



EURODIS
Rare Diseases Europe



EUCERD JOINT-ACTION WP6

SPECIALISED SOCIAL SERVICES AND INTEGRATION OF RDS INTO SOCIAL
POLICIES: STATE OF THE ART & TRAINING SOCIAL SERVICES PROVIDERS

Raquel Castro, Social Policy and Specialised Social Services Manager



CNA CEF

OCTOBER 2013

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



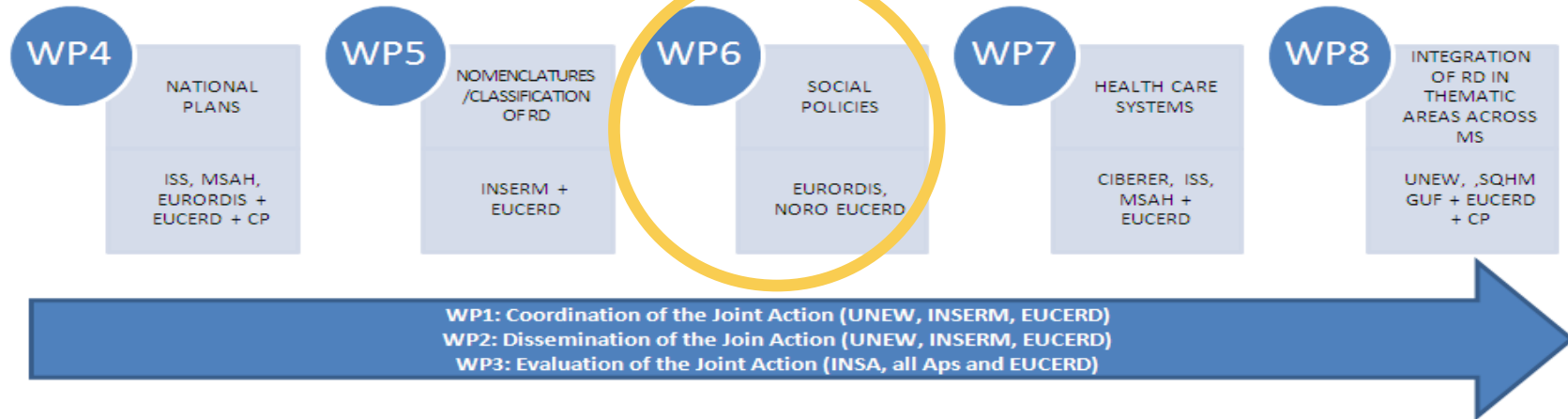
Social Services [and policies] are instrumental to the empowerment of people living with rare diseases and are essential to the improvement of their well-being and health

Source: EUROPLAN Final Report based on the 15 National Conferences



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

Task 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 2013

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

Connecting to other initiatives on Social Services and Policies

Mapping of Specialised Social Services

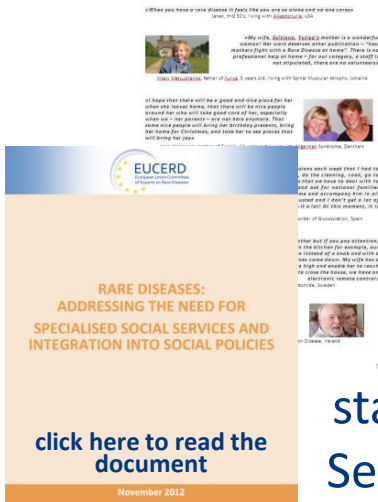
Workshop Guiding Principles for Specialised Social Services

