



INTEGRATION OF RARE DISEASES INTO SOCIAL SERVICES AND POLICIES IN  
EUROPE: STATE OF THE ART

Raquel Castro, Social Policy Manager - EURORDIS



OCTOBER 2014

The number of **rare diseases for which no treatment is currently available is estimated to be between 4,000 and 5,000 worldwide.**

Source: ORPHANET

**Twenty-five to 30 million people are reported to be affected by these diseases in Europe.**

Source: ORPHANET



Social Services [and policies] are instrumental to the empowerment of people living with rare diseases and are essential to the improvement of their well-being and health

Source: EUROPLAN Final Report based on the 15 National Conferences



## The voice of Rare Disease Patients in Europe

### → WHAT WE DO

#### HEALTH & SOCIAL POLICY , HEALTHCARE & SOCIAL SERVICES

- Promote RD health and social policies development
- Putting RD patients at the heart of the health care system
- Support specialised services to patients

#### RESEARCH, DRUGS & THERAPIES

- Shaping research policy
- Promoting drug development & access to treatments
- Supporting clinical research

#### CAPACITY BUILDING OF PATIENT ADVOCATES

- Training programme (Summer School)
- Capacity Building workshops
- Webinars, eLearning

#### ADVOCACY

- Advocating for patients rights and for policies that address the needs of patients and their families within the European Commission and other European Institutions

#### INFORMATION & NETWORKING

- Community building
- Informing & raising awareness
- Information services to patients

**633** rare disease patient **organisations**

covering over **4000** rare diseases

**59** countries

**30 million** people in Europe



## → Composition

*«Member States, the relevant European authorities in the fields of research and public health action and other relevant stakeholders acting in the field»*

**8** Individual **experts** appointed in his/her personal capacity

**12 organisations** (including patient representatives, industry, insurance)

National Administrations **28 MS** + Norway, Iceland, Switzerland

## → Mission

- *«aiding the European Commission with the preparation and implementation of Community activities in the field of rare diseases, in cooperation and consultation with the specialised bodies in MS»*

**The European Union Committee of Experts on Rare Diseases (2010-2013) was replaced from 2014 onwards by the European Commission Expert Group on Rare Diseases**



**EUCERD JOINT ACTION WORKING FOR RARE DISEASES  
(2012-2015)**



# EUCERD JOINT ACTION WORK PACKAGE 6

## Provision of Specialised Social Services and Integration of RD into Social Policies and Services



**Time Frame:** 2012-2015 (42 months)

**Total Budget:** 357.524€

**EAHC Funds (60%):** 214.514€

**Other partners:**

Caisse Nationale de Solidarité pour l'Autonomie (CNSA), France

Fonds Léa Rose, Belgium

**1:** Identification and Mapping of Specialised Social Services

**Task 2:** Training of Social Services Providers

**Task 3:** Integration of Rare diseases into Social Policies and Services

**Report on EUCERD guiding principles for Social Care in RD**  
**Draft of EUCERD recommendations in the social field**



*«We're allowed to need it and to want it.»*

*Lara Chappell, Mother of Pierre, 6 years old, living with Angelman Syndrome, France*



**Therapeutic Recreation Services:** any organised recreation activity (camp, ad hoc trip) giving patients the possibility to take a break from thinking about diseases/treatments and focus on fun and leisure

**Respite Care Services:** short term basis care so that the carers can have a break from care giving

**Adapted Housing:** group homes aiming to help people living with rare diseases to enjoy the highest possible level of autonomy, in their own home, where they are supported by specialised staff

**Resource Centres:** training courses, information and guiding, documentation and research, daily support therapies, medical and psychological consultations

March 2012

October 2014

Paper: Need for Specialised Social Services and Integration of RD into Social Policies

Fact Sheets

Respite Care Services  
Therapeutic Recreation Programmes  
Adapted Housing  
Resource Centres

Country Visits

Sweden, Norway,  
Hungary,  
Denmark, Spain,  
France

Connecting to other initiatives on Social Services and Policies

EMM 2014 Berlin  
Learning from each other:  
Education and Employment

Mapping of Specialised Social Services

Workshop Guiding Principles for Specialised Social Services

Document on Guiding Principles for Specialised Social Services

Document Training Social Services Providers

EMM 2014 Berlin  
Capacity Building Workshop:  
training for social services providers + EURORDIS position paper

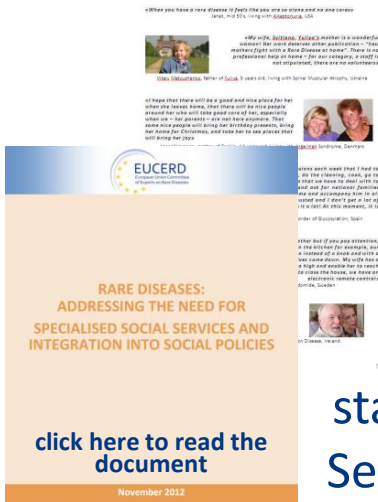
ECRD 2014 Berlin  
Theme 6: Beyond Medical and Medicinal Care  
Poster Award

Workshop EURORDIS Membership Meeting 2013

Workshop Training Social Services Providers



# PAPER: NEED FOR SPECIALISED SOCIAL SERVICES AND INTEGRATION OF RD INTO SOCIAL POLICIES



## Background information and statistics on Specialised Social Services and Social Policies for PLWRD

Definitions of 4 types of Specialised Social Services

Present how EJA WP6 is addressing these particular issues

Reinforce the need for Services and Policies



**Encourage action at national levels in order to make Specialised Social Services a reality for PLWRD**

*«When you have a rare disease it feels like you are so alone and no one cares»*

Janet, mid 50's, living with Alkaptonuria, USA





«Services provided seem to differ from area to area. It is not possible to get a 'check list' of all the people you need to talk with.»

