

# **EUCERD JOINT ACTION WORKSHOP TRAINING FOR SOCIAL SERVICES PROVIDERS**



**Copenhagen, 10-11 October 2013**

# INTRODUCTION

The workshop was organised in the context of the ongoing activities of the [European Union Committee of Experts on Rare Diseases \(EUCERD\)](#), namely under the framework of the [EUCERD Joint Action \(N° 2011 22 01\) \(EJA\)](#), Work Package 6 (WP6): [‘Provision of Specialised Social Services and Integration of Rare Diseases into Social Policies and Services’](#). ‘Training for Social Services Providers’ was the main subject of the workshop. The agenda was composed of several presentations followed by group and plenary discussions (see [Appendix I – Agenda](#)).

The workshop was attended by 26 experts, coming from 13 countries, representing the various stakeholder groups: members of the EUCERD and/or representatives of National Health/Social Authorities, training providers, Specialised Social Services, national alliances for rare diseases (RDs), social workers, scientists and health care professionals (see [Appendix II – List of Participants](#)).

## Main Objectives

- To provide a forum to share information with EUCERD members and other interested parties on ‘Training for Social Services Providers’ in order to better care for people living with a rare disease;
- To incite debate on ‘Training for Social Services Providers’, and elaborate an outcome document composed of main guidelines and good practices for the implementation and functioning of training programmes for social services providers (social workers, carers, psychologists, therapists, etc.).

## Specific Questions Addressed

- What are the goals of the EUCERD Joint Action (EJA) and the specific goals of WP6?
- Why do we need to train social services providers for RDs? And how can we make sure the document(s) produced after the workshop emphasise the specificity of RDs?
- Which guiding principles are current training programmes following?
- Which guiding principles and good practices shall be systematic for the setting up and running of training programmes for social services providers?
- What type of document(s) should be produced to raise awareness of these guidelines and advocate for the development of these training programmes?
- Who are the audiences of the document(s) produced? And how can we make sure the message will reach each audience successfully?

## The Starting Document

A draft document was compiled in collaboration with some experienced training services. This document was sent out in advance to all participants who then had ten days to comment on this first draft. Comments were compiled into a separate document and sent out to all participants three days before the workshop. The draft, the comments and other questions raised during the first day of the workshop were used as the starting point of the group discussions.

The draft covered:

- Background information on RDs, on the EUCERD Joint Action and on WP6;
- Workshop agenda, goals and methodology;
- Information on Training for Social Services Providers:
  - The expressed need for training;
  - Mission and objectives;
  - Target groups;
  - Scope of the guiding principles;
- Methodologies and Principles:
  - Global standards regarding the conception of training programmes;
  - Different possible training frameworks;
  - Content of the training programmes;
  - Supplying information:
    - The role of Centres of Expertise, patient groups, families and patients;
  - Providing tools:
    - Precaution charts;
    - Orphanet disability charts and disability database;
    - Help lines for Rare Diseases;
    - EURORDIS InfoHub;
  - Preparing to act;
  - Establishing feedback and a follow-up system;
- Appendixes with detailed background information;
- Bibliographic references.

## **Format of the Workshop and Methodology of Group Discussions**

The Workshop agenda was planned for a set of two complete days, starting from a more general background approach, narrowing down to the specifics of the actual guiding principles for Training of Social Services Providers.

Part of Day 1 was dedicated to introductory issues such as the EUCERD Joint Action and WP6, and a visit to the workshop venue, the [House of Disabled People's Organisations](#).

The rest of Day 1 was dedicated to gaining familiarity with training programmes for social services providers, presented by different training promoters: Frambu (Norway), Prader-Willi Association (Romania), Ågrenska (Sweden), French Muscular Dystrophy Association (AFM-Téléthon, France), Group Homes for Prader-Willi syndrome (Germany).

There was still time to introduce workshop participants to two very interesting tools that can be used in the training of social services providers: the Social Profiles project, promoted by Rare Disorders Denmark, and the two disability projects developed by Orphanet.

After becoming familiar with the workshop's context and concepts, participants spent Day 2 actively debating the draft document, in discussion groups first, and in plenary after.

The discussion groups were composed of diverse profiles and countries of origin, in order to stimulate discussions between participants facing different professional and societal realities, enhancing the quality of discussions and of the consequent conclusions.