Document on Guiding Principles for Specialised Social Services

Workshop EURORDIS Membership Meeting

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



MAP OF SPECIALISED SOCIAL SERVICES IN

EUROPE

«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

Give Visibility to Services



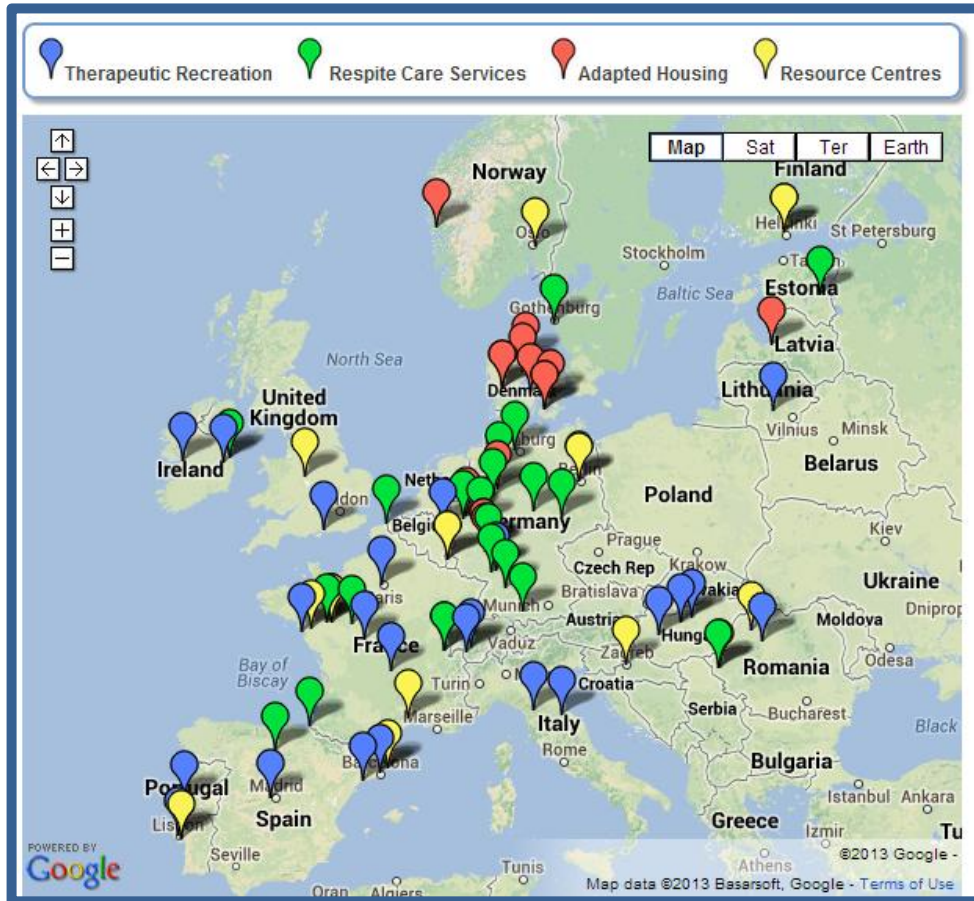
Improve patients' access to services

Promote the need for services

72 Services

20 Countries

Information on activities,
target population and
contacts for all services



[click picture to access the map](#)



«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

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

2013 EURORDIS POLICY FACT SHEET - RESOURCE CENTRES FOR RARE DISEASES

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

Resource Centres services include information and guidance services, training courses, provision of information concerning social benefits, and documentation and research services. Only specially trained, multidisciplinary consultations and therapeutic-recreation activities are often also provided by these centres. Resource Centres could be defined as a 'one-stop shop style' service for rare diseases.

Why ARE RESOURCE CENTRES NEEDED?
Several studies and documents have recognised the need for Specialised Social Services (which include RC), both at European and National levels.

The European Commissioner's Communication on Rare Diseases: Europe's Challenge¹ specifically mentions:

Why ARE RESOURCE CENTRES IMPORTANT?
and integrate PLURD into existing social services (education, integration into school and workplaces, recreation and respite services), while recognising their specificities and providing quality services in response to their needs (RIS.9).

Why ARE RESOURCE CENTRES IMPORTANT?
The European Commissioner's Communication on Rare Diseases: Europe's Challenge¹ specifically mentions:

«...stop shop... for the total support here on the territory and beyond the art... 2009»

can PLURD... therapeutic... directly

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2013 EURORDIS POLICY FACT SHEET - ADAPTED HOUSING SERVICES FOR RARE DISEASES

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 (PLURD) to develop and enjoy some level of autonomy by living within the comfort of their own home, alone or with peers, assisted by support 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 housing 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 Commissioner's Communication on Rare Diseases: Europe's Challenge¹ specifically mentions:

Why ARE ADAPTED HOUSING SERVICES IMPORTANT?
Adapted housing services make it possible for PLURD to live as independently as possible, while being monitored by supportive staff members to ensure 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 into a community of peers without prejudicing their living nor their social and therapeutic needs.

and integrate PLURD into existing social services (education, integration into school and workplaces, recreation and respite services), while recognising their specificities and providing quality services in response to their needs (RIS.9).

Why ARE ADAPTED HOUSING SERVICES IMPORTANT?
Adapted housing services make it possible for PLURD to live as independently as possible, while being monitored by supportive staff members to ensure assistance for any daily routine activities that cannot be performed independently.

The final report of EUROPLAN, based on 15 National Conferences organised in 2010-2011, states that «Specialised Social Services are a support for people living with a chronically debilitating rare disease and their family carers and establishing need to be developed to improve»

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2014 EURORDIS POLICY FACT SHEET - THERAPEUTIC RECREATION PROGRAMMES FOR RARE DISEASES

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

- **'Single illness'** TRP: for people living with a specific condition, or their siblings;
- **'Mixed illness'** TRP: for people living with a variety of conditions and/or their siblings/siblings;
- **'Mainstream or integrated'** TRP: for people living with a variety of conditions, siblings/siblings.

