

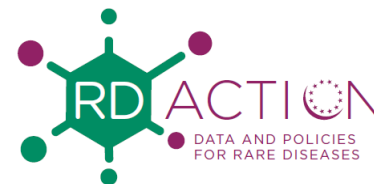


Integrated Care at the core of European Policy for Rare Diseases

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Rare Diseases – Prioritisation in the Policies of European Commission

- Challenges or rare diseases across border, collaboration
- Priority area for European Commission
- Commission Communication on Rare Diseases: European Union Strategy (2008)
- Council Recommendation on the field of Rare Diseases (2009)
- EUCERD and Commission Expert Group on Rare Diseases



Commission Communication

- (Goal) “ensuring effective and efficient recognition, prevention, diagnosis, treatment, care, and research for rare diseases in Europe”

5.2. Access to specialised social services

Centres of expertise may also have an essential role in developing or facilitating specialised social services which will improve the quality of life of people living with a rare disease. Help Lines, Respite care services and Therapeutic Recreation Programmes, have been supported¹¹ and need to be sustainable to pursue their goals: awareness-raising, exchange of best practices and standards, pooling resources using Health Programme and the Disability Action Plans.

Council Recommendation 2009

- (5) Most people “suffer from less frequently occurring diseases affecting one in 100 000 people or less. These patients are **particularly isolated and vulnerable**.
- (6) Because of their low prevalence, their specificity and the high total number of people affected, rare diseases call for a global approach based on special and combined efforts to prevent significant morbidity or avoidable premature mortality, **and to improve the quality of life and socioeconomic potential of affected persons**.
- (16) Cooperation and knowledge sharing between centres of expertise has proven to be a very efficient approach to dealing with rare diseases in Europe.
- (17) The centres of expertise could follow a **multidisciplinary approach to care**, in order to address the complex and diverse conditions implied by rare diseases.

Council Recommendation

Recommendations (!)

- NP/NS: MS asked to “ensure that patients with rare diseases have access to high-quality care, including diagnostics, treatments, **habilitation for those living with the disease**”
- “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**”