The groups were asked to respond to a set of questions related to the issues presented in the draft. Participants were encouraged to:

- Comment on the issues mentioned in the draft and on possible additions, amendments, deletions and merges to be applied;
- Reply to a set of questions compiled using all participants' comments to the draft;
- Suggest what type of document(s) should result from the exercises performed during the workshop, to ensure the best sharing and use of all the information collected and the best results in terms of policy and advocacy actions.

## WORKSHOP REPORT

### **EUCERD Joint-Action , by Victoria Hedley (VH)**

VH's presentation laid the groundwork for the understanding of the context of the workshop by providing the wider context on the EJA, its background, goals, partners and 8 work packages. VH gave a clear notion of the general goals of the EJA as a whole – ultimately, the implementation and realisation of the Council Recommendation and the Commission Communication.

Being now mid-way through the project, the specific goals and progress to-date of the five core work packages were presented. Three key sets of EUCERD Recommendations have been generated by the EJA thus far, dedicated to [European Reference Networks \(ERNs\) for RD](#), [RD Registration and Data Collection](#), and [Core Indicators for RD National Plans](#). Key tools and resources have been elaborated, including two annual editions of the '[State of the Art](#)' Report, summarising RD activity across Europe.

Significant progress has been made in the area of coding and classification of RD, through the harmonisation of terminologies and the integration of RDs into the forthcoming ICD 11. Analysis is underway regarding real-life activities and operations 'on the ground' in RD healthcare, examining similarities and differences between Member States and identifying examples of 'best practice'.

Finally, significant emphasis continues to be placed on integrating and harmonising RD efforts across such key topics as networking, registration and genetic testing, to ensure the sustainability of RD initiatives. [Download the presentation](#).

### **Specialised Social Services and Integration of RD into Social Policies: State of the Art, by Raquel Castro (RC)**

The presentation started by clearly stating the definitions of Specialised Social Services and social policies, in order to clarify from the beginning the scope of the work package's actions.

RC presented the three-year project's timeline, highlighting its three main activities: identification and mapping of Specialised Social Services; training of Social Services Providers; and integration of RDs into social policies and services.

RC then focused specifically on progress made since March 2012 (when the project officially commenced) until October 2013, highlighting the following:

- Elaboration of the paper '[Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies](#)';
- [Mapping of Specialised Social Services](#) and creation of an EURORDIS website section with information on [Therapeutic Recreation Programmes](#), [Respite Care Services](#), [Adapted Housing Services](#) and [Resource Centres](#);
- Elaboration of factsheets on [Therapeutic Recreation Programmes](#), [Respite Care Services](#), [Adapted Housing Services](#), [Resource Centres](#);
- Country visits to: [Agrenska](#) RCS (Sweden); [Frambu](#) RC (Norway); [Bátor Tábor](#), TRP (Hungary); and [Group Homes](#) AH for Prader-Willi Syndrome (Denmark);
- [Workshop on 'Guiding Principles for Specialised Social Services'](#) (Romania, December 2012), with 28 participants from 16 countries elaborating the [document on 'Guiding Principles for Specialised Social Services'](#) ;
- Organisation of 2 workshops at [EURORDIS Membership Meeting](#) ;

RC then presented the future tasks and the communication actions which have been carried out so far via [EURORDIS](#) and [EUCERD website](#), partners' newsletters, [EURORDIS eNews](#) and [Facebook](#), highlighting that these had reached over 56000 people in less than 7 months. [Download the presentation.](#)

**Introduction to the Workshop: context, theme, purpose, methodology and expected outcomes, by Dorica Dan, Project Leader, EURORDIS**

DD gave an introduction to the workshop, presenting its context, objectives, methodology and expected outcomes:

- Context: EUCERD Joint-Action and previously identified patient needs, via [EUROPLAN Report on the 15 National Conferences \(2010-2011\)](#);
- Why train for RDs: reinforcement of the need for training specifically on RDs due to the lack of information and knowledge around these rare, complex diseases that require a multidisciplinary approach;
- Objectives: compose a consensual document and tools to advocate for and help promote training for social services providers, which will better prepare professionals to integrate patients with RD into their social services, empowering them, and providing them with tools and new knowledge;
- Methodology: presentations on existing case studies; discussions in groups and in plenary; discussion of the draft document prepared in advance; the document goes through a final revision to include comments from workshop debates and reflections;
- Case study presentations: Frambu, Norway; Edubolirare, Romania; Agrenska, Sweden; AFM-Téléthon, France; Group Homes PW Syndrome, Germany;

