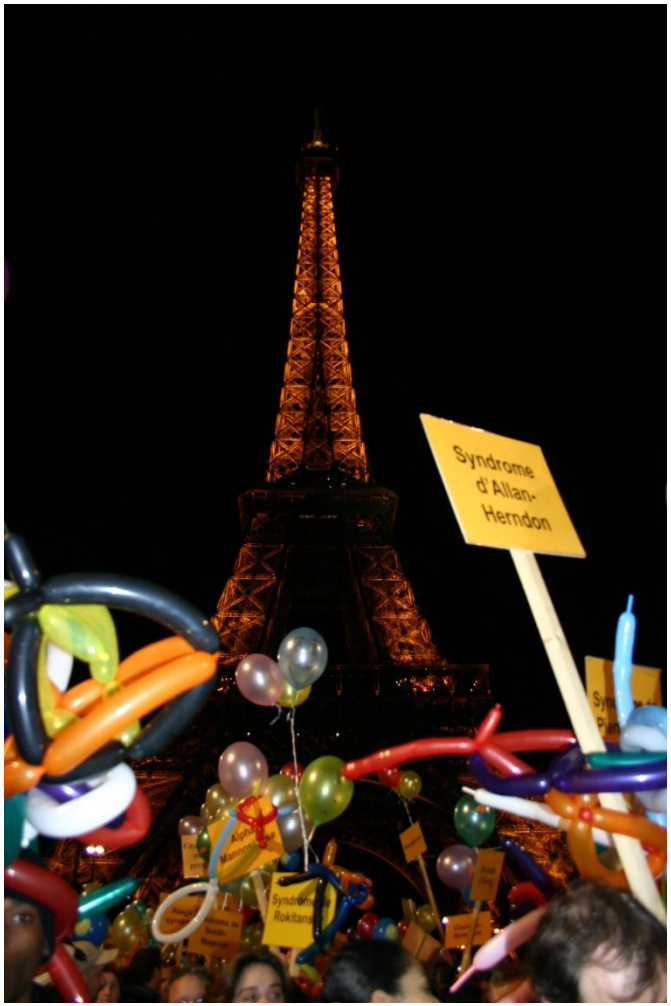
The 2 strategic plans for rare diseases in France : 2005- 2008 and 2011-2014

- Objective of the 1st Plan**:**
- **« Ensuring equity in the access to diagnosis, treatment and provision of care »**

- Objectives of the 2nd Plan**:**
- **A. Improve patient's and carers' health and social care**

- **B. develop research,**

- **C. develop European and international cooperations**



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Strategic plans for rare diseases in France : stakeholders involvement

- **2nd Plan managed by**
  - a steering committee, and working groups including Ministries of Health, Research and Social affairs, patients' organisations, health professionals, researchers, HTA, scientific agencies, health insurance, and CNSA: National Fund for Solidarity and Autonomy (of people living with disabilities and ageing)
  - In relation with the Regional Health Agencies, to support a better articulation between health and social care.

- **Strong involvement of patient associations, mostly AFM, Alliance Maladies Rares, EURORDIS :**
  - in working groups in charge of drafting and monitoring the 2 Plans,
  - in the steering committee and working groups
  - In the evaluation of the 1st Plan

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Among the major achievements of the 1st Plan

- **131 National centres of expertise were designated (2005-2007),**
- **then 500 centres of competence at regional level (2007-2008)**
- **Missions of the centres of expertise** (« reference » in French) **:**
  - Improve diagnosis, organise pluridisciplinary care from birth to end of life
  - Expertise and second opinion
  - Research, epidemiological surveillance and clinical trials
  - Production of National protocols for diagnosis and care, participation in European guidelines if possible
  - Information and training of health and social professionals, patients and their family,
  - Coordination with provision of primary care, medical and social :

  apart from a few pilot experiences, most centres were not able to achieve this mission in the 1st Plan
- ***What is the point of taking good care of people in hospitals, if they do not have access to adapted social services to support them when they come back home? Hospital costs explode.***

Social policies and services in the second Plan (1) linking centres of expertise with social care