Denis Ryan, husband of Anne, living with Huntington Disease, Ireland

click picture to access the map



**105 100 views!!!**

Give Visibility to Services



Improve patients' access to services

Promote the need for services

**84 Services**

**22 Countries**

Information on activities,  
target population and  
contacts for all services

Clarify definitions, highlight advocacy actions, reinforce need for services



Improve patients' access to services

Definition of Services  
Why are they needed?  
Why are they important?

How to address the issue? role of National Plans and EUCERD Joint-Action Related Issues / References and additional information



Actions performed by Resource Centres (RC) are generally specifically targeted to people living with rare diseases (PLWRD). These centres often function in partnership or cooperation with Centres of Expertise or constitute part of a Centre of Expertise themselves.

Resource Centres provide information and guidance services, training courses, provision of information concerning social benefits, and accommodation and research services. Only support frameworks, medical/psychological consultations and therapeutic, recreational activities are often also provided by these centres. Resource Centres could be defined as a 'one-stop shop style' service for rare disorders.



Adapted Housing Services (AHS) represent a particular type of service, often associated with multiple disabilities. Sometimes called 'therapeutic apartments', these services allow people living with rare diseases (PLWRD) to develop and enjoy some level of autonomy by living within the comfort of their own home, alone or with peers, assisted by supportive staff, rather than being placed in an institution.

Adapted Housing Services might also refer to a specific local/regional grant awarded to the patient and/or family in order to pay for any house adaptation work, to prevent families from having to move into other facilities, or with the purpose of adjusting regular buildings to certain specific needs (wheelchair, small size, hearing disabilities, autistic spectrum disorders, etc.).

**WHY ARE ADAPTED HOUSING SERVICES NEEDED?**  
Several studies and documents have recognised the need for Specialised Social Services (which include AHS), both at European and National levels.

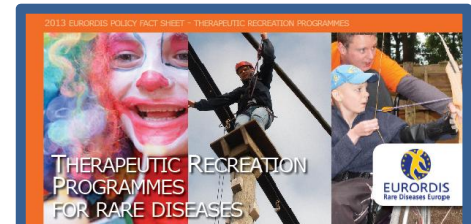
The European Commission's Communication on Rare Diseases, 'Europe's Challenges', specifically mentions Specialised Social Services in its article addressing the 'Access to Specialised Social Services and their importance for PLWRD'. The Communication further states that these services 'need to be sustainable to permit their gradual awareness-raising, exchange of best practices and standards, leading responses using Health Programme and Disability Action Plans'.

The European Project for Rare Diseases 'Holistic Plans Development' (EUROPLAN) guidance document, developed by partners and experts, mentions that 'Specialised Social Services (including AHS) are instrumental to the empowerment of PLWRD and improve well-being and health. For people living with a rare, chronic and debilitating disease, care should not be restricted to medical and paramedical aspects, but should also take into account social and psychological or educational developments'.

The final report of EUROPLAN, based on 15 National Communications prepared in 2012/2011, states that 'Specialised Social Services are a support for people living with a chronically debilitating rare disease' and 'their family carers and structures need to be devised to recognise and integrate PLWRD into existing social services (rehabilitation, integration into school and workplaces, recreation and respite services), while recognising their specificities and providing quality services in response to their needs' (p.57).

**WHY ARE ADAPTED HOUSING SERVICES IMPORTANT?**  
Adapted Housing Services make it possible for PLWRD to live as independently as possible, while being monitored by supportive staff (notified to provide assistance for any daily routine activities that cannot be performed independently).

People living with rare diseases can thus enjoy a high level of independence and autonomy, while being integrated with a serenity of their social environment, their safety and their physical and therapeutic needs.



Therapeutic Recreation Programmes (TRP) are any organised recreation activity (summer camp, ad hoc trip) which gives people living with rare diseases (PLWRD) the possibility to take a break from their daily routine.

TRP can also be provided in a person's own home.

TRP are three types of activities:

- Therapeutic Recreation Programmes (TRP)
- Therapeutic Recreation Programmes (TRP)
- Therapeutic Recreation Programmes (TRP)



Respite care is provided, on a short term basis, for people living with rare diseases (PLWRD), so that their carers can have a short relief from care giving. Respite Care Services (RCS) can be offered in various ways:

- Residential: the person living with the RD attends an adapted centre to be looked after by a 'respite care family';
- Domestic care: some services provide a caregiver who comes to the family home, and takes over care giving duties so that the regular carer can have rest from the daily routine of care giving;
- Day care: day care centres, nursing homes, institutions or respite group homes with assisted living facilities (no overnight facilities);
- Emergency: services that give access to respite on a short notice in the event of an unexpected emergency.

**WHY ARE RESPITE CARE SERVICES NEEDED?**  
Several studies and documents have recognised the need for RCS, both at European and National levels.

The European Commission's Communication on Rare Diseases, 'Europe's Challenges' specifically mentions respite care services in its article addressing the 'Access to Specialised Social Services and their importance for PLWRD'. The Communication further states that RCS 'need to be sustainable to permit their gradual awareness-raising, exchange of best practices and standards, pooling resources using Health Programme and Disability Action Plans'.