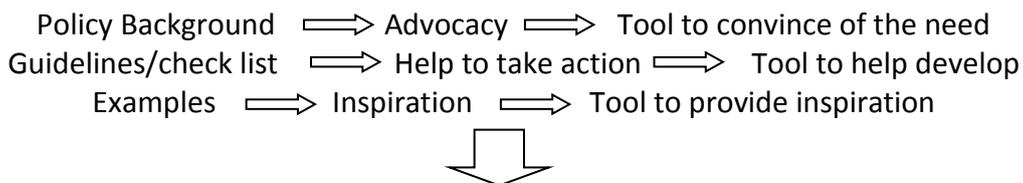
- Expected outcomes: consensual document(s) on good practices and guiding principles for the training of social services providers and a distribution plan identifying the potential audience of the document and the key messages to deliver. [Download the presentation.](#)

**Introduction to the Document: purpose, contents, annexed case studies, expected outcomes, by Raquel Castro, Social Policies Manager, EURORDIS**

RC presented the document index and recalled the document's expected outcomes:

- To collect references to the need for the training of social services providers;
- To present consensual methodologies for the conception of these trainings and good practices, tools, and guidelines for their implementation;
- To provide information on examples of existing trainings.

RC then presented the following scheme illustrating the document's contents and goals:



An increase of trainers, equipped with resources and good practices, will lead to more trained service providers, better prepared to offer quality services, ultimately increasing the quality of life for people living with a rare disease. [Download the presentation.](#)

**Training for professionals working with RD patients, Frambu (Norway), by Lisen Mohr (LM)**

In order to better contextualise [Frambu's](#) training programmes, LM started by providing some background information on the institution and on the Norwegian context surrounding health and social care.

LM then moved into presenting concrete information about Frambu's training programmes:

- Costs: all costs are included in Frambu's budget. Participants pay a moderate fee, covering accommodation and subsistence costs while staying at Frambu for the training programme;
- Subjects: Frambu's courses revolve around RDs and the home environment, information on diagnosis, medical information, special education/work places and facilitation;
- Target public: health professionals, local health services, professionals in the education system and other professionals working on behalf of individuals with one of Frambu's focal RDs;

- Types of courses: specialised courses, brief courses and local guidance, and development of expertise;
- Framework of training: trainings use face-to-face time and videoconference involving service providers from all over the country.

LM then gave concrete examples of training for Neurofibromatosis Type 1, for Prader Willi Syndrome and for Velocardiofacial Syndrome, 22q11 and DiGeorge Syndrome, presenting for each course: subject, target public, framework, trainers' background, partners and description of the programme.

During her presentation, LM also shared some of the videos that Frambu has produced, in which patients share their experiences and needs with the trainees: an innovative and safe way to involve patients in the training without invading their privacy. [Download the presentation.](#)

**Edubolirare: training for professionals in the RD field, Romanian Prader-Willi Association, by Dorica Dan (DD)**

DD began by presenting the Romanian context for RDs and then moved to presenting examples of training programmes promoted by [Edubolirare](#), an online platform for information and education on RDs:

- Target public: courses are specifically directed towards professionals involved in the diagnosis and management of RDs, such as personal assistants, therapists, social workers, psychologists, volunteers, nurses, doctors;
- Framework of training: programmes have different time frames and use both face-to-face and eLearning, always dedicating 2/3 of the training time to practical issues as opposed to theory;
- Costs: training one professional costs about 100€ and these costs are covered 100% by the trainees when there is no project or source of funding to cover them;
- Trainers' background: therapists, doctors, psychologists, special education teachers all trained as instructors for adults;
- Partners: Romanian National Alliance for RDs, Romanian Genetics Society, Ministry of Health, Romanian Doctors' Colegium, Frambu, Ministry of Work and Education, Medical Universities;
- Objectives of the courses: create curricula for professionals and add knowledge about RDs, in order to provide them with the necessary skills to integrate people living with a RD in their services;
- Accreditation: services are accredited by the competent authorities in Romania.

DD then provided examples of courses for rehabilitation teachers and showed the audience the intranet system for trainees and different kinds of courses available at the online training platform. Courses use text, photos, quizzes and other innovative interactive approaches. [Download the presentation.](#)

### **Ågrenska – A Holistic Approach, Ågrenska (Sweden), by Anders Olauson (AO)**

AO dedicated started by presenting [Ågrenska](#)'s holistic approach to care for people living with a rare disease. To illustrate this, AO started by showing how the patient sits at the intersection of numerous different realities, at the centre of hospital, parents, family, friends, siblings, school, etc.