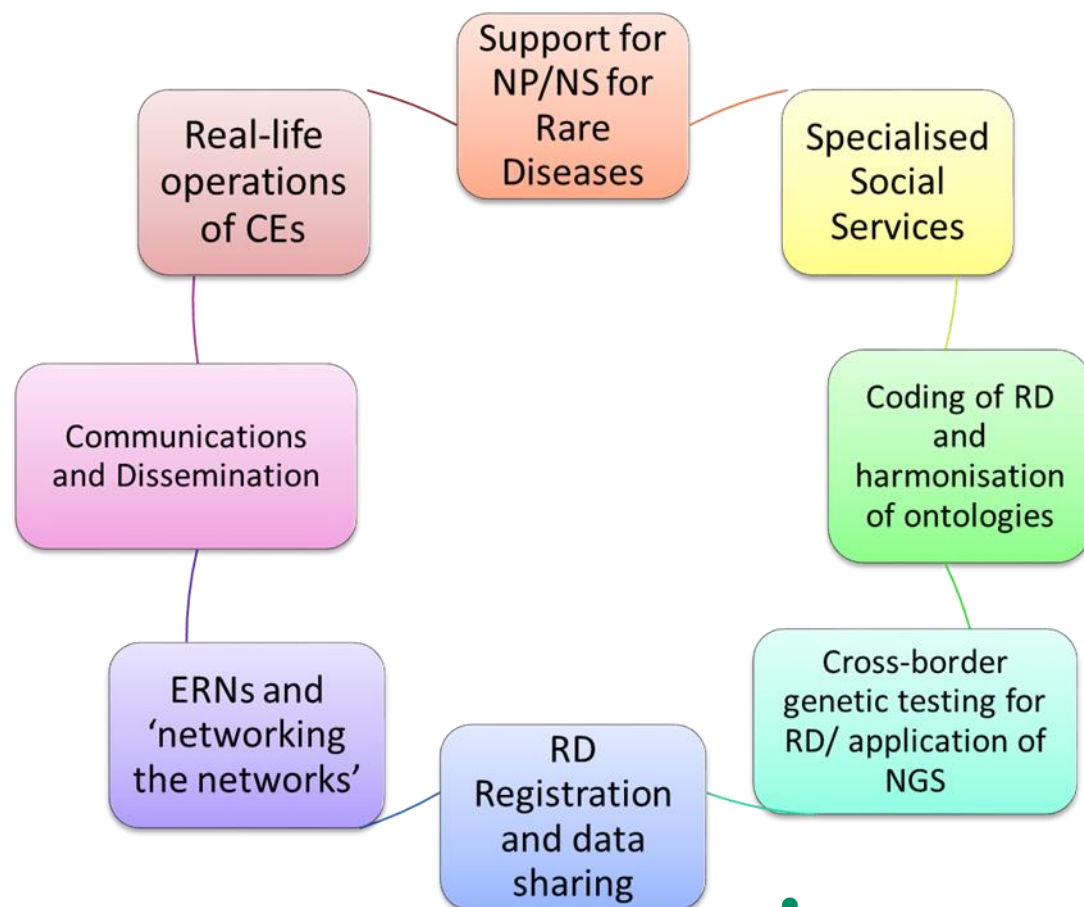
Council Recommendation

Recommendations (!) (cont.)

- 7. Identify needs and priorities for basic, clinical, translational **and social research** in the field of rare diseases and modes of fostering them, and promote interdisciplinary cooperative approaches to be complementarily addressed through national and Community programmes.
- 16. Encourage centres of expertise to be based on a multidisciplinary approach to care when addressing rare diseases.
- 17. 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;**

Joint Actions for Rare Diseases

- EUCERD Joint Action 2012-2015
- Very broad focus!
- Around the time when countries were adopting National Plans and Strategies for Rare Diseases:
- Succeeded by RD-ACTION (2015-2018)



<https://www.eurordis.org/specialised-social-services>

Specialised Social Services

Specialised Social Services are instrumental to the empowerment of people living with rare diseases and are essential to the improvement of their well-being and health. This section provides the list of services in Europe, as well as facts, case studies and guidelines for these services. Testimonies of both patients and volunteers can also be found below.

Overview

Therapeutic Recreation

Respite Care

Adapted Housing

Resource Centres



Therapeutic Recreation Centres



Respite Care Services



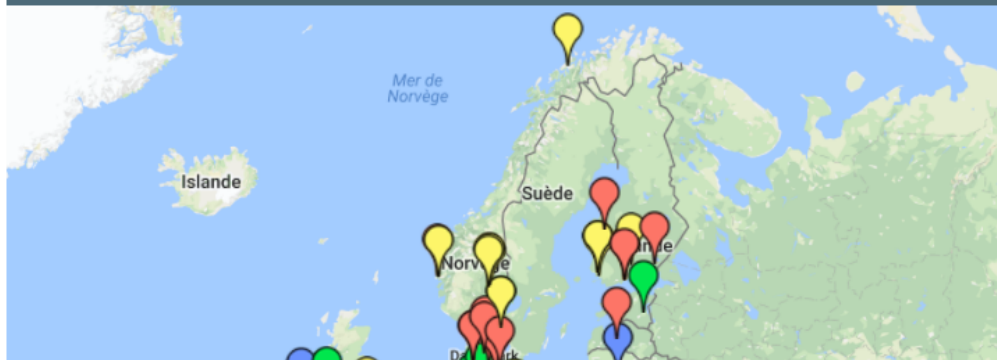
Adapted Housing



Resource Centres



Specialised Social Services



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- [Funding Opportunities for Specialised Social Services: Structural Funds for Health](#)

Contact us

This information is provided by **Raquel Castro**, Social Policy Manager, EURORDIS.

Recommendations



Several Sets of EU Recommendations have a bearing on Integrated, Holistic care

- 1. Criteria for Centres of Expertise for Rare Diseases
 - Emphasis on CEs to fulfil a broad role to support PLWRD:
 - Important, because CEs were envisaged as being at centre of ERN concept
 - If all was well, we wouldn't need this workshop 😊
- 2. Recommendations on ERNs
- 3. Recommendations on Incorporating RD to Social Policies and Services

Commission Expert Group Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies

Advising EU Member States and the European Commission on issues that should be considered when organising holistic care for people living with a rare disease within national health and social care systems

10 recommendations

Unanimously adopted by representatives of all EU Member States (April 2016)

What do our Recommendations Say?

