

# Specialised Social Services And Integration of RD into Social Policies

## EUCERD Joint Action 2012-2015

3 tasks:

- 1) Identification and Mapping of Specialised social Services
- 2) Training of Social Services Providers
- 3) Integration of Rare Diseases into Social Policies and Services

Guiding Principles for Social Care in RD/Draft of EUCERD recommendations in the social field



### Specialised Social Services

Specialised Care Services which provide short term based care so that the carers can have a break from care giving.

**Therapeutic:** Recreation services which consist of any organised recreation activity (leisure time) and help (trip) giving patients the possibility to take a break from thinking about diagnosis and treatment and focused on fun and leisure.

Offer rehabilitation services (physical therapy) which aim to help keep the patients at home enjoying a higher level of autonomy, instead of being placed in an institution.

Residence Centres providing training, courses, information and guiding, information about social services, documentation and research, daily support (therapeutic, medical and psychological) consultation.

Complex Care Managers that can ensure better coordination in the care pathway of PLMRD, particularly in situations most complex due to the course of care and the need for the intervention of multiple structured and professionals.

### Paper with EUCERD

#### EJA WP6

Advocacy tool for the development and/or sustainability of existing services and policies.

- by showing best practice models have been identified by studies done by different organisations
- by clarifying the concept of these services
- by reminding everyone that actions at local, national or EU level
- Tool to advocate for the inclusion of social domain into National Plans

### Mapping Exercise

NA, EP, authorities, other patient groups participating in the mapping survey

- Contact with all services to check data and contacts
- Contributions are still welcome!
- Add in the service

### Making Services Visible

- Displaying contacts and information at EURORDIS website
- Showing services via social networks

### Country Visits - Case Studies

- Live visit to services that can serve as a role model
- Collection of the same categories of information on all services: activities, structures, governance, funding
- Dissemination of information as case study documents to be available online and distributed via e-news and social networks
- Inspiration tool for the creation of new services and for the improvement of existing ones: guidelines, funding, etc.

### Website Section

EURORDIS has often been cited as the first step to design the social field research.

EURORDIS can also take only go as far as to design the social field research.

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Guiding Principles for Social Care in  
RD/Draft of EUCERD recommendations in  
the social field



**What are we  
talking about  
when we say  
Specialised  
Social Services?**





# Specialised Social Services

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

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

Other Rehabilitation Services/Adapted Housing which aim to help keep the patients at home, enjoying a higher level of autonomy, instead of being placed in an institution

Resource Centres providing training courses, information and guiding, information about social services, documentation and research, daily support therapies, medical and psychological consultations

·Complex Case Managers that can ensure better coordination in the care pathway of PLWRD, particularly in situations most complex due to the course of care and the need for the intervention of multiple structures and professionals

## EJA - WP6 Timeline

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

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42
2012										2013												2014						2015													
Mar	Apr	May	Jun	July	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	July	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	July	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	July	Aug
<b>Task 1: Identification and Mapping of Specialised Social Services</b>																																				Extension Period					
<b>Task 2: Training of Social Services Providers</b>																																									
<b>Task 3: Integration of Rare diseases into Social Policies and Services</b>																																									
Meeting with CNSA 29-03-2012	Preparation of ECRD Conf. Call with NA & EF	Deadline for Data for Paper EJA WP6	Presentation All Staff	Presentation Help Lines	Agrenska Visit	ERTC Networking	Frambu Visit	Presentation CNA CEF	Workshop 1 M1 - Report on WS 1	Paper EJA WP6 Dissemination to EUCERD	Distribution of Report to EUCERD POSITION PAPER Social Challenges	Membership Meeting Croatia Workshop Country Visit	State of the Art Report Interim Report	Country Visit	Workshop 2 M3 - Report on WS 2	M4 - Validation of WS Report by EUCERD Distribution of Report to EUCERD	Country Visit	State of the Art Report	M5 Identification of existing SSS and good practices on training for SS and of existing social guidelines	Country Visit	Workshop 3 M7 - Report on WS 3	M8 - Validation of WS Report by EUCERD D - Report on EUCERD guiding principles for Social Care in RD/Draft of EUCERD recommendations in the social field	Dist. Report to EUCERD	Final Report																	