AO also provided background information on Ågrenska and on the Swedish legal framework for disabilities and additionally presented some key reflections from the Ågrenska team, following more than 20 years of experience as a specialised social service for RDs. AO then moved to present the training and education programmes at Ågrenska, delivered via the training for professionals during family stays, the training for medical students and the tailor-made trainings.

The training of professionals during family stays was then presented:

- Background: parents attending the family stays invite the staff working with their child in the local community for a 2 day training and experience;
- Objectives: to increase knowledge, understanding and collaboration;
- Target groups: teachers, preschool teachers, support staff, habilitation staff, personal assistants, student health team, respite care personnel, etc.;
- Contents: lectures and discussions together with the parents about medical issues, education aspects, etc.;
- Unique opportunity to get updated knowledge, meet colleagues in the same situation and share experiences, take note of the differences and similarities of up to 10 children with the same diagnosis, understand the situation of the family, and define a common platform for further work.

AO then presented the Swedish National Function for RDs (NFRD) and how its activities are connected to the dissemination of knowledge and, increased collaboration with health care and social actors. Via the NFRD, Ågrenska and other Swedish institutions are now looking into cooperative agreements to achieve holistic care for people living with a RD via care programmes, guidelines, and competence centres. [Download the presentation.](#)

### **Training process for Case Managers, AFM-Téléthon, (France), by Jean-Pierre Lamorte (JPL)**

JPL first presented the French Muscular Dystrophy Association ([AFM-Téléthon](#)) and the mission of the AFM's Complex Case Managers. These are acting like advisors, coaches, mediators.

JPL used the metaphor of a GPS navigation system to illustrate the functions of these professionals and later showed a graphic of the patient and all dimensions around him (such as medicine at home, hospital, home care, handicap compensation, leisure, medico-social institutions, transports and school) demonstrating the relations between these dimensions, the patient, the AFM and its Case Managers.

JPL then explained the training system for the Complex Case Managers, starting with the initial training - social services or paramedical diploma - and moving to the specific trainings on different complementary disciplines and issues.

Complex Case Managers undergo a training on "adaptation to the neuromuscular environment" composed of 4 different levels - of increased complexity over time - starting with basic knowledge on muscular dystrophies before delving into greater detail about the most common types and their genetic, psychological, therapeutic and familiar characteristics. Each Complex Case Manager might then be specifically trained on complementary issues as part of his/her individual training.

The Complex Case Managers are submitted to quarterly team supervision performed with an external clinical psychologist who helps them to deal with the emotional aspects of difficult situations they encounter in the field work. [Download the presentation.](#)

**"Curricula Prader-Willi-Syndrome", Adapted Housing Service for Prader-Willi Syndrome, Diakonische Stiftung Wittekindshof (Germany), by Norbert Hödebeck-Stuntebeck (NHS)**

NHS started by introducing [Diakonische Stiftung Wittekindshof](#), currently providing adapted housing for 68 people with Prader-Willi Syndrome (PWS), in 4 different places in Germany. He then presented the training program for the staff working with the residents with PWS:

- Target public: educators, nurses, teachers, psychologists, staff of the institution and some external professionals from other private or public institutions;
- Framework of training: the training is done in groups of 10-20 participants. It is composed of 150 hours, 100 of which are face to face sessions. 50% of the content is practical training;
- Trainers' background: psychologists, nutritionists, endocrinologist and supervisor;
- Partners: Hospital (Nutrition and Endocrinology), Heart and Diabetes Centre (Diabetes, Endocrinology), University of Duisburg-Essen (Genetics) and the PWS Association in Germany;

- Costs: 2100€ per person for the total 14 days of training. External professionals need to cover their own costs while internal staff has access to the course for free;
- Objectives of the courses: to help professionals be informed, understanding, empowered, and prepared to communicate with people with PWS, leading to a more independent life for residents and a consequent decrease in the costs of care for the institution;
- Programme contents: the programme is divided into 10 modules: 1) introduction to PWS; 2) Behaviour analysis; 3) Behaviour modifications; 4) Communication; 5) Nutrition management for PWS; 6) Neuropsychology for PWS; 7) Case supervision; 8) Supervised internship; 9) Team supervision; and 10) De-escalation management. A detailed programme for each module was provided;
- Certification: participants receive a certificate after completing the 10 modules and this is the only education certificate for PWS in Germany. [Download the presentation.](#)

### **Orphanet's role in supporting people with Rare Diseases - New tools about disabilities, Orphanet (France), by Odile Kremp (OK)**

OK firstly presented the French context around RDs – the [French National Plans](#) – and the multiple resources provided by [Orphanet](#) encyclopaedia and directories.