The EUROPLAN guidance document for the National Plans, developed by partners and experts, mentions that 'Specialised Social Services (including RCS) are instrumental to the empowerment of PLWRD and improve well-being and health. 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 or educational developments'.

The final report of EUROPLAN, based on the 15 National Communications (2012-2011), clearly states that 'Specialised Social Services are a support for people living with a chronically debilitating rare disease and their family carers' and mechanisms need to be devised to recognise and integrate PLWRD into existing social services (rehabilitation, integration into school and workplaces, recreation and respite services), while recognising their specificities and providing quality services in response to their needs' (p.57).

**WHY ARE RESPITE CARE SERVICES IMPORTANT?**  
Respite care enables the caregivers to maintain the ability to continue care giving. The benefits to carers described in the literature fall into these two broad categories: stress reduction and self-esteem increase; improved family functioning (Merriman and Casneau, 2007).

A second purpose of RCS is to make it possible for PLWRD to live according to their usual daily routine and to provide a place to experience and perform recreational and meaningful activities away from their paramedical caregivers. Benefits to service users mentioned in literature are socialisation, and enjoyment of experiences outside the home (Merriman and Casneau, 2007).

click on each picture to access respective fact sheet

«They need to spend some days in an environment where they can stop thinking about their disease, where they can meet, socialise»

*Elaine, mother of Ella (3), living with Acute Lymphoblastic Leukaemia, attending Therapeutic Recreation Programme, Ireland*

## Agrenska

Respite Care Service –  
Sweden

Rare Diseases



## Frambu

Resource Centre –  
Norway

Rare Diseases



## Bátor Tábor

Therapeutic Recreation  
Programme – Hungary

Serious Illnesses



## Group Homes

Adapted Housing -  
Denmark

Prader-Willi Syndrome



Highlight good practices



Improve quality of services

Improve access to services

## CREER

Resource Centre – Spain

Rare Diseases



## Hendaye Hospital

Respite Care Service & Re-  
education Unit

Neurologic Diseases, Severe  
Disabilities  
Prader-Willi Syndrome



click on each picture to access services' websites

Integration of RDs into Social Services and Policies in Europe, Norway, October 2014

Establishing important partnerships



Receive and share valuable information  
Make the message stronger



orphanet



Orphanet: indexing the functional consequences of rare diseases with the Orphanet Disability Thesaurus, based on the International Classification of Functioning, Disability and Health of WHO and production of fact sheets on diseases and their consequences on daily life ([example here](#))

BURQOL RD : quantify the socio-economic costs and Health Related Quality of Life (HRQOL) , of both patients and caregivers, for up to 10 rare diseases in different European countries – [Preliminary results](#) have just been released!

French NA Group Social-Medical Services: share experiences and find solutions together with French NA, patient groups, Orphanet and invited authorities

Contacts with [International Federation of Social Workers](#) to look into the possibility of expressing common positions and needs



# WORKSHOP: GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES

Collect Consensual Good Practices



Improve quality of services

**Where:** Zalau, Romania, December 2012  
At NoRo Resource Centre for Rare Diseases

**Who:** 28 participants from 16 countries  
EUCERD, services, National Alliances, EUROPLAN advisors,  
academia => multi stakeholder group

**What:** reach consensus on a set of essential Guiding  
Principles for Specialised Social Services

**How:** Presentations of EUCERD and EJA WP6  
Presentations of role model Services: 1 of each kind (TRP, RCS, AH, RC)

**Group discussions on draft of Guiding Principles for Specialised Social Services**  
**Conclusions and consensus in plenary session**

[Click here to read the workshop report](#)



# WORKSHOP: GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES

[EUCERD Joint Action, by Victoria Hedley, Newcastle University \(EJA's leading Partner\)](#)

[EUCERD Joint Action WP on Specialised Social Services and Integration of RDs into Social Policies, by Raquel Castro, Social Policies Manager, EURORDIS](#)

[Funding Opportunities for Specialised Social Services: Structural Funds for Health, by Jaroslaw Waliqora, EU Health and Consumers General-Directorate](#)

[Respite Care Service – Ågrenska \(Sweden\), by Gunilla Jaeger](#)

[Therapeutic Recreation Programme – Federation of European Williams Syndrome \(Europe\), by Gábor Pogány](#)

[Resource Centre – Frambu \(Norway\), by Lisen Mohr](#)



[Adapted Housing - Danish PWS Association, by Susanne Blichfeldt](#)

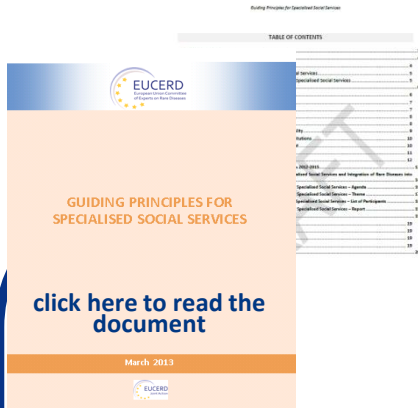
[NoRo Centre for RD – Prader Willi Association \(Romania\), by Dorica Dan](#)