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2013 EURORDIS POLICY FACT SHEET - RESPITE CARE SERVICES FOR RARE DISEASES

Respite care is provided, on a short term basis, for people living with rare diseases (PLURD), 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 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 Commissioner's Communication on Rare Diseases: Europe's Challenge¹ specifically mentions respite care services in its article addressing the «Access to Specialised Social Services» and their importance for PLURD. The Communication further states that RCS need to be sustainable to promote their growth, awareness-raising, exchange of best practices and standards, pooling resources using Health Programme and Disability Action Plans.

The EUROPLAN guidance document for the National Plans², developed by partners and experts, mentions that «Specialised Social Services (including RCS) are instrumental to the empowerment of PLURD and improve well-being and health. For people living with a rare, chronic and debilitating disease, care should not only be reserved to medical and paramedical aspects, but should also take into account social inclusion and psychological and educational developments».

The final report of EUROPLAN, based on the 15 National Conferences (2010-2011), 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 PLURD 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 (RIS.9)».

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 three broad categories: stress reduction and self-esteem increase, improved family functioning (Merriman and Carstairs, 2007³).

A second purpose of RCS is to make it possible for PLURD to live according to their usual daily routine and to provide a place to experience and perform recreational and meaningful activities away from their parents/caregivers. Benefits to service users mentioned in literature are socialisation and enjoyment of experiences outside the home (Merriman and Carstairs, 2007³).

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click on each picture to access respective fact sheet

Highlight good practices



Improve quality of services

Improve access to services

«The children and their families are very lucky to have such a good service available to them and all at no cost to them»

Health Care Professional cooperating with Therapeutic Recreation Programme, United Kingdom

Agrenska

Respite Care Service – Sweden

Rare Diseases

Total beneficiaries: 170 children/year

Private Foundation

No costs for patients

Programmes for Patients, Families,
Professionals

70 everyday staff; 120 intermittent

Frambu

Resource Centre – Norway

Rare Diseases: 100 (300 w/ subgroups)

Total beneficiaries: 28.250/year

State Funded Service

No costs for patients

Programmes for Patients, Families,
Professionals

89 everyday staff, 150 intermittent

Bátor Tábor

Therapeutic Recreation Programme – Hungary

Serious Illnesses

Total beneficiaries: 800
children/year

Private Foundation

No cost for patients

Programmes for children, siblings

22 everyday staff, 600 intermittent



[click on each picture to access services' websites](#)

Establishing important partnerships



Receive and share valuable information
Make the message stronger



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

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

«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.»

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

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

Collect Consensual Good Practices



Improve quality of services

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

28 participants from 16 countries:
EUCERD, services, National Alliances, EUROPLAN advisors, academia

Presentations of EUCERD and Project
Presentations of Services: 1 of each kind (TRP, RCS, AH, RC)

Group discussions on draft of Guiding Principles for Specialised Social Services

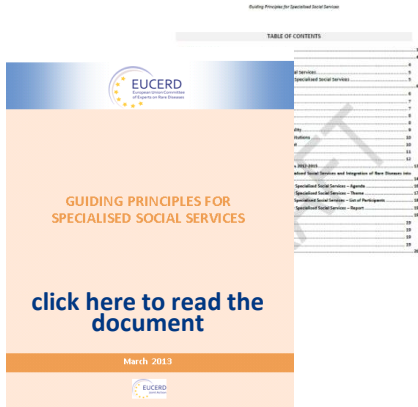
Conclusions and consensus in plenary session



DOCUMENT: GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES

«We were evaluated first by an interdisciplinary team: psychologist, physiotherapist, doctor, social worker and a special education teacher.»

Ana Maria, living with Thalassaemia, attending NoRo Resource Centre, Romania



Highlight good practices



Improve quality of 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



«Attending a camp can increase a child/young person's confidence in so little time, bringing so many long term benefits to their well-being»

Health Care Professional cooperating with Therapeutic Recreation Programme, United Kingdom

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](#)

WORKSHOP: TRAINING SOCIAL SERVICES PROVIDERS

«The staff, employed by the municipality, are trained and interested in doing their best to support Markus and his neighbours in managing their lives»

Lisen, mother of Markus (30), living with a developmental disability, attending an Adapted Housing Service, Norway

Share good practices for training of staff



Improve quality of services

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



26 participants from 13 different countries:
EUCERD, services, National Alliances, EUROPLAN advisors

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

October 2013

May 2014

Document
Training Social
Services Providers

Fact Sheet
Specialised
Social
Services

EURORDIS
Position Paper
Social Challenges

Case Study
Documents

Agrenska
Frambu
Bátor Tábor
Group Homes PWS-
DK

Country Visits

Spain
France

ECRD 2014 Berlin
Theme 6: Beyond
Medical and
Medicinal Care

Sharing a set of different approaches to care



Improve the quality of care

**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**



7th European Conference on Rare Diseases & Orphan Products

8 - 10 May 2014 - Andel's Hotel, Berlin, Germany



Call for posters

Deadline submission of abstracts - 15th December

-Theme 6: Beyond Medical Care. Research or studies identifying the specific social challenges of rare diseases; innovative solutions, services and programmes that address the social and other non-medical needs of rare disease patients; innovative schemes that may serve as models for promoting independent living; personal experiences of service users; methodologies and programmes for the training of social services providers; research or studies on the benefits for patients and families of respite, therapeutic recreation and adapted housing.