More detail was provided concerning the encyclopaedia, which is available in 7 languages and is composed of abstracts, review articles by professionals, clinical guidelines and review articles for patients. These articles for patients (128 texts in French) include information on the disease, diagnosis, genetic aspects, treatment, management and prevention, living with the disease and ongoing research.

Since 2010, information on disabilities has been added to these charts, using three questions: what are the disabilities resulting from the disease? What aids are available to limit and prevent the disability? How is it to live with the disability on a daily basis?

The Orphanet encyclopedia on disability is intended for social and medico-social services and workers as well as health professionals, and derives from both the Orphanet encyclopaedias for professionals and for the general public. The charts contain medical information, a description of the disabilities, supportive measures and consequences in daily life. Texts are exclusively in french and the first 13 fact sheets are already available online (example [here](#) and all current texts available in [Appendix III – Bibliography](#)).

OK then presented the Orphanet Disability Project on indexing the functional consequences of RDs with the International Classification of Functioning, Disability and Health (ICF). This project cross-references the biopsychosocial model of disability with the ICF and has established a new methodology to adapt the ICF to RD populations.

The Orphanet functioning thesaurus combines 10 different topics from all areas of life and uses four qualifiers for limitation type, loss of abilities, severity and frequency in the population and crosses these with environmental factors as well. Detailed questionnaires and methodology were presented.

Data has been collected among medical experts, ICF experts and patient groups from 33 countries. Data is now being indexed and validated by Orphanet and will originate a functioning database. This database will be available in 7 languages at Orphanet's online platform. [Download the presentation.](#)

**Social Profiles as a dialogue/training tool for social workers, Rare Disorders Denmark, by Lene Jensen (LJ)**

LJ started by presenting [Rare Disorders Denmark](#), the national alliance of 47 smaller RD societies and their documentation strategy: the alliance affirms that patients and their societies hold unique experience-based knowledge and therefore collects data in a systematic way, documenting effects of their activities and cases, and making alliances with professionals.

The Social Profiles project has been developed over 4 years, within the framework of a state financed project, enhancing skills for patient society advisers, providing a virtual toolkit for RD patient groups, and raising awareness for RDs in order to avoid stigmatisation.

Why Social Profiles? People living with a RD are often in unknown territory. Because the diseases are rare, social workers and other professionals have no knowledge of their consequences and necessary support; the real expertise as to what is needed is still located among patients and their representatives.

LJ then explained that Social Profiles are a tool for facilitating dialogue between RD patients and professionals, providing only verified facts and a short description of the diagnosis and its characteristics in lay terms, as well as a check-list of relevant support which should be considered in a life time perspective.

Further details were provided on the contents of the description of diagnosis and on the check list. LJ also presented and distributed the example of the social profile for Haemophilia, translated in English, and demonstrated where these resources can be found online. [Download the presentation.](#)

## Outcome of the Workshop

The discussions revolved around all aspects of the draft document: its purpose, target public, content and wording. Some issues were recurrently discussed by the 3 groups and then debated in plenary to reach consensus:

- **The target audience of the document(s):** the groups agreed that authorities and policy makers are one of the main target audiences of the document, considering the need to raise awareness among these decision-makers in order to be able to create the political context in favour of the implementation of trainings. The groups also identified additional audiences who would likely be interested in the document's contents and good practices, such as patient groups, private and publicly-funded social care providers and the RD community at large. Therefore, the groups have concluded during the plenary that, if possible, the document(s) should take into account these publics and a way should be found in order to make sure that all relevant information was shared and target to each corresponding interested group;
- **The type of document(s) that should be produced after the workshop:** the groups agreed on the fact that a political/advocacy document should result from the discussions. The participants suggested it should be an official EUCERD document, in order to ensure its power to influence the current political scenario at national level. During the plenary it was also concluded that the more detailed technical information on training programmes should not be disregarded as it can have immense value to different organisations wishing to set up training courses. Therefore, the consensus was that two documents should be conceived: one advocacy document and one technical document, the later possibly to be complemented by case studies of current trainings;
- **The need to make it clear that this is a document for RDs** and that these have specificities compared to more prevalent diseases: several participants did not consider that the content of the draft document adequately conveyed the specificities of RDs and why it is necessary to train social service providers to deal with RDs as opposed to more frequent medical conditions. Participants suggested that the document should stress more the specificities of RDs such as lack of information, the complexity of cases and the necessity for a multidisciplinary holistic approach;
- **The need to organise the document's content in the most efficient way**, avoiding repetitions but making sure all required information is presented: several discussions were held on the document levels of information and detail. Participants were in favour of a certain amount of detail up to a level of including just the necessary information in order to get the right message to the right audience. Groups agreed that if two documents were to be compiled, the level of detail into the actual technical details of the training programmes should be lower