[Therapeutic Recreation in Camp Programming – SeriousFun Children's Network \(Europe\), by Terry Dignan](#)

click on each title to access the corresponding presentation



# DOCUMENT: GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES



## **Mission:**

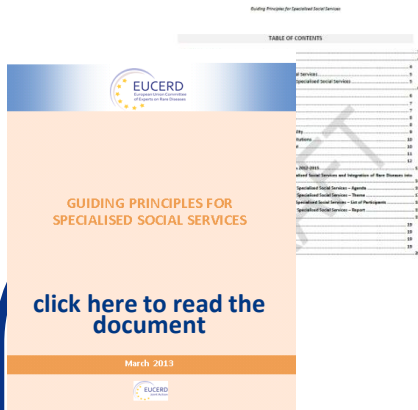
To collect consensual essential guiding principles for the implementation and management of Specialised Social Services integrating patients with Rare Diseases in order to increase quality and sustainability of services

## **Distribution:**

EURORDIS Membership Meeting 2013 Dubrovnik  
European Committee of Experts on RD (June 2013 meeting)  
EURORDIS Website  
EURORDIS eNews  
EUCERD Website



# DOCUMENT: GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES



- 1) Rights and Personal Identity
- 2) Person/Family Centeredness
- 3) Holistic, Comprehensive, Integrated Approach
- 4) Governance Structure
- 5) Organisation and Administration
- 6) Evaluation and Permanent Improvement of Quality
- 7) Connection to Centres of Expertise/Medical Institutions
- 8) Admission Procedures and Individual Assessment
- 9) Training of Staff and Volunteers
- 10) Rare Diseases and Health Care Needs





# BEYOND THE DOCUMENT: MAKING GUIDING PRINCIPLES A REALITY

How to Make Guiding Principles for Specialised Social Services a Reality



Encouragement to take action

Coordination of efforts between PLWRD/families, patient representatives, national authorities, EU and services' funders

**Patients** may use the document to fight for their right to access quality services

**National Alliances** may use the document to advocate for improvement of quality of specialised social services

**Services' providers** may use the document to improve their services or to advocate for the necessary tools/means to apply certain principles in their services

**National Authorities** may use the document to develop a recognition and evaluation system for Specialised Social Services in the country

**Funders** may use the document to evaluate services and take decisions on the allocation of their funds



# WORKSHOP: TRAINING SOCIAL SERVICES PROVIDERS

Improve the training of professionals and the quality of services provided

Facilitation of the integration of RD into 'mainstream' services, generating a bigger optimisation of resources

**Where:** Copenhagen, Denmark, 10-11 October 2013  
At the House of Disabled People's Organisations

**Who:** 26 participants from 13 different countries:  
EUCERD, services, National Alliances, EUROPLAN advisors  
=» multi stakeholder group

**What:** reach consensus on a set of essential Guiding Principles for Training of Social Services Providers

**How:** Presentations of project status  
Presentations of Role model training programmes

**Group discussions on draft document 'Training for Social Services Providers'**  
**Conclusions and consensus in plenary session**



[Click here to read the workshop report](#)



# WORKSHOP: TRAINING SOCIAL SERVICES PROVIDERS - PRESENTATIONS

[EUCERD Joint Action, by Victoria Hedley, Newcastle University](#)

[Specialised Social Services and Integration of RDs into Social Policies: State of the Art, by Raquel Castro, Social Policies Manager, EURORDIS](#)

[Introduction to the Workshop: context, theme, purpose, methodology and expected outcomes by Dorica Dan, Project Leader, EURORDIS](#)

[Introduction to the Document: purpose, contents, annexed case studies, expected outcomes by Raquel Castro, Social Policies Manager, EURORDIS](#)

[Training for professionals working with RD patients by Lisen Mohr, Frambu \(Norway\)](#)

[Edubolirare: training for professionals in RD field by Dorica Dan, Romanian Alliance for Rare Diseases \(Romania\)](#)

[Ågrenska: a holistic approach by Anders Olauson, Ågrenska \(Sweden\)](#)

[Training process for Case Managers at AFMTELETHON by Jean Pierre Lamorte, AFM \(France\)](#)



[“Curricula Prader-Willi-Syndrome”, Adapted Housing Service for Prader-Willi Syndrome by Nobrert Hödebeck-Stuntebeck, Diakonische Stiftung Wittekindshof \(Germany\)](#)

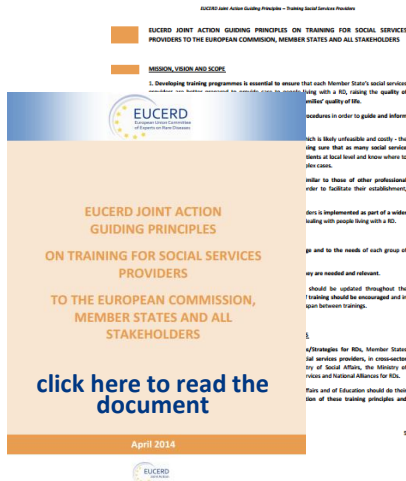
[Orphanet’s role in supporting people with Rare Diseases: New tools about disabilities by Odile Kremp, Orphanet \(France\)](#)

[Social Profiles as a dialogue/training tool for social workers by Lene Jensen, Rare Disorders Denmark \(Denmark\)](#)

click on each title to access the corresponding presentation



# DOCUMENT: GUIDING PRINCIPLES TRAINING SOCIAL SERVICES PROVIDERS - POLICY



## Mission:

To collect consensual essential guiding principles for the implementation of training programmes for social services providers, encouraging different stakeholders to initiate and/or improve the training of professionals

## Distribution:

EURORDIS Membership Meeting 2014 Berlin  
ECDR 2014 Berlin  
Commission Expert Group on RD (July 2014 meeting)  
EURORDIS Website  
EURORDIS eNews  
EUCERD Website