Relevant actions in Objective A : Improve patient's and carers' health and social care

- **1. Group centres of expertise in networks to strengthen them, share ressources and tools, cover all rare diseases and patients with unclear diagnosis in the long term : call for tender in June**

- **2. Disease networks and clusters of centres of reference at regional level are encouraged to establish formal links with local authorities in charge of the compensation of disabilities « Maisons Départementales des Personnes Handicapées (MDPH)»: STARTING**

- **3. Support development of telemedecine in order to disseminate the expertise of centres : TO DO Jan: inspiring visit to Frambu**

Social policies and services in the second Plan (2) Improving daily life

4. Develop links with local health and social professionals :

- **Establish complex case managers : ONGOING**
- **Develop and disseminate knowledge about consequences of rare diseases on daily life: limitation of activities, schooling, quality of life : ONGOING (Orphanet Disability project)**
- **Develop respite care for people with rare diseases and their carers : from ½ day to 3 months : ONGOING**
  - Survey by CNSA to centres of expertise and MDPH
  - Mapping (EURORDIS)
  - Training of MPs and pediatricians **TO DO** and of MDPH staff
- **Support carers : Many local or patient groups led initiatives**

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Social policies and services in the second Plan (3) information and training

5. Better inform and train health and social professionals in the framework of :

their studies and continuing vocational training ONGOING

the organisation of care at National level for rare disabilities ONGOING

Promote online trainings : TO DO

6. Promote « Maladies Rares Info Service », the French helpline on rare diseases, which provides information on their rights, and support to patients, families and professionals DONE, however 2/3 budget cut announced last week

Support and fund the European network of helplines: in the Plan, may be questioned now

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Social policies and services in the second Plan (4)
Orphanet : Coding and informing
Support to patient associations

7. Develop the use of the Orpha Code in hospitals (DONE), in the National Data bank (ONGOING), as well as in the MDPH (TO DO)

8. Develop and disseminate fact sheets and good practice guidelines for all diseases and all audiences in Orphanet : ONGOING,

soon available on mobile phones with a free application, thus particularly useful for emergency units and social workers in daily practice when internet connections fail!

9: Support innovative projects of patient associations. Few ex : regional projects in the field of therapeutic education (presented by Alliance Maladies Rares), creation of social guidelines with videos for social workers (Prader Willi France)…

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Creation of a new concept : « rare disabilities » 2009-2013

- **Ministry of Social Affairs and CNSA stressed that all rare diseases are not associated to rare disabilities : some people living with RD can find the support they need in existing social services**
- **However they recognised that for children and adults living with**
  - Impairment of multiple sensory functions : ex seeing and hearing
  - Cerebral palsy resisting to treatment
  - Severe behavioural problems : such as communication problems: autistic spectrum disorders, Prader Willi syndrome…,
- **there is a need for a pluridisciplinary approach linking with expert centres, for dissemination of relevant information, and for provision of specific care. Stated in the 1975 disability law, and not implemented…**
- **A National scheme for the organisation of care for rare disabilities was funded from 2009 to 2013: many meetings, an INSERM study, reports on the state of the art in all regions, a national report issued in 2013… : obviously raised awareness, still we need more concrete actions!**

Establishment of complex case managers

- **Complex care managers empower families to coordinate:**
  - Medical care: centre of expertise, medical specialists, local paediatricians or GP,
  - Paramedical care: nurses, physiotherapists, dieteticians…
  - Social care: social workers, psychologists, occupational therapists, carers, assistants, MDPH evaluation teams
- **Three excellent models already implemented :**
  - « techniciens d'insertion », funded by AFM, the French association against muscular dystrophies, and coordinators SLA, amyotrophic lateral sclerosis
  - « Maisons pour l'Autonomie et l'Intégration (MAIA) for people with Alzheimer » : funded by the CNSA as a pilot, was considered costly, because of the number of people concerned.
- **However less costly than multiple stays in hospitals, say families!**
- **A new job: issue of recruitment and training**
- **Experimentation on all rare diseases concerned, project submitted to the regional health agency of Rhone Alpes,**