Activities			
3 Workshops:	6 Country Visits:	Other Missions/Presentations:	Other Activities:
6-7 December 2012 - Zalau November 2013 November 2014	31st August 2012 - Agrenska 15-18 October 2012 - Frambu July 2013 September 2013 July 2014 September 2014	Presentation at ECRD 05/2012 Presentation for ENRDHL 06/2012 Presentation Staff EURORDIS 06/2012 Networking at ERCT 09/12 Presentation CNA CEF 10/2012 Membership Meeting 2013 - Worksho Country Visits withing France - CNSA	Updating Contacts (ongoing) Updating Online Info (ongoing) Live/Phone Meetings with NA FR, BE, IT, DK Development of Survey and Distribution Interview Guide/Study Case Model Data Collection - Country Visits PAPER EJA WP6 - Literature Review EURORDIS Position Paper Development of Reports Update Factsheets   Develop Case Studies





# Paper within EUCERT EJA Wp6

- Advocacy tool for new services and/or sustainability of existing services and policies:
- By showing how these needs have been identified by studies done by different organisations
- By clarifying the concepts of these services
- By reminding everyone that action is being taken at EU level
- Tool to advocate for the inclusion of social issues into national plans

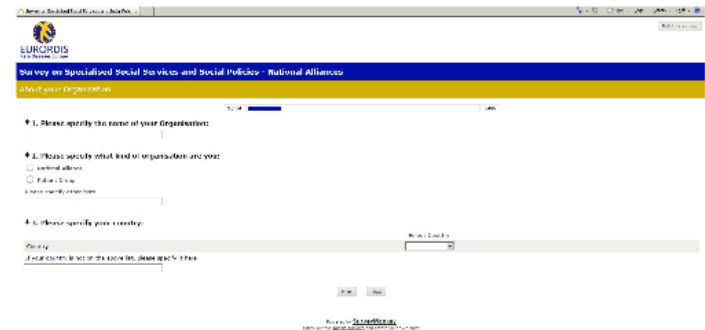
# Mapping Exercise

- NA, EF, authorities, other patient groups participating in the mapping Survey

- Contact with all Services to check data and contacts

Contributions are still welcome!

Help us map services!



The screenshot shows a web browser window displaying a survey form. The browser's address bar shows the URL 'http://www.eurodis.eu'. The page header includes the 'EURODIS' logo and the text 'Survey on Specialised Social Services and Social Inclusion - National Alliance'. Below the header, there is a yellow bar with the text 'About your Organisation'. The main content area contains three numbered questions:

1. Please specify the name of your organisation:
2. Please specify what kind of organisation are you:  
 National Alliance  
 Public Law  
 Non-Profit/charities
3. Please specify your country:  
Country:

At the bottom of the form, there are 'Next' and 'Back' buttons, and a footer with the text 'EURODIS' and 'www.eurodis.eu'.

# Making Services Visible

# Bringing it to public!

- Displaying contacts and information at EURORDIS website

- Showing Services via social networks







## EURORDIS - European Rare Diseases Organisation

Gostei · 12/10

Today EURORDIS is visiting a Norwegian Resource Centre for Rare Diseases catering for approximately 100 different rare disorders. Frambu is a place for families and professionals to meet and receive essential support: <http://www.frambu.no/index.asp?lang=en>

Identificar ... Adicionar l... Editar

Gosto · Comentar · Partilhar · Editar

41 pessoas gostam disto.

33 partilhas



Escreve um comentário...





