EURORDIS
Rare Diseases Europe

EUCERD
Joint Action

CAPACITY BUILDING ON TRAINING FOR SOCIAL SERVICES PROVIDERS

WHAT TO CONSIDER WHEN IMPLEMENTING RD TRAINING PROGRAMMES FOR SOCIAL SERVICES PROVIDERS?

RAQUEL CASTRO
MAY 2014

EMM Berlin 2014
Workshop 4
Integration of RD into Social Policies

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

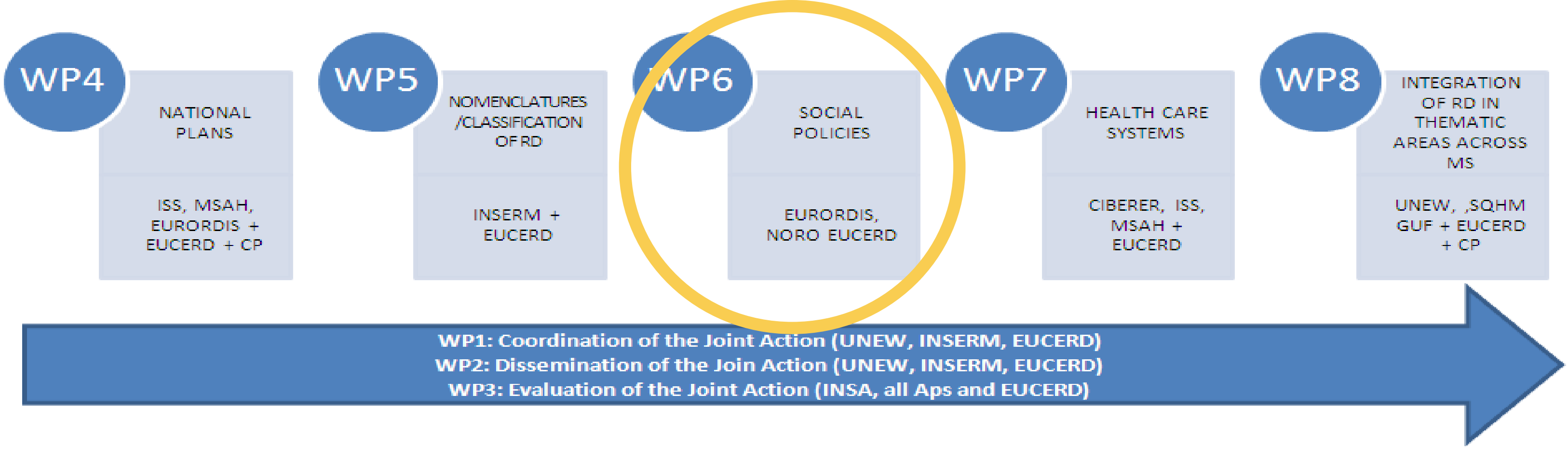
Twenty-five to 30 million people are reported to be affected by these diseases in Europe.
Source: ORPHANET

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

EURORDIS
Rare Diseases Europe

BACKGROUND: EUCERD JOINT ACTION

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



WP4
NATIONAL PLANS
ISS, MSAH, EURORDIS + EUCERD + CP

WP5
NOMENCLATURES /CLASSIFICATION OF RD
INSERM + EUCERD

WP6
SOCIAL POLICIES
EURORDIS, NORO EUCERD

WP7
HEALTH CARE SYSTEMS
CIBERER, ISS, MSAH + EUCERD

WP8
INTEGRATION OF RD IN THEMATIC AREAS ACROSS MS
UNEW, ,SQHM GUF + EUCERD + CP

WP1: Coordination of the Joint Action (UNEW, INSERM, EUCERD)
WP2: Dissemination of the Join Action (UNEW, INSERM, EUCERD)
WP3: Evaluation of the Joint Action (INSA, all Aps and EUCERD)

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

Documents compiled and disseminated:

Guiding Principles for Specialised Social Services

Guiding Principles on Training for Social Services Providers

Case Studies

Fact Sheets

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

BACKGROUND: EUCERD JOINT ACTION GUIDING PRINCIPLES ON SOCIAL ISSUES

EUCERD

GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES

April 2013

EUCERD

+

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES PROVIDERS

TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

April 2014

EUCERD

Guiding Principles for Specialised Social Services
&
Guiding Principles for Training of Social Services Providers
Are **key**:

- To the **integration of people living with RDs into social services**
- For the improvement of the **quality** of the services provided
- Helping more professionals to be fully prepared to handle RDs

Streamlining of resources
Higher quality of care
Empowered and more active patients and families

GUIDING PRINCIPLES ON TRAINING OF SOCIAL SERVICES PROVIDERS

EUCERD

European Union Committee of Experts on Rare Diseases

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES PROVIDERS

TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

April 2014

EUCERD Joint Action

ORIGIN OF THE DOCUMENTS

need for training of social sector professionals in order to prepare them to handle rare complex cases and need to collect consensual guiding principles on a policy level and on a more technical level

=» Workshop from EUCERD JOINT ACTION WP6

Taastrup, Denmark, October 2013

At the [House of Disabled People's Organisations]()

WORKSHOP: TRAINING SOCIAL SERVICES PROVIDERS

Address the issue at policy level and grass roots level

Click here to read the workshop report

Improve the training of professionals and the quality of services provided

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

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

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

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

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

Group discussions on draft document 'Training for Social Services Providers'

Conclusions and consensus in plenary session

EURORDIS
Rare Diseases Europe

WORKSHOP: TRAINING SOCIAL SERVICES PROVIDERS - PRESENTATIONS

EUCERD Joint Action, *by Victoria Hedley, Newcastle University*

SpecialisedSocial 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*

Trainingfor professionals working with RD patients byLisen Mohr, Frambu (Norway)

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

Ågrenska*:* a holistic approach *by Anders Olauson, Ågrenska (Sweden)*

Training process for Case Managers at AFMTELETHON *by Jean Pierre Lamorte, AFM (France)*

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

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

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

click on each title to access the corresponding presentation

DOCUMENT: GUIDING PRINCIPLES TRAINING SOCIAL SERVICES PROVIDERS - POLICY

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD Joint Action Guiding Principles – Training Social Services Providers

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

5

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES PROVIDERS

TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

click here to read the document

April 2014

EUCERD

Mission:

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

EURORDIS Rare Diseases Europe

The Voice of Rare Disease Patients in Europe

Specialised Social Services

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

- Guiding Principles for Training of Social Services Providers - NEW
- Training Principles for Social Services Providers - Workshop Report
- Guiding Principles for Specialised Social

EUCERD European Union Committee of Experts on Rare Diseases

The **European Union Committee of Experts on Rare Diseases** is charged with aiding the European Commission with the preparation and implementation of Community activities in the field of rare diseases, in cooperation and consultation with the specialised bodies in Member States, the relevant European authorities in the fields of research and public health action and other relevant stakeholders acting in the field. Read more

Rare Disease Day 2014: Join together for better care

2013 edition of the State of the Art of RD Activities report now

8th EUCERD meeting: New recommendations adopted

IRDiRC delivers a successful and inspiring conference: a common

Distribution:

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

EURORDIS Rare Diseases Europe

DOCUMENT: GUIDING PRINCIPLES TRAINING SOCIAL SERVICES PROVIDERS

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD Joint Action Guiding Principles – Training Social Services Providers

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

1. Developing training programmes is essential to ensure that each Member State's social services
iving with a RD, raising the quality of
amilies' quality of life.
rocedures in order to guide and inform
hich is likely unfeasible and costly - the
king sure that as many social service
tients at local level and know where to
plex cases.
imilar to those of other professional
rder to facilitate their establishment,
iders is implemented as part of a wider
dealing with people living with a RD.
ge and to the needs of each group of
ey are needed and relevant.
should be updated throughout the
f training should be encouraged and in
span between trainings.
s/Strategies for RDs, Member States
cial services providers, in cross-sector
try of Social Affairs, the Ministry of
rvices and National Alliances for RDs.
ffairs and of Education should do their
tion of these training principles and

5

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES
PROVIDERS

TO THE EUROPEAN COMMISSION,
MEMBER STATES AND ALL
STAKEHOLDERS

click here to read the document

April 2014

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

MISSION, VISION, SCOPE

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD Joint Action Guiding Principles – Training Social Services Providers

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

1. Developing training programmes is essential to ensure that each Member State's social services

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES
PROVIDERS

TO THE EUROPEAN COMMISSION,
MEMBER STATES AND ALL
STAKEHOLDERS

click here to read the document

April 2014

- **Developing training programmes is essential to ensure** the **