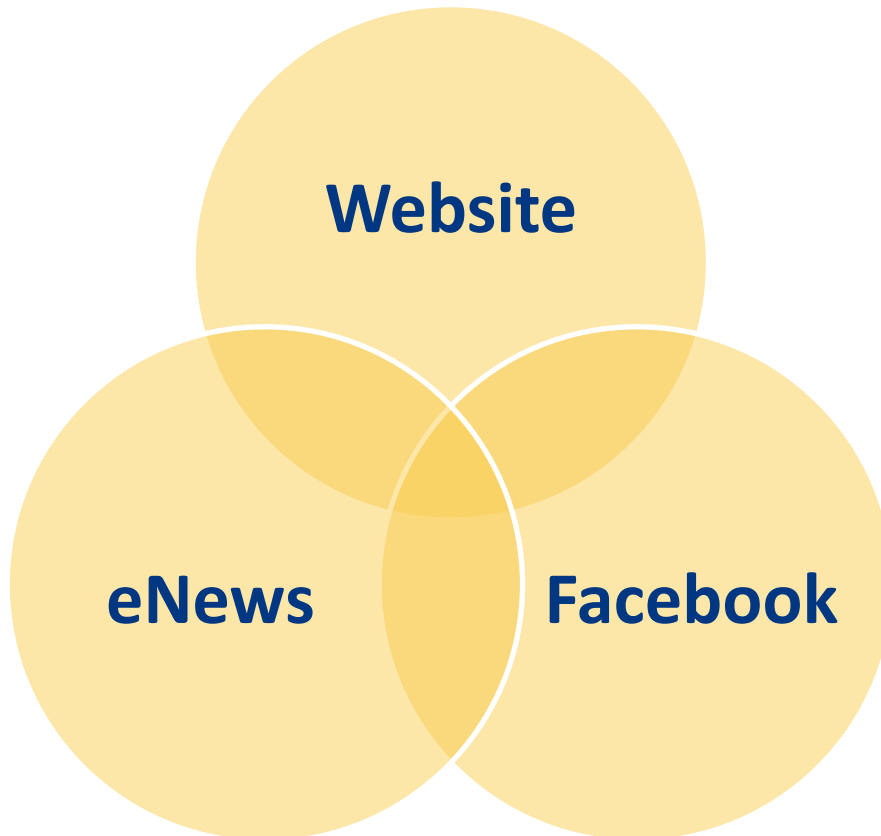


Raising awareness and Reaching out to more publics

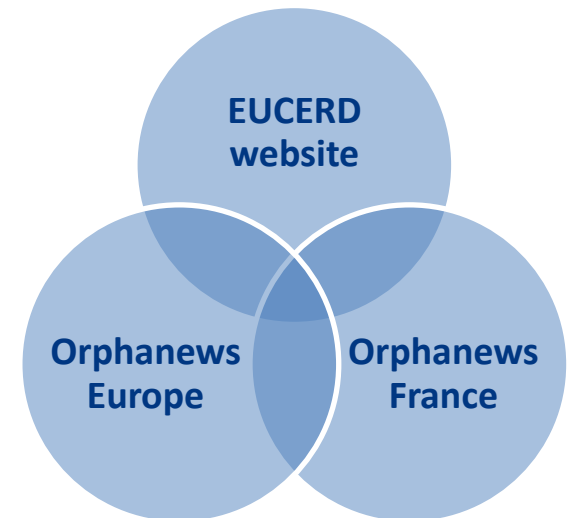
Creating a European movement around Specialised Social Services and Social Policies for PLWRD



EURORDIS Communication Tools



Partners Communication Tools



WEBSITE SECTION: SPECIALISED SOCIAL SERVICES

The screenshot shows the EURORDIS website interface. At the top, the logo and tagline 'The Voice of Rare Disease Patients in Europe' are visible. A navigation bar includes links for 'About EURORDIS', 'About Rare Diseases', 'Rare Disease Policy', 'Orphan Drugs & Treatments', 'Living with a Rare Disease', 'Services to Patients', 'Training Resources', and 'News & Events'. Below this, a 'Home > Services to Patients' breadcrumb is shown. The main heading is 'Specialised Social Services', followed by a paragraph explaining their importance. A 'Share This' button is present. A map of Europe is displayed with various colored pins indicating service locations across countries like Norway, Denmark, Germany, France, Italy, and others. To the right of the map are buttons for 'Map', 'Sat', 'Ter', and 'Earth'. Below the map, there are sections for 'eNews', 'Related documents', 'Contact us', and 'Social Networks'. The 'Social Networks' section includes icons for Facebook, Twitter, YouTube, and Flickr, and a Facebook widget showing the organization's profile.

click picture to access the website section

Raising awareness and Reaching out to more publics



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!