# DOCUMENT: GUIDING PRINCIPLES TRAINING SOCIAL SERVICES PROVIDERS - POLICY



- MISSION, VISION AND SCOPE
- TRAININGS AND THE NATIONAL PLANS/STRATEGIES FOR RDS
  - FUNDING, EVALUATION AND ACCREDITATION
- COLLABORATIVE CROSS-SECTOR MULTI STAKEHOLDER HOLISTIC APPROACH
- CONTENT AND ORGANISATION



How to make  
Training for Social Services Providers  
a Reality



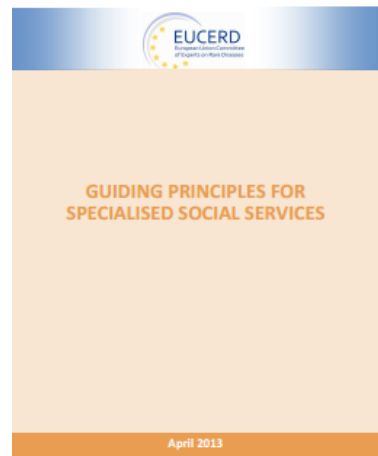
Various stakeholders need to take action

**Coordination** of efforts between multi sector national authorities, service providers, patient organisations, etc. is needed

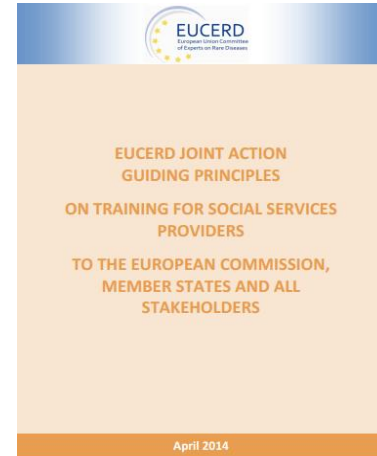
**Strategy and Funding** for training of staff dealing with RD patients need to be implemented

**Contents need to be refined: a complementary document** will be prepared with the examples of training programmes currently developed, including programmes developed by Edubolirare (Romania) and Frambu (Norway)

# EUCERD JOINT ACTION GUIDING PRINCIPLES ON SOCIAL ISSUES



+



||

- Integration of RD patients into existing services
  - Increase of quality of services provided
- More professionals fully prepared to handle RDs



Streamlining of resources  
Higher quality of care  
Empowered patients and families



Reporting on advocacy actions, sharing good practices



Incentive patient groups to advocate for more services, with more quality

2 workshops dedicated to:

Report on progresses made so far

Sharing of documents: concept paper, fact sheets, guiding principles document  
Presentation of role model services run by public institutions, private foundations and patient groups

Services represented include all types (TRP, RCS, AH, RC) from 7 different countries

Over 90 participants; Participants in EMM made a positive evaluation of these workshops!



[click here to access Presentations](#)





Rare Diseases Europe @eurordis · May 9

Social challenges of people living with #rarediseases now being discussed at #ECRDBerlin



**6 sessions**

**over 26 chairs, speakers and panellists**

- **Advocacy**
- **Policy**
- **Sharing of good practices**
- **Patient stories**
- **Innovation**
- **Vision for the future in connection to Centres of Expertise**