Fotos da cronol... 5 de 9 Identificar foto Opções | Partilhar Gosto



## EURORDIS - European Rare Diseases Organisation

Gostei · 29/8

EURORDIS is visiting Ågrenska today, a Specialised Social Service providing Respite Care to patients and families affected by rare diseases. Find out all about this service: <http://www.agrenska.se/en/>

Identificar ... Adicionar l... Editar

Gosto · Comentar · Partilhar · Editar

44 pessoas gostam disto.

2 partilhas



**David García Borràs** Me parece una gran iniciativa, además de muy interesante.

31/8 às 9:34 · Gosto



**EURORDIS - European Rare Diseases Organisation** Estimado David García Borràs, gracias por su comentario. Eurordis tendrá más información disponible sobre este y otros servicios sociales para los pacientes de enfermedades raras pronto! Este atento a nuestra página!

3/9 às 17:18 · Gosto



Escreve um comentário...



Therapeutic Recreation  
Housing



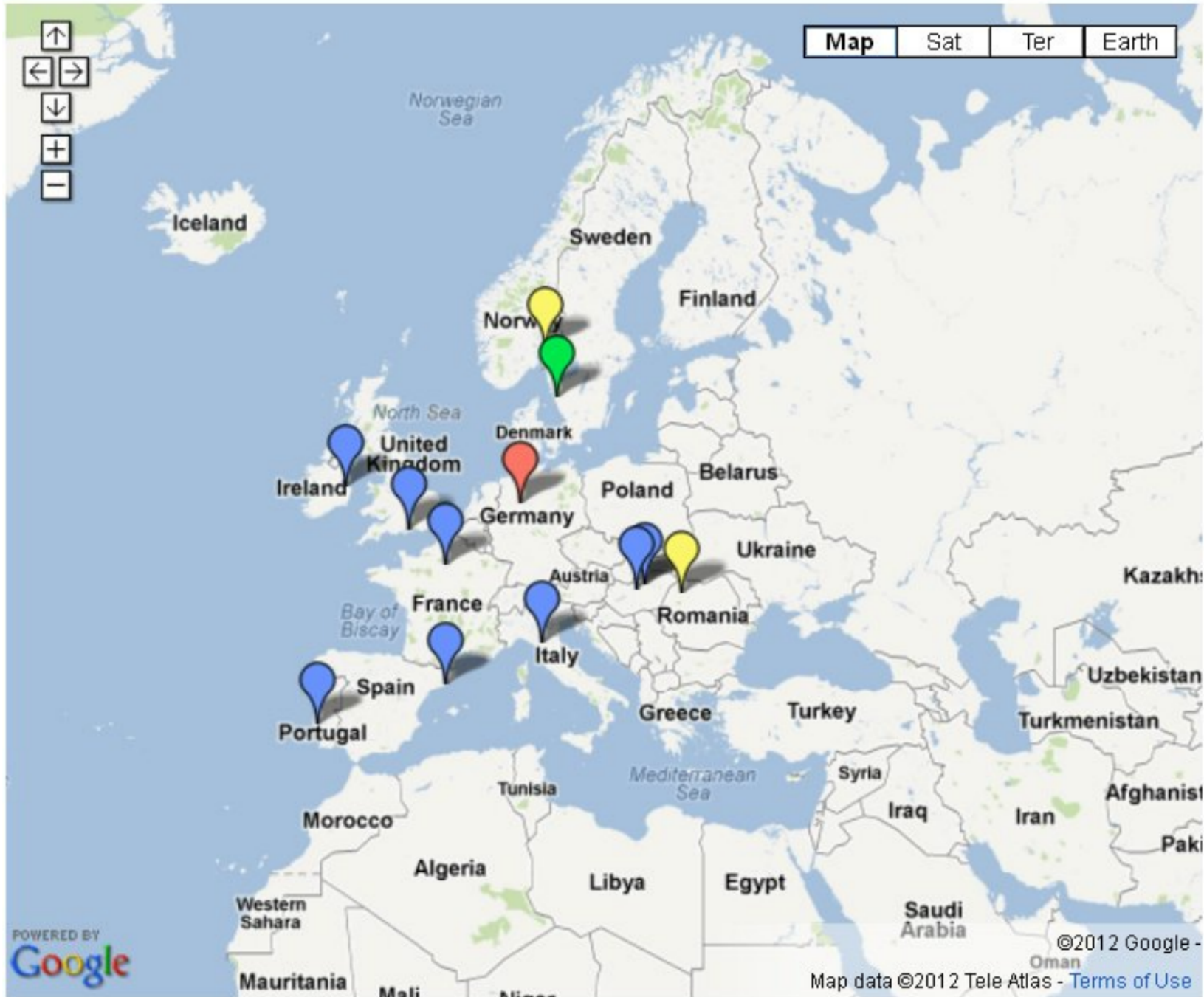
Resource Centres



Respite Care Services



Adapted





# Country Visits - Case Studies

- Live visit to services that can serve as a role model
- Collection of the same categories of information on all services: activities, structure, governance, funding
- Dissemination of information as case study documents to be available online and distributed via e-news and social networks
- Inspiration tool for the creation of new services and for the improvement of existing ones: guidelines, funding, etc.

Showing the best there is!





Sharing and learning  
from each other!

Workshop 6-7th  
December  
NoRo, ROMANIA

- Stakeholders together around Social Services: EUCERD, Services Representatives, EUROPLAN Advisers, Academia, Authorities nominated by EUCERD or EUROPLAN advisers: 30 people, from 16 countries