PATIENTS, ORGANISATIONS, SERVICES

Read about living with a rare disease and the services available

Therapeutic Recreation Programmes: take a break from focusing on the disease and concentrate on fun and leisure.



Reaching out beyond our members and followers



Strengthening the global movement

Communicating to general public sharing information on:

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

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

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

Barretstown 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 2 19

1.969 pessoas viram esta publicação Impulsionar promoção

Reaching out to the RD community



Strengthening the advocacy movement



Specialised social services

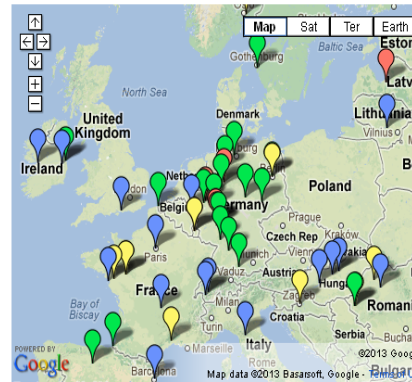
The EUCERD has chosen to examine the area of specialised social services for rare diseases (RD), as concerns both the provision of specialised rehabilitation services for RD as well as the integration of RD into mainstream social policies and services.

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.

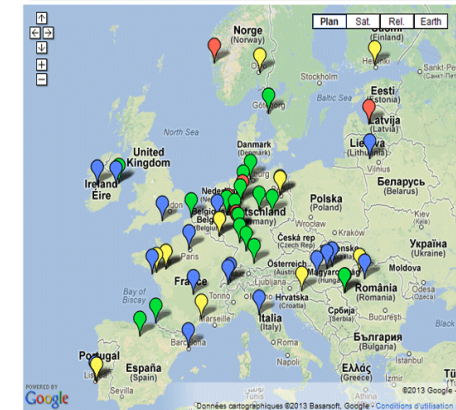
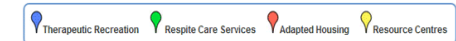


Specialised social services in Europe for rare disease patients



Eurordis now has a section of their website dedicated to Specialised Social Services for rare disease 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), Eurordis 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, Eurordis 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 socialised services currently mapped by Eurordis which include, Therapeutic Recreation Programmes (TRP), Respite Care Services (RCS), Adapted Housing (AH), Resource Centres (RC). Apart from mapping these services Eurordis will also be involved in "addressing the issues concerning the training of the staff/volunteers working at these services" ([Link to the EURORDIS 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](#)).

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



Eurordis 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), Eurordis 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. A cet effet, Eurordis 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). Eurordis se penche aussi sur les questions relatives à la formation du personnel et des aidants qui travaillent dans ces services ([voir pdf](#)). 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'Eurordis. 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