in the political document and higher in the technical document. The groups also worked on making sure repetitions of content were avoided and that phrasing was clear and adequate.

As a result of the discussions, two final documents are to be compiled: an advocacy document on 'Training for Social Services Providers' and a document of good practices for the creation and implementation of training programmes, the later possibly complemented by and a third document with some curricula of exemplary existing trainings for social services providers.

### **Next Steps**

The original draft document will be then divided into three documents which will go through the following steps:

- Revision of comments with group rapporteurs: Group 1 - Helena Kääriäinen, Finland, Ministry of Social Affairs and Health; Group 2 - Victoria Hedley, United Kingdom, Newcastle University; Group 3 - Odile Kremp, France, Orphanet ;
- Revision by further advisors: EURORDIS volunteers, National Alliances and European Federations for RDs;
- These documents will be disseminated among EJA partners, EUCERD/the replacement 'Expert Group on Rare Diseases' at large, workshop attendees, EURORDIS members and the general public, via [EURORDIS](#) and [EUCERD](#) web pages.

### **Evaluation**

An evaluation questionnaire has been circulated after the workshop by Instituto Nacional de Saúde Doutor Ricardo Jorge (INSA), responsible for EJA WP3 – Evaluation.

The rate of response was 64% and the results of the questionnaire indicate "all respondents agreed (or tended to agree) that the workshop's goals were accomplished, particularly on introduction to EUCERD, EJA and WP6 and on the gathering of diverse stakeholders and the stimulation of debate around the workshop theme and the draft document". All respondents also agreed (93%) or tended to agree (7%) that this was a good opportunity to network and to add value to their previous knowledge on the subject.

Additionally, respondents have mentioned they would use the workshop in "developing training activities", "to emphasize to others, at conferences, the importance of the subject", "in running discussions of development in relation to national strategy", and "to prepare project proposals".

## APPENDIX

### I) AGENDA

#### DAY 1: Thursday 10 October

09:15 Welcome to all participants, *by Dorica Dan, Project Leader, EURORDIS*

09:30 EUCERD Joint Action, *by Victoria Hedley, Newcastle University*

10:00 Specialised Social Services and Integration of RDs into Social Policies: State of the Art, *by Raquel Castro, Social Policies Manager, EURORDIS*

10:30 Coffee Break

11:00 Introduction to the Workshop: context, theme, purpose, methodology and expected outcomes *by Dorica Dan, Project Leader, EURORDIS*

11:30 Introduction to the Document: purpose, contents, annexed case studies, expected outcomes *by Raquel Castro, Social Policies Manager, EURORDIS*

12:00 Visit to the [House of Disabled People's Organisations](#)

12:30 Lunch

14:00 Training programmes for social services providers – Case Studies (30min/each):

Training for professionals working with RD patients *by Lisen Mohr, Frambu (Norway)*

Edubolirare: training for professionals in RD field *by Dorica Dan, Alliance for Rare Diseases (Romania)*

Training for professionals working with RD patients *by Anders Olauson, Ågrenska (Sweden)*

15:30 Coffee Break

16:00 Training programmes for social services providers – Case Studies (30min/each):

Complex Case Managers training programme *by Jean Pierre Lamorte, AFM (France)*

Staff training programme at Adapted Housing Service for Prader–Willi Syndrome *by Norbert Hödebeck-Stuntebeck, Diakonische Stiftung Wittekindshof (Germany)*

17:00 Beyond training programmes: essential tools for the work of social services providers (30min/each):

Orphanet Disability Project and disability charts *by Odile Kremp, Orphanet (France)*