1. BACKGROUND TO THE RECOMMENDATIONS

Providing holistic care to people living with Rare Diseases (RD) is particularly challenging because:

- Expertise and knowledge on RD and their consequences are scarce and difficult to access;
- RD are often chronic, highly complex, severely disabling and frequently affect life expectancy¹;
- No specific treatment is currently available for most RD and existing treatments are not always able to minimise all the complex impairments generated by the disease;
- A high percentage of people with a RD are affected by motor, sensorineural or intellectual impairments, which can occur simultaneously²;
- Even when they are not associated with a disability, RD will in many cases influence the person's health condition and impact on daily life in a disabling way³.

This recommendation focuses specifically on those RD that generate complex impairments. The combination of rarity, complexity and lack of effective treatment creates huge obstacles to the provision of holistic care and in many cases significant medical, psychological and social needs remain unmet.

People with a RD often need follow up care and support from different categories of health professionals, often from several different medical specialities, as well as by social workers and other social and local service providers⁴ which requires a level of coordination not easy to organise in most health care systems.

Professionals lack knowledge of the condition and the appropriate routines⁵ as the standard of care is not established for most diseases. Additionally, service-providers within a range of sectors seem to be reluctant to get involved in managing diseases that are unknown to them⁶.

Studies have demonstrated that the quality of life of people with a rare chronic disease compares unfavourably to that of people affected by more prevalent chronic disorders, both physically and psychosocially⁷ and that RD patients have a more negative experience in terms of medical care and of loss of social-economic activities⁸.

Background cont.

- Failure to meet the serious unmet social needs of people with a RD and their families affects people's dignity, autonomy and other fundamental human rights expressed in the Universal Declaration of Human Rights and in the United Nations Convention on the Rights of Persons with Disabilities
- The EUROPLAN final report based on 15 EUROPLAN National Conferences (2010-2011) recommends that «for people living with a rare, chronic and debilitating disease, care should not only be restricted to medical and paramedical aspects, but should also take into account social inclusion and psychological and educational development» and recognises that «social services are instrumental to the empowerment of people with a RD and to improve their well-being and health»
- Effectively coordinated integrated care and support services, involving health, social and local services as well as the community at large, are essential to overcome the particular challenges of RD and to ensure that people affected by a RD can secure the assistance they require from mainstream social and local services.

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

1. The incorporation of RD specificities into mainstream social services and policies is a necessary element to be considered in future National Plans and Strategies (NP/NS) for RD and should be incorporated when existing NP/NS are evaluated and revised

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

2. Centres of Expertise have a key role in facilitating integrated care provision in line with the EUCERD recommendations on Quality Criteria for Centres of Expertise on Rare Diseases:

- Centres of Expertise (CEs) bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services;
- CEs provide education and training to (...) non-healthcare professionals (such as school teachers, personal/homecare facilitators);
- CEs contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals.

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

3. European Reference Networks for RD have a key role in facilitating integrated care provision in line with the EUCERD recommendations on European Reference Networks for Rare Diseases (10)23 and the Directive on patients' rights in cross-border healthcare:

- Rare Disease European Reference Networks (RD ERNs) need to collaborate with each other, as well as with patient groups, health and social care providers;
- RD ERNs follow a multi-disciplinary approach;
- RD ERNs could function as a platform to share experiences and promote cooperation between MS, to develop precise descriptions of the services required and elaborate common guidelines.

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

4. Member States (MS) should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases, supporting them in the full realisation of their fundamental human rights

- 6. Transfer of information between care providers, within the limits of data protection legal frameworks, should be promoted to support holistic care provision.**
- 7. MS should promote coordination and networking between all parties involved in the care provision of persons affected by RD, including public, private and civil society organisations as well as between providers and patient/disability organisations.**
- 8. RD specificities should be integrated into national systems assessing a person's level of functioning, in line with the United Nations Convention on the Rights of Persons with Disabilities.**
- 9. The elaboration and dissemination of good practices for social care in RD should be encouraged.**
- 10. Socio-economic research in the field of RD care provision/organisation should be supported both at MS level and at European Union level. Support should be provided for research on the following topics:**
 - Socio-economic burden of RD;
 - Accessibility and appropriateness of healthcare services, including social services, for people living with a RD and their families;
 - Effectiveness and cost-effectiveness of social services and support, as well as rehabilitation and assistive technologies for people with a RD;
 - Innovative care practices in health and social services and their impact on the quality of life of people living with RD.

How can ERNs and/or their HCPs
add value to this broad topic?
Remember social care not part of CBHC
Directive...

What do the official Acts governing
ERNs say about this?