**Poster on EJA WP6 - Won Poster Award!**

**- Posters from different Specialised Social Services were submitted and accepted**

# WHAT NEXT? WITHIN THE JOINT-ACTION

WORK

February 2014

August 2015



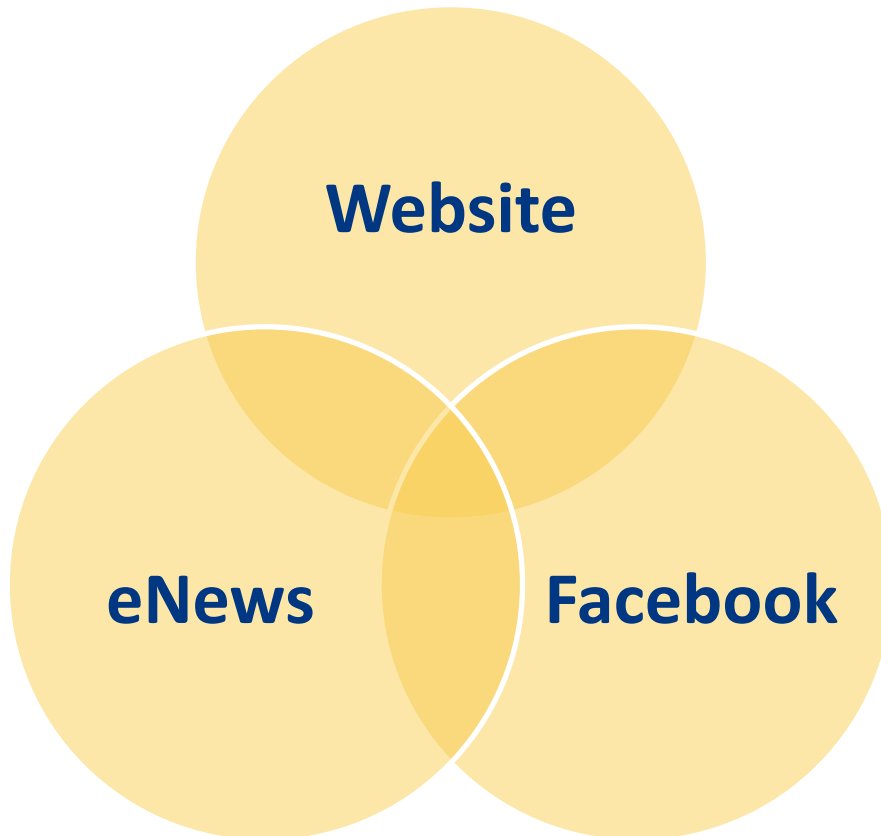
# COMMUNICATION ACTIONS

Raising awareness and Reaching out to more publics

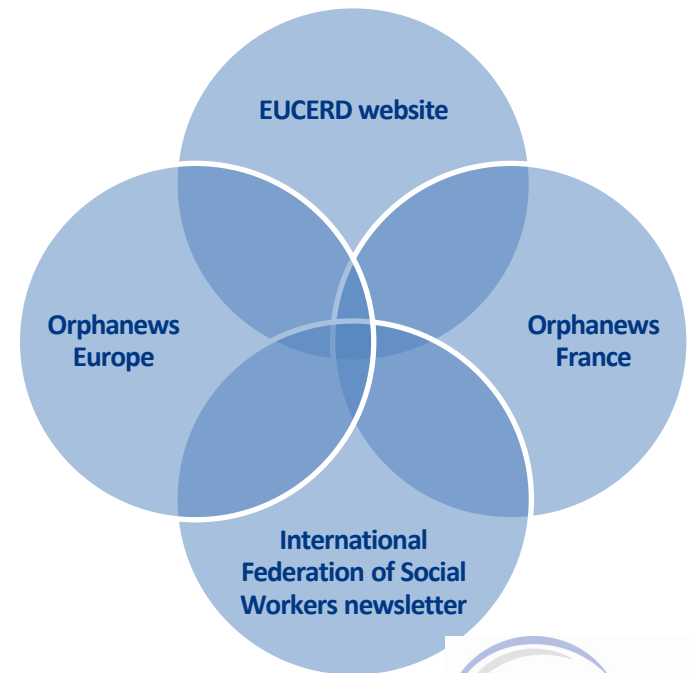
Creating a European movement around Specialised Social Services and Social Policies for PLWRD



## EURORDIS Online Communication Tools



## Partners Online Communication Tools



# WEBSITE SECTION: SPECIALISED SOCIAL SERVICES

**EURORDIS**  
Rare Diseases Europe

The Voice of Rare Disease Patients in Europe

About EURORDIS | About Rare Diseases | Rare Disease Policy | Orphan Drugs & Treatments

Home > Services to Patients

### Specialised Social Services

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

Overview | Therapeutic Recreation | Respite Care | Adapted Housing | Resource Centres

Therapeutic Recreation | Respite Care Services | Adapted Housing | Resource Centres

Map | Sat | Ter | Earth

What are Specialised Social Services?

Related documents

- Guiding Principles for Specialised Social Services - EUCERD Joint-Action Document
- Guiding Principles for Specialised Social Services - Workshop Report

Contact us

This information is provided by Raquel Castro, Social Policy and Specialised Social Services Manager, EURORDIS.

Social Networks

FACEBOOK

EURORDIS - European Rare Diseases Organisation

You and 4,474 others like EURORDIS - European Rare Diseases Organisation.

click picture to access the website section

Giving visibility to the European movement around Specialised Social Services and Social Policies for PLWRD

Map

List of services with info on each service Sections for TRP, RCS, AHS RC

Fact Sheets

Case Studies

Good Practices documents

Reports from Workshops

Presentations from all Workshops

Testimonials from patients, families, volunteers, professionals



# WEBSITE SECTION: SPECIALISED SOCIAL SERVICES

## SERVICES

Sharing data on role model services



Giving visibility Specialised Social Services and good practices in the field

All presentations from workshops and meetings available by type of service. Presentations have common set of data and information, with a collection of facts on the service budget, governance structure, costs, target population, history, etc.



### Fact Sheet and Case Studies



Consult our Fact Sheet and Case Studies to learn more about Resource Centres and well established RC across Europe.

Actions performed by Resource Centres (RC) are generally specifically targeted to people living with rare diseases. These centres often function in partnership or cooperation with Centres of Expertise or constitute part of a Centre of Expertise themselves.

[Download the Fact Sheet.](#)



### Case Study Presentations

2013

[Casa dos Marcos Resource Centre, Portugal](#)

Paula Brito e Costa, Rarissimas, Portugal

*EURORDIS Membership Meeting 2013 Dubrovnik, Workshop 10: Social & medical services initiated by patient organisations*



[Frambu Resource Centre, Norway](#)

Lisen Mohr, Frambu, Norway

*EURORDIS Membership Meeting 2013 Dubrovnik, Workshop 6: Specialised Social Services: need, policy, case studies*



[NoRo Resource Centre, Romania](#)

Dorica Dan, RONARD, EUCERD & EURORDIS, Romania

*EURORDIS Membership Meeting 2013 Dubrovnik, Workshop 10: Social & medical services initiated by patient organisations*



2012

[Frambu Resource Centre, Norway](#)

Lisen Mohr, Frambu, Norway

*EUCERD Joint-Action Workshop on "Guiding Principles for Specialised Social Services", 2012, Romania*



[NoRo Resource Centre, Romania](#)

Dorica Dan, RONARD, EUCERD & EURORDIS, Romania

*EUCERD Joint-Action Workshop on "Guiding Principles for Specialised Social Services", 2012, Romania*



[click picture to access the website section](#)

Reaching out to our members and followers

Strengthening the European  
movement by having a 2-way channel

**Sharing information on:**

Map

Services

Documents

Events

New developments/studies

Testimonials

**Calling for action on:**

Mapping exercise

Contribution to documents

on good practices



**Receiving feedback and  
contributions**

**PATIENTS, ORGANISATIONS, SERVICES**

Read about living with a rare disease and the services available

Over 50 social services for patients and families have been identified in 18 countries so far!