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Develop and disseminate knowledge about consequences of rare diseases on daily life : Orphanet disability project

- **Since 2010, Orphanet is tackling the huge task of assessing consequences of specific rare diseases or groups of diseases on disabilities on daily life : a major research field**

- **Using the International Classification of Functioning, Disability and Health-Children and Youth version (ICF-CY 2007), WHO's framework for measuring health and disability at the population level, providing**
- **- a list of body functions and structures,**
- **- a list of activity limitations and participation restrictions, with their severity, temporality and frequency in the population**
- **- also a list of environmental factors, since an individual's functioning and disability occurs in a specific context.**

Develop and disseminate knowledge about consequences of rare diseases on daily life : Orphanet disability methodology

ICF lists had to be adapted and simplified :

creation of an Orphanet Thesaurus of disabilities in English, French (already available), Spanish, German, Italian, Portuguese

Methodology:

State of the art in the litterature

1422 questionnaires sent to clinicians, patient associations, carers, disabilities experts to collect data at international level (33 countries already participated to data collection on 781 diseases),

Indexation,

Validation

If you wish to participate, contact : myriam.de-chalendar@inserm.fr

disability.orphanet@inserm.fr

The development of resource centres
2 outstanding regional initiatives : 1 Pays de la Loire

- **1. PRIOR, Pays de la Loire region :**
- **regional platform informing, supporting and and dispatching patients and families, training health and social professionnals, teachers, school assistants, associations**
- **Funded by the regional health agency**
- **Supported and hosted by the University hospitals of Nantes and Angers**
- **A multidisciplinary on call team: 1 coordinating nurse, 1 genetic counsellor, 1 psychologist, 1 occupational therapist, 1 social worker, 1 medical assistant, 1 coordinating assistant , directed by 1 genetician and supported by 2 neurologists, 1 dermatologist**
- **A help line**
- **Evaluations at home**
- ***PRIOR does not provide any diagnosis and care***

The development of resource centres
2 outstanding regional initiatives : 2 Languedoc

- **2. réseau VALDR, « Live with a developmental anomaly », coordinated by the University hospital of Montpellier and the centre of reference developmental anomalies of Languedoc Roussillon, member of the FECLAD, national network of 8 centres of expertise**
- **Partnership with**
  - 16 regional patient groups: Ehler Danlos, Kabuki, 22q11, Fragile X, Rett, Prader Willi, Down syndrome, Alliance Maladies rares…
  - a children rehabilitation hospital : 111 beds, 54 day care facilities, and with two health professionals networks: Réseaux Grandir et naître
- **Missions:**
  - mapping and coordination of medical and paramedical professionals,
  - trainings including social workers, school medical doctors and psychologists, teachers, school assistants, patient and families
  - Support to inclusion of children in mainstream or specialised schools
  - Link with social services, support to families about their rights regarding MDPH, Social Security…

Today initiatives are mushrooming all over France

In all regions:

- **Multistakeholders conferences**

supported by Alliance Maladies Rares,

Groupama foundation

and the Rare Diseases Foundation for research

- **Rare diseases Marchs**
- **Awareness events for Rare Diseases Day and the téléthon**
- **Support to researchers**

and more…

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How to improve medical certificates used by the MDPH local authorities coordinating social services, financial support, schooling, employment of people with disabilities

- **The MDPH lack human resources: in 2012, 81% of their decisions were based on files, without meeting people with disabilities and families or visiting them at home. This results in poor decisions, paperwork and delays for families, and appeals.**
- **The quality of informations provided in the medical certificate about diagnosis, evolution of the disease, limitations of activities, also potentials, is therefore essential**
- **On April 8, a workshop brought together centres of expertise, CNSA and MDPH to share experiences on common situations**
- **Recommendations:**
  - pluridisciplinary teams in expert centres to fill medical certificates
  - Experts centres to create diseases specific check lists for social workers
  - common staff meetings on complex cases(videoconferences)
  - Training of staff of centres and MDPH
  - Development of fact sheet by Orphanet, available on mobile phones

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This is only the beginning…
We must go on
and better coordinate all our initiatives across Europe

Thank you !