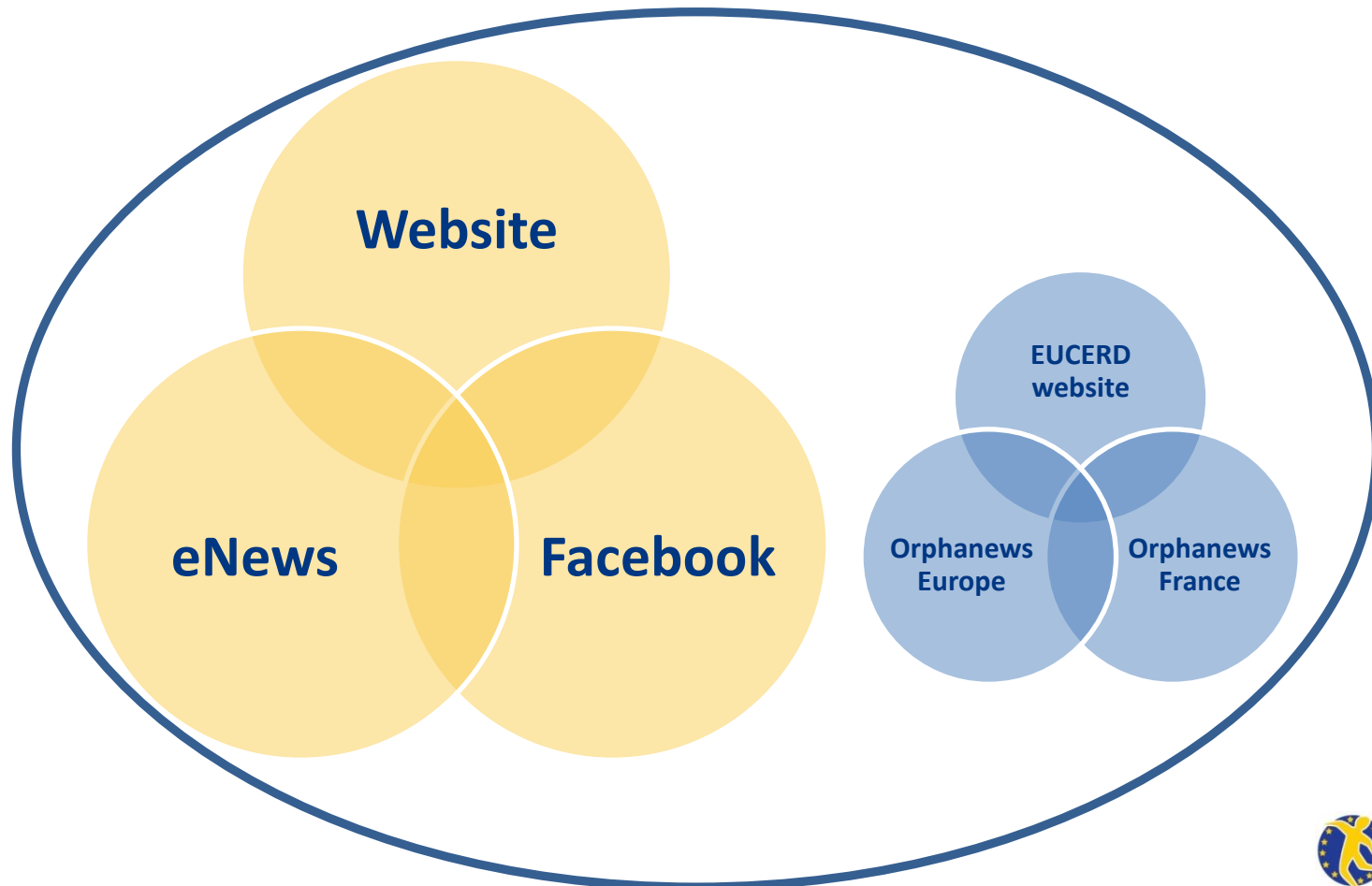
Reaching EU, national authorities, patient advocates, health professionals.

click on each picture to access respective article

March 2013

October 2013

OVER 56000 PEOPLE REACHED!



EUCERD JOINT-ACTION WORKSHOP
TRAINING FOR SOCIAL SERVICES PROVIDERS



Copenhagen, 10-11 October 2013

WORKSHOP: TRAINING SOCIAL SERVICES PROVIDERS



WORKSHOP: TRAINING SOCIAL SERVICES PROVIDERS

«The staff, employed by the municipality, are trained and interested in doing their best to support Markus and his neighbours in managing their lives»

Lisen, mother of Markus (30), living with a developmental disability, attending an Adapted Housing Service, Norway

Share good practices for training of staff



Improve quality of services

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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

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



Why? The EUROPLAN I final report recommendations based on the 15 EUROPLAN National Conferences (2010-2011): «**mechanisms need to be devised to recognise and integrate people living with RDs 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»; one of the **solutions «ad hoc training for staff involved in the care of RD patients»**.

Target of the document: EUCERD, National Authorities, Patient Representatives, Service Providers, etc.

Targets of the training: Social Services Providers (Social Workers, Psychologists, Teachers, Special Education Teachers, Occupational Therapists, Speech Therapists, Kinesiotherapists, Students, Carers, Personal Assistants, Volunteers, etc.)

PROVIDERS - PURPOSE

Address the need of training for social services providers



In consensus



Outcome of multi stakeholder discussions

Guiding principles and good practices

+

Useful tools

+

Step wise approach/check-list for the implementation of training programmes

+

Examples



Presenting **European context**

Emphasising the **need for the training of social services providers** in order to prepare them to handle patients with RD

Clarify that **training social services providers is an efficient path** to ensure that people living with RDs can be integrated in specialised or mainstream social services and policies

Indicating **guideline methodologies** and principles which can help training providers conceiving and implementing their training programmes