## Reaching out beyond our members and followers



Strengthening the global movement

**EURORDIS - European Rare Diseases Organisation**  
1/4

Over 50 social services for patients and families have been identified in 18 countries so far! <http://www.eurordis.org/specialised-social-services>  
If you know a service that could be on this map, contact us at [raquel.castro@eurordis.org](mailto:raquel.castro@eurordis.org)

Therapeutic Recreation   Respite Care Services   Adapted Housing   Resource Centre

Gosto · Comentar · Partilhar   64 2 63

11.017 pessoas viram esta publicação   Impulsionar promoção

click pictures to access Facebook posts

**EURORDIS - European Rare Diseases Organisation**  
29/4

Barrestown 2013 Therapeutic Recreation Programmes have just started! Sessions for campers and families run until autumn <http://www.eurordis.org/content/therapeutic-recreation-list#barrestown>

Gosto · Comentar · Partilhar   47 20

1.969 pessoas viram esta publicação   Impulsionar promoção

Communicating to general public sharing information on:

- Map
- Services
- Documents
- Events
- New developments/studies
- Testimonials

Reaching out to the RD community



Strengthening the advocacy movement



RD > EUCERD Joint Action > Specialised social services

## Specialised social services

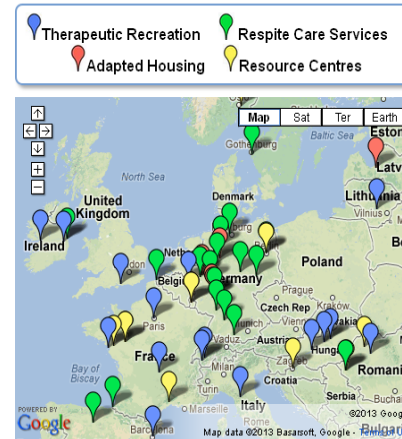
The EUCERD has chosen to examine the area of specialised social services for rare diseases (RD), as concerns both the provision of specialised rehabilitation services for RD as well as the integration of RD into mainstream social policies and services.

This work will include:

- Identifying and mapping of existing specialised social services such as therapeutic recreational programmes, respite care services and other rehabilitation services (e.g. adapted housing) and the identification of good practices;
- Facilitating access to information on specialised social services for RD patients and their families;
- Defining guiding principles for Member States and stakeholders on why and how to develop training sessions for social services providers;
- Promoting the integration of RD into social policies and services by identifying existing social guidelines and defining guiding principles for social care in the field of RD.

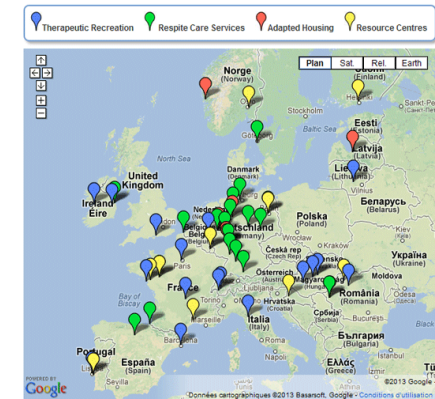


Specialised social services in Europe for rare disease patients



Eurodis now has a section of their website dedicated to Specialised Social Services for rare diseases patients that will be of great help to improve their health and quality of life as well as empowering them. As part of the Eucerd Joint Action (2012-2015), Eurodis is committed to helping rare disease patients to obtain access to "Specialised Social Services and Integration of Rare Diseases into Social Policies and Services". For this purpose, Eurodis is performing a mapping exercise of the places that provide Specialised Social Services for rare disease patients in Europe as well as raising awareness about the significance and increasing need for such services. This is presented as a google map (see above) of the specialised services currently mapped by Eurodis which include: Therapeutic Recreation Programmes (TRP), Respite Care Services (RCS), Adapted Housing (AH), Resource Centres (RC). Apart from mapping these services Eurodis will also be involved in "addressing the issues concerning the training of the staff/volunteers working at these services" ([Link to the EURODIS Paper on "Rare Diseases: addressing the need for SSS and integration into social policies](#)). This is a continuous exercise and you can also contribute to helping rare disease patients by providing suggestions of services available. ([Email here](#)).

Eurodis lance un recensement des services sociaux spécialisés pour les patients atteints de maladies rares en Europe



Eurodis développe sur son site une section consacrée aux services sociaux spécialisés pour les patients atteints de maladies rares, pour les aider à améliorer leur santé et leur qualité de vie et à renforcer leur autonomie. Dans le cadre de l'action conjointe EUCERD (2012-2015), Eurodis s'est engagé à aider les patients atteints de maladies rares à avoir accès à des « services sociaux spécialisés et à l'intégration des maladies rares dans les politiques et les services sociaux ». À cet effet, Eurodis a lancé un recensement systématique des services sociaux spécialisés pour les patients atteints de maladies rares en Europe, dans l'idée aussi de sensibiliser à l'importance et à la nécessité croissante de ces services. L'information est présentée sur une carte Google (voir ci-dessus), avec la localisation et les coordonnées des services sociaux actuellement répertoriés : programmes de loisirs thérapeutiques (TRP), services de soins de répit (RCS), logements adaptés (AH), centres de ressources (RC). Eurodis se penche aussi sur les questions relatives à la formation du personnel et des aidants qui travaillent dans ces services ([voir ici](#)). En France, le plan national maladies rares 2011-2014 a dans ses objectifs l'amélioration de la prise en charge sociale. La Caisse nationale de solidarité pour l'autonomie est partenaire de cette action d'Eurodis. Ce recensement est un exercice continu auquel vous pouvez contribuer en proposant les coordonnées de services existants ([contact](#)). [Plus d'informations](#)