Preamble & Definitions (Art 2) of Delegated Decision

- (4) The provision of highly specialised healthcare, one of the criteria to be fulfilled by the Networks, should be based on high quality, accessible and cost-effective healthcare services. It requires experienced, highly skilled and multi-disciplinary healthcare teams and, most likely, advanced specialised medical equipment or infrastructures which commonly imply concentration of resources.

- (8) Further horizontal and structural criteria and conditions related to the exchange of expertise, information systems and eHealth tools should help developing, sharing and spreading information and knowledge and fostering improvements in the diagnosis and treatment of diseases within and outside the Networks and to collaborate closely with other centres of expertise and networks at national and international level. Interoperable and semantically compatible information and communication technology (ICT) systems would facilitate the exchange of health data and patients' information, and the establishment and maintenance of shared databases and registries.

- (c) 'Complex disease or condition' means a particular disease or disorder which combines a number of factors, symptoms, or signs that requires a multidisciplinary approach and well-planned organisation of services over time because it implies one or several of the following circumstances:
 - a large number of possible diagnoses or management options and comorbidity,
 - difficult interpretation of clinical and diagnostic tests data,
 - a high risk of complications, morbidity, or mortality related to either the problem, the diagnostic procedure or the management;

- (d) 'Multidisciplinary healthcare team' means a group of health professionals from several fields of healthcare, combining skills and resources, each providing specific services and collaborating on the same case and coordinating the healthcare to be provided to the patient;

Annex 1- Network criteria

- (3) To fulfil the requirement set out in point (ii) of Article 12(4)(a) of Directive 2011/24/EU ('follow a multi-disciplinary approach'), the Networks must:
 - (a) identify areas and best practices for multi-disciplinary work;
 - (b) be made up of multi-disciplinary healthcare teams;
 - (c) offer and promote multi-disciplinary advice for complex cases.
- (4) To fulfil the requirement set out in point (iii) of Article 12(4)(a) of Directive 2011/24/EU ('offer a high level of expertise and have the capacity to produce good practice guidelines and to implement outcome measures and quality control'), the Networks must:
 - (a) exchange, gather and disseminate knowledge, evidence and expertise within and outside the Network, in particular on the different alternatives, therapeutic options and best practices with regard to the provision of services and the treatments available for each particular disease or condition;
- (6) To fulfil the requirement set out in point (v) of Article 12(4)(a) of Directive 2011/24/EU ('organise teaching and training activities'), the Networks must:
 - (a) identify and fill training gaps;
 - (b) encourage and facilitate the development of training and continuous education programmes and tools for healthcare providers involved in the chain of care (within or outside the Network).

Annex 2 – HCP Criteria

- Strong emphasis on Patient-centredness and patient empowerment
- (b) with regard to organisation, management and business continuity, applicant providers must:
 - (i) apply transparent and explicit organisation and management rules and procedures, including in particular the procedures for managing cross-border patients in their area of expertise;
 - (ii) ensure that tariffs are transparent;
 - (iii) have a business continuity plan over a given time frame, including ensuring:
 - the provision of essential medical care in the case of unexpected resource failure, or access or referral to alternative resources if necessary,
 - the maintenance of the stability and technical capacity and expertise of the provider, such as a plan for managing human resources and updating technology;
 - (iv) ensure coordination with and easy access of the provider to other resources or specific units or services necessary for managing patients;
- (e) with regard to expertise, good practices, quality, patient safety and evaluation, applicant providers must:
 - (i) have a quality assurance or management system and plans including governance and evaluation of the system;
 - (ii) have a patient safety programme or plan consisting of specific goals, procedures, standards and process and outcome indicators focusing on key areas, such as information, a system for reporting on and learning from adverse events; training and education activities; hand hygiene; healthcare related infections; medication errors and the safe use of medication; safe procedures and surgery; safe patient identification;
 - (iii) commit itself to using the best knowledge- and evidence-based health technologies and treatments;
 - (iv) develop and use clinical guidelines and pathways in their area of expertise.

In Summary

- Strong commitment from EC (DG Sante and DG EMPL in supporting this work via two Joint Actions and through dedicated INNOVCare initiative
- Next steps are not so clear... 😞
- There is VERY strong support for ERNs however:
- *ERNs will provide concrete results for tens of thousands of rare disease patients so that they are no longer looking for answers in the dark, and can benefit from the best expertise available in Europe so they may live longer and healthier lives”*
- Tendency to see them as a beacon for rare and specialised fields