EUROPLAN
European Project for Rare Diseases National Plans Development
Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health
2012-2015

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## EUCERD Joint Action / Work Package 4
## EUROPLAN National Conference

# Workshop Theme 6
# SOCIAL SERVICES FOR RARE DISEASES

EUCERD
Joint Action

Co-funded by the European Commission

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# Relevant extracts from the

# COUNCIL RECOMMENDATION on an action in the field of rare diseases (2009/C 151/02)

## 8 June 2009

# COUNCIL RECOMMENDATION

(The Council of the EU) “HEREBY RECOMMENDS that Member States:

I. PLANS AND STRATEGIES IN THE FIELD OF RARE DISEASES

Establish and implement plans or strategies for rare diseases at the appropriate level or explore appropriate measures for rare diseases in other public health strategies, in order to aim to ensure that patients with rare diseases have access to high-quality care, including diagnostics, treatments, habilitation for those living with the disease and, if possible, effective orphan drugs, and in particular:

- (a) elaborate and adopt a plan or strategy as soon as possible, preferably by the end of 2013 at the latest, aimed at guiding and structuring relevant actions in the field of rare diseases within the framework of their health and social systems;

# COUNCIL RECOMMENDATION

## V. GATHERING THE EXPERTISE ON RARE DISEASES AT EUROPEAN LEVEL

- Gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support:
- (a) the sharing of best practices on diagnostic tools and medical care as well as education and social care in the field of rare diseases;”

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# EUCERD RECOMMENDATIONS ON CORE INDICATORS FOR RD NATIONAL PLANS / STRATEGIES

EUCERD Core Indicators, full version:
http://www.eucerd.eu/wp-content/uploads/2013/06/EUCERD_Recommendations_Indicators_adopted.pdf

# Core Indicator

17. Existence of programmes to support the integration of RD patients in their daily life

**Examples of social services to integrate patients in their daily life are:**

**a) educational support for patients, relatives and caregivers**

**b) individual support at school, for both pupils with RDs and teachers, including disease-specific good practices**

**c) activities aimed to foster higher education for people with rare diseases**

**d) supporting mechanisms to participate in work life for people with disabilities**

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# GUIDELINES FOR DISCUSSION

## Workshop Theme 6
## SOCIAL SERVICES FOR RARE DISEASES

# 1. Social resources for people with disabilities

- What national social security schemes support families and patients with disabilities?

- How are existing social resources mapped at national level? Is there an official directory of social resources for people with disabilities?

# 1. Social resources for people with disabilities

One of the findings of the EURORDIS publication “The voice of 12,000 Patients” was that **«social security systems are usually designed around common diseases and are not flexible enough to take into consideration unprecedented health needs».** Considering the national schemes supporting people with disabilities, the way disability is detected and assessed so to trigger the entitlement to measures of public support:

- How do rare diseases “perform”?
- How “visible” are they?

# 1. Social resources for people with disabilities

- **What mechanisms do support the take-up of social security benefits by people living with rare diseases?**

  Suggestion from Final Report of the EUROPLAN I conferences:

  “It is important modifying the disability evaluation procedures to consider other factors apart from the functional character of the disorder, such as its chronic character, degenerative processes, behavioural aspects and outbreaks.”

# 2. Specialised social services for rare diseases

- What actions of the national plan or strategy on RDs are or will be aimed at “guiding and structuring relevant actions in the field of rare diseases within the framework of …the social systems?” (Council Recommendation)

- What role do **Centres of Expertise** have in developing or facilitating specialised social services aimed to improve the quality of life of people living with a rare disease?

- How are existing social resources for people living with RD mapped at national level? Is there an official **directory of social resources specifically for people with RDs?**

# 2. Specialised social services for rare diseases

- What national schemes do exist that promote access of people living with RD and their families to :
  - Respite Care Services
  - Therapeutic Recreational Programmes
  - Adapted housing
  - Resource Centres

*Please refer to Content Guidelines pages 11 -14 for the most updated definition of each type of services listed above*

# 2. Specialised social services for rare diseases

- What level and sources of **information** do RD patients have on existing social resources?

- Is there any specific information path that RD patients could use to find their way through existing legislation and schemes?

- What **ad hoc training** modules or initiatives are envisaged for providers of social services and care to RD patients?

- How are specialised social services for rare diseases funded? Is there a specific fund to support the **long-term sustainability** of such measures?

- How are specialised social services for people living with RDs **evaluated**? What **quality systems** are adopted or guidelines followed to ensure an adequate level of service provision?

# 3. Policies to integrate people living with RDs into daily life

- What national schemes do exist that promote the educational support for patients, relatives and caregivers?

- What of the following measures do exist and which ones need to be fostered? (examples from EUROPLAN Recos):
  - educational support for patients, relatives and caregivers;
  - individual support at school at different schooling level, for both pupils with RD and teachers, including disease-specific good practices;
  - promotional activities to foster higher education for RD patients;
  - supporting mechanisms to enter and stay in school and participate in work life for people with disabilities.

# 3. Policies to integrate people living with RDs into daily life

- In addition to support in school and work life, what support is provided to improve accessibility, in particular to public services?

- Please discuss about patient-centred measures based on individual intervention plans or **"Complex Case Managers".**

  → In the French National Plan they are defined as the element that can ensure a better coordination in the care pathway of RD patients, functioning as a link between the medical and the social needs of the patient.

# 4. International –supranational dimension

- What social guidelines can be shared based on the experiences in some European countries?

- How existing tools can be best disseminated, validated?
- How to raise awareness on the existence of such tools?

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# PROPOSALS

# Workshop Theme 6
# SOCIAL SERVICES FOR RARE DISEASES