Working with partners towards sharing our tools and information:

EUCERD Website

Orphanews Europe & Orphanews France

International Federation of Social Workers

Reaching EU, national authorities, patient advocates, health and social sector professionals...

click on each picture to access respective article

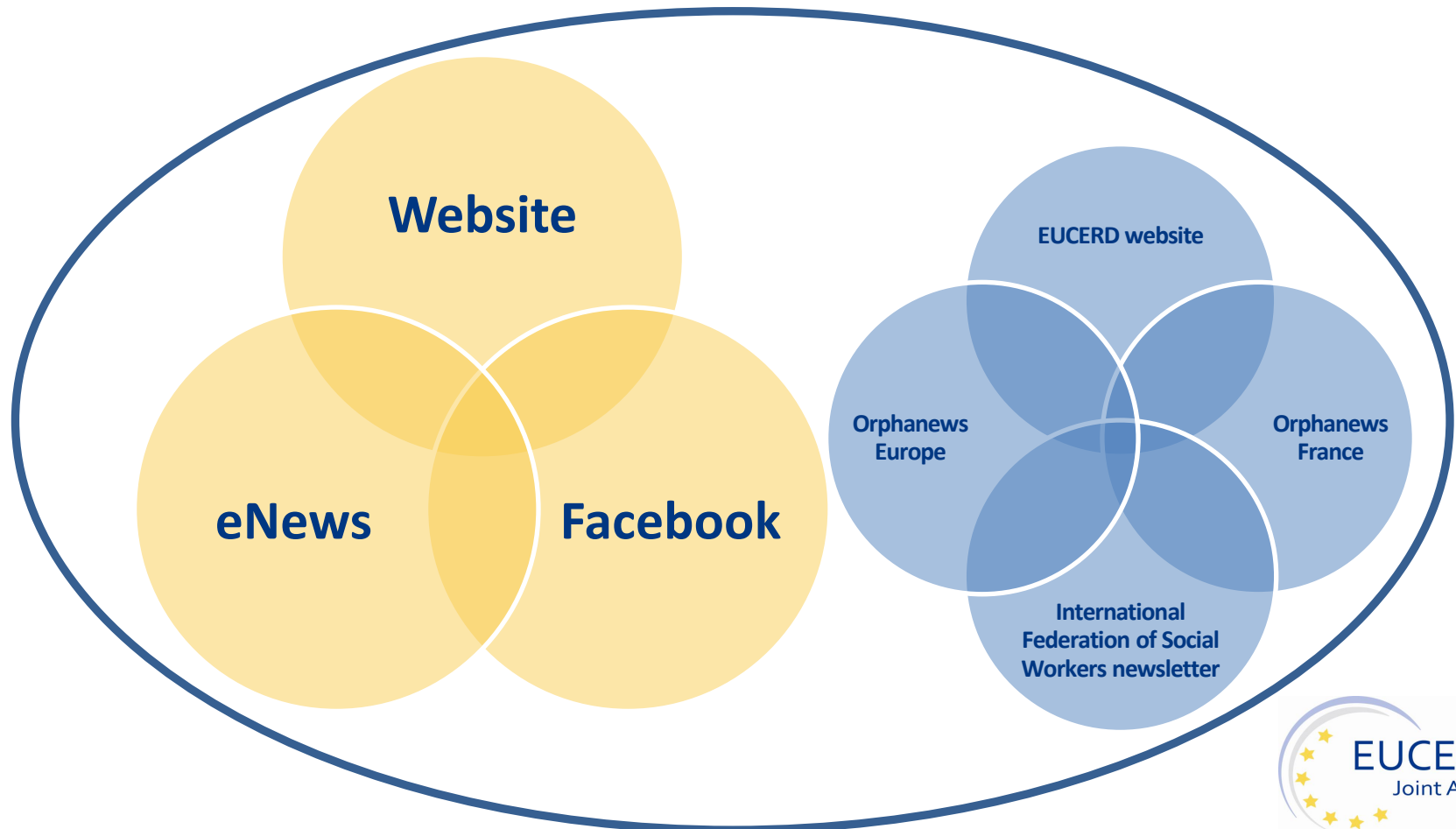




March 2013

October 2014

**OVER 252.000 PEOPLE REACHED!**



*«My son is at camp as I speak. It took two staff and I to carry just his meds and feeds. But while he's there he's going to be like any other boy»*

*«I go to bed exhausted and I don't get a lot of help. I loved my work and I miss it a lot! At this moment, it is impossible for me to find a job»*

*«When your child is diagnosed with a serious illness your whole life revolves around hospitals. Everything else in life is put on the back burner»*

*«We were relieved to know that professionals were taking care of him in a place adapted to his needs. If we leave him with family, they don't always know what to do.»*





Norway, October 2014  
[raquel.castro@eurordis.org](mailto:raquel.castro@eurordis.org)

ALL PHOTOS USED IN THIS PRESENTATION WERE TAKEN AT SPECIALISED SOCIAL SERVICES

ALL QUOTES USED IN THIS PRESENTATION ARE REAL STORIES