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

18:00 End of the first day

19:30 networking dinner

#### DAY 2: Friday 11 October

9:30 Wrap up from the first day and preparation of second day, *by Raquel Castro, Social Policies Manager, EURORDIS*

10:00 Group discussions on Guiding Principles for Specialised Social Services (coffee in rooms)

12:30 Lunch

13:30 Presentation of conclusions in plenary, *chaired by Dorica Dan, Project Leader, EURORDIS*

14:30 Discussion of conclusions to reach consensus, *chaired by Dorica Dan, Project Leader, EURORDIS*

15:30 Coffee Break

16:00 Wrap-up of workshop and future plans, *by Raquel Castro, Social Policies Manager, EURORDIS*

16:30 End of the second day

## II) LIST OF PARTICIPANTS

### On Set

Country	Name	Authority/Institution
SPAIN	Africa Villanueva Felez	EUCERD/EJA/CIBERER
SPAIN	Aitor Aparicio	SERVICES - RCS/TRAINING - CREER
SWEDEN	Anders Olauson	SERVICES - RCS/TRAINING - AGRENSKA
ROMANIA	Dorica Dan	EURORDIS BOD/NORO/RONARD
ROMANIA	Gheorghe Paun	AUTHORITIES/MoW
FINLAND	Helena Kääriäinen	EUCERD/EJA
EUROPE (UK)	Ian Johnston	IFSW - INTERNATIONAL FED SOCIAL WORKERS
SPAIN	Isabel Peña-Rey	EUCERD
POLAND	Jacek Gralinski	EUCERD
FRANCE	Jean Pierre Lamorte	SERVICES - TI/TRAINING - AFM
DENMARK	Lene Jensen	NA/EUROPLAN - RARE DISORDERS DK
NORWAY	Lisen Julie Mohr	SERVICES - RC/TRAINING - FRAMBU
PORTUGAL	Maria João Freitas	NA/SERVICES - RC - CASA MARCOS
DENMARK	Marianne Jespersen	EUCERD
GERMANY	Norbert Hödebeck-Stuntebeck	SERVICES - AH/TRAINING - GROUP HOMES PWS
FRANCE	Odile Kremp	ORPHANET
EUROPE (FR)	Raquel Castro	EURORDIS
SPAIN	Rosa Sanchez	NA/BOD/HELP LINE - FEDER
PORTUGAL	Susana Candeias	HELPLINE/NA/SERVICES - RC - RARISSIMAS
DENMARK	Sven Fandrup	NA/TRAINING TOOLS - RARE DISORDERS DK
DENMARK	Terkel Andersen	EURORDIS BOD/FIELD WORK
UNITED KINGDOM	Victoria Hedley	EUCERD/EJA/UNEW

### Remote Connections

Country	Name	Authority/Institution
CZECH REPUBLIC	Anita Gaillyová	NA/Nominated by EUCERD/ SOCIAL WORKER
SPAIN	Isabel Fernández Aldeguer	HELPLINE/NA/ SOCIAL WORKER
CROATIA	Nikolina Covic	HELPLINE/NA/ SOCIAL WORKER
FRANCE	Tuy Nga Brignol	HELPLINE/AFM/SOCIAL WORKER

### III) BIBLIOGRAPHY

Paper "Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies", written in the context of EUCERD Joint Action, Work Package 6, November 2012: <http://www.eurordis.org/sites/default/files/paper-social-policies-services-eja-wp6.pdf>

#### EU Documents

Communication from the Commission on Rare Diseases: Europe's Challenge: [http://ec.europa.eu/health/ph\\_threats/non\\_com/docs/rare\\_com\\_en.pdf](http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf) [accessed 29 July 2012].

Council Recommendation of 8 June 2009 on an action in the field of rare diseases (2009/C 151/02): <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF> [accessed 29 July 2012].

Communication from the Commission on European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:EN:PDF> [accessed 29 July 2012].

#### National Plans and National Conferences

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### **Standards of training for Social Service Providers**

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### **Other Relevant Documents**

[Map and information on Specialised Social Services](#)

['Guiding Principles for Specialised Social Services'](#)

[Workshop Report: 'Guiding Principles for Specialised Social Services'](#)

### **Case Studies and Fact sheets on Social Services**

[Therapeutic Recreation Programmes](#)

[Respite Care Services](#)

[Adapted Housing Services](#)

[Resource Centres](#)