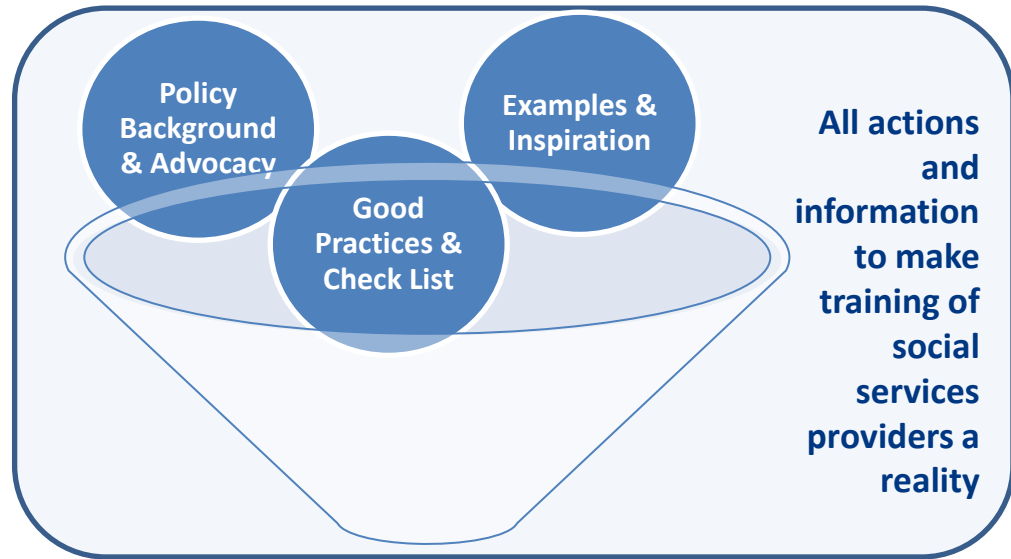
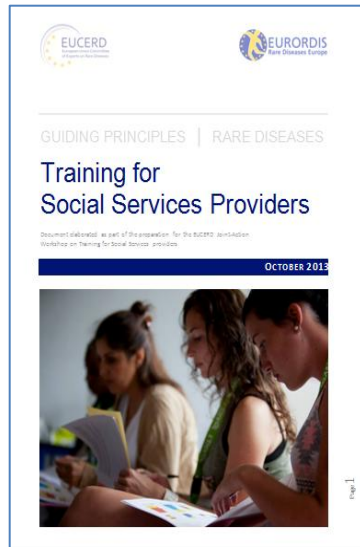
Informing on some **tools** being developed by important RD which can inform and support social service providers and should be part of the training programmes' contents

Providing **examples** of current programmes being developed in several European Countries

Contents

Contents	2
1 Introduction.....	3
1.1 Background.....	3
1.2 Training of Social Services Providers: The Expressed Need.....	5
1.3 Training of Social Service Providers: Mission and Objectives.....	6
1.4. Training of Social Services Providers: Target Groups.....	6
1.5 Scope of the Guiding Principles for Training of Social Service Providers.....	7
2 Methodologies and Principles	8
2.1. Global Standards Regarding the Conception of the Training Programmes.....	8
2.2. Different Possible Training Frameworks	9
2.3. Content of the Training Programmes.....	10
2.3.1 Feeding Information.....	10
2.3.1.1 The Role of Centres of Expertise, Patient Groups, Families and Patients	11
2.3.2 Providing Tools	12
2.3.4 Establishing a Feedback and Follow-up System.....	16
Appendix.....	17
Appendix I: EUCERD Joint Action working for Rare Diseases 2012-2015	17
Appendix II: EUCERD Joint Action Work Package 6: Specialised Social Services and Integration of Rare Diseases into Social Policies and Services	18
Appendix III: EJA WP6 Workshop on Training for Social Services Providers – Agenda.....	20
Appendix IV: EJA WP6 Workshop on Training for Social Services Providers – List of Participants.....	22
Appendix V: EJA WP6 Workshop on Training for Social Services Providers – Report.....	23
Appendix VI: Bibliographic References and Related Documents	23