- Workshop done at a specialised Social Service in itself

# Workshop 6-7th December NORO, ROMANIA

- Presentations by 1 representative of each of the 4 types of services (standard and comparable, shared online afterward)
- Presentation on funding opportunities
- Discussion on Guiding Principles for Specialised Social Services: development of workshop report containing the consensual guiding principles (to be disseminated to different partners): organisation and governance, rights, ethics, comprehensive approach, individual plans, partnerships, evaluation, continuous improvement



Home

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### Specialised Social Services

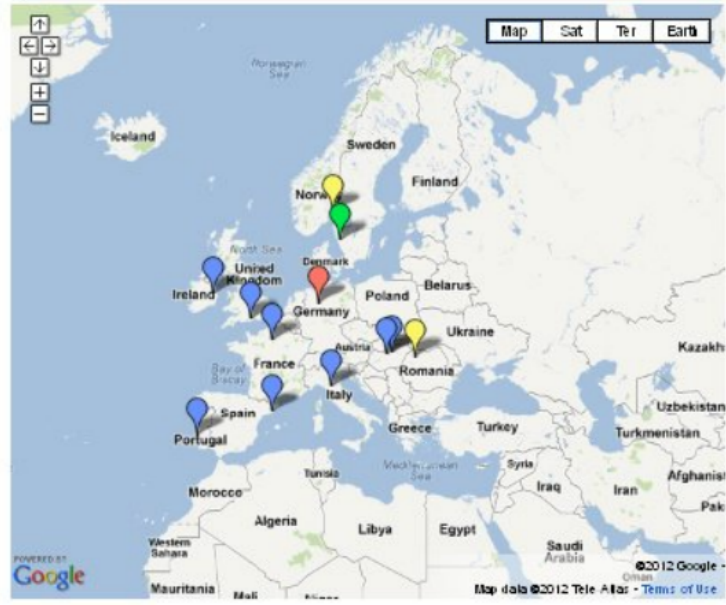
Specialised Social Services are instrumental to the empowerment of people living with R.D.s and are essential to the improvement of their wellbeing and health. The section provides the list of services in Europe, facts, case studies and guidelines for these services. Testimonials of both patients and volunteers can also be found below.

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

### European Map of Specialised Social Services

Share This

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



### What are Specialised Social Services?

When referring to Specialised Social Services, it is important to clarify what different types of services exist and how these can be of assistance to families and patients affected by R.D.s. Each tab above is dedicated to a type of Specialised Social Service, including a definition of the service, the list of services, a fact sheet and case studies or guidelines.