DOCUMENT TRAINING SOCIAL SERVICES PROVIDERS – COMMENTS TO DRAFT

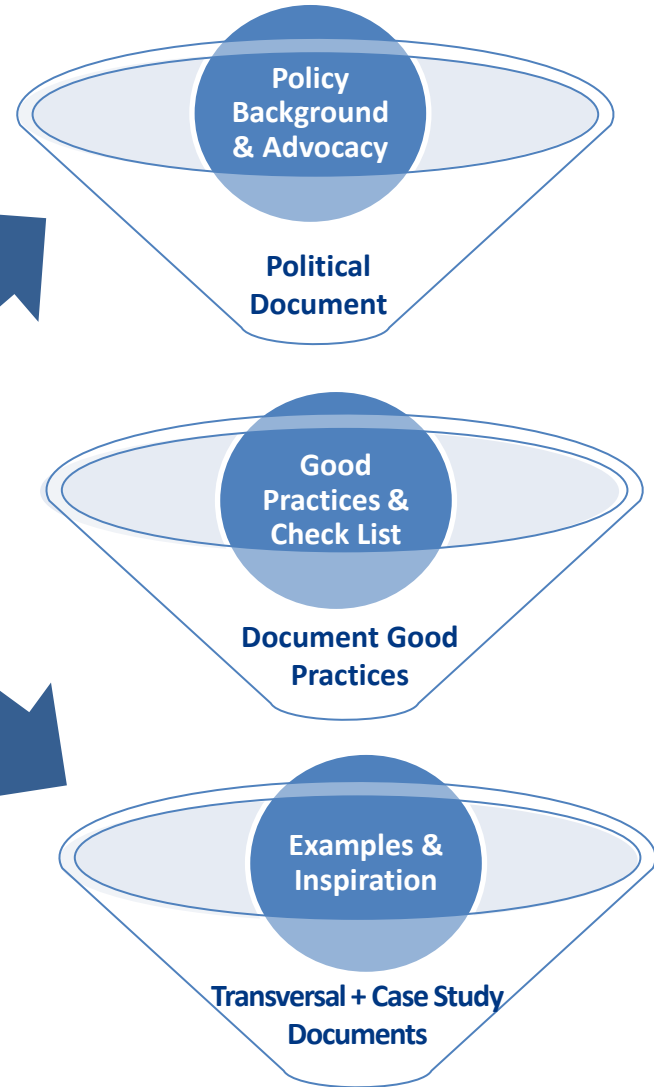
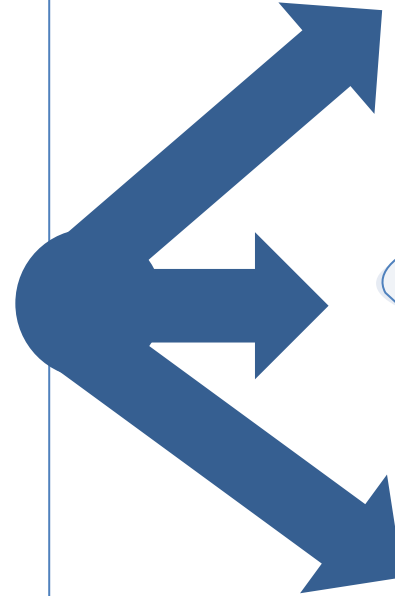


But, when we actually put all these actions and information together in one document...



... the message is not too clear

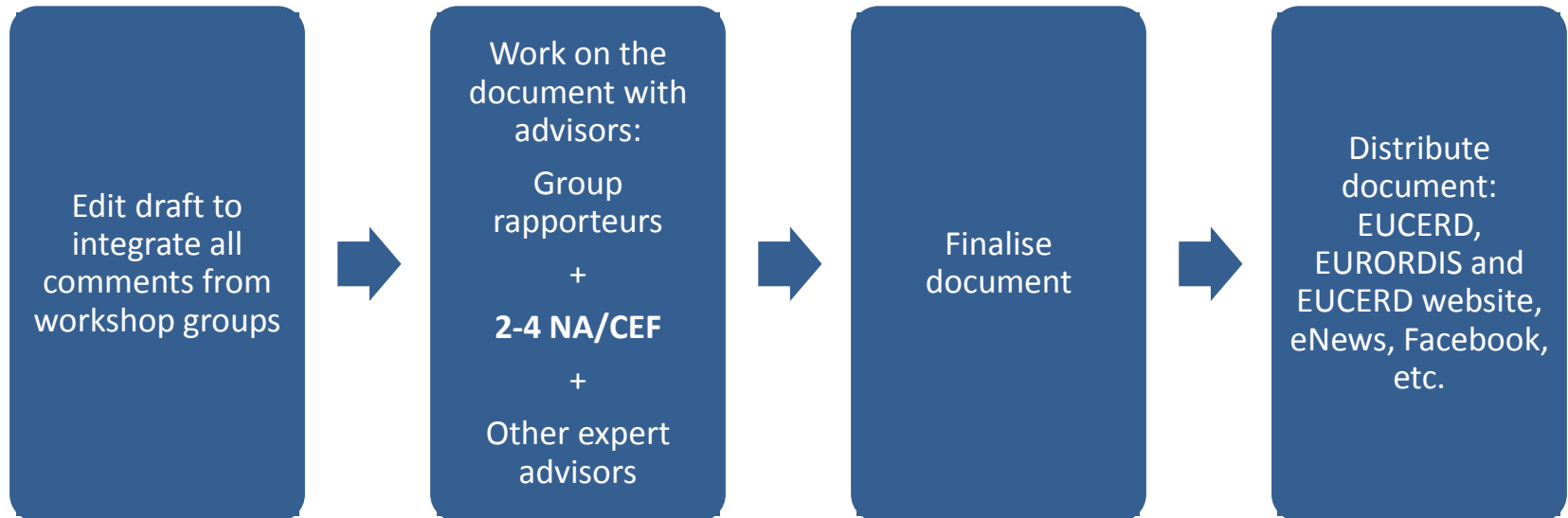
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DOCUMENT TRAINING SOCIAL SERVICES PROVIDERS – NEXT STEPS

November 2013

January 2014



contact raquel.castro@eurordis.org to be part of the advisors



«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.»



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

ALL QUOTES USED IN THIS PRESENTATION ARE REAL STORIES



Paris, October 2013