### Why are they needed?

Specialised Social Services are instrumental in the empowerment of people living with R.D.s and improve wellbeing 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 support, inclusion and psychological or educational development. Therapeutic Recreation, Respite Care, Adapted Housing Services and Resource Centres are essential in providing this vital support to people living with rare diseases. Patients' and volunteers' testimonials available at each service centre, available on the respective web pages, and brochures are also available on the website.

What are you looking for:

### eNews

Find out the latest news from the rare disease community!

Email:

Subscribe to our eNews

Now available in Press kit!

### Social Networks



EURORDIS - European Rare Diseases Organisation on Facebook

You like this.

3,133 people like EURORDIS - European Rare Diseases Organisation



Follow @eurordis 1,946 followers

### Rare Connect

A social network of Rare Disease Communities led by NORD and EURORDIS in partnership with leading disease-specific patient groups. List of Rare Disease Communities:

- Ataxia/Ataxia (AHU)
- Alternating Hemiplegia
- Atypical Hemolytic Uremic Syndrome
- Belgian Syndrome
- CAPS
- CDG
- Cysticosis
- Draet Syndrome
- Dys Net, Dysmetria - Limb Distresses
- Epilepsy-Dawson Syndrome
- Epilepsy-Epilepsy
- Familial Mediterranean Fever
- Gifts DS
- Hereditary Spastic Paraplegia

# Bringing public!





### List of services

All about the TRPs indicated on the map: what their activities are, who can attend each service, how to contact the services and where their exact location is.



[read more...](#)

### Fact Sheet and Case Studies

This section contains documents providing facts about TRPs, guidelines for these services and case studies of experienced services.



[read more...](#)

### Testimonies

Patients and volunteers share their experiences and feelings from attending or cooperating with Therapeutic Recreation Services.



[read more...](#)

## What are the Therapeutic Recreational Programmes?

Therapeutic Recreation Programmes (TRP) for people living with rare diseases are any organised recreation activity (summer camp, ad hoc trip) which gives patients the possibility to take a break from focusing on their disease and treatment to concentrating on fun and leisure. TRPs can also focus on different empowerment and disease/symptom management activities.

### Why are they needed?

Leisure and recreational activities will help patients gain self-confidence and feel empowered to deal with everyday challenges. Ultimately, patients and their close ones need time off. They need to spend some days in an environment where they can stop thinking about their disease, where they can meet, socialise and play with other patients and families. TRP allow patients with RDs and their families to meet these needs in a safe, friendly and well-adapted environment.

The study "Outcomes associated with participation in a therapeutic recreation camping programme for children from 15 European countries: Data from the Barretstown Studies" mentions that «benefits were noted in their [patients'] experience of physical symptoms, affect pertaining to physiological hyperarousal and quality of life in the short and longer term. Positive changes were also noted in relation to self-esteem as it pertains to global self-worth and physical attractiveness». The study then concluded that «these findings clarify previous research and suggest that camping programmes have an important role to play as a complementary intervention in facilitating adjustment to chronic illness» (Kiernan, Gormley and MacLachlan, 2004).

TRPs extreme importance for siblings has also been already reported. Siblings tend to share common difficulties which include a lack of understanding and knowledge about their brother or sister's disorder, also the feeling of being left out and potential embarrassment at their brother or sister looking and behaving differently (McGarvey and Hart, 2009).





- EUCERD EJA WP6 can only go so far due to scope, time and budget reasons
- EURORDIS can take some steps further:
  - Position Paper on Social Challenges for PLWRD (2013)
  - Workshop at Membership Meeting (2013)
  - Facilitating communication among services and between services and partners
  - Performing other visits resulting in case studies anytime possible within opportunities of EURORDIS work activities

EUCERD EJA WP6 as a first visible step of many to be taken!



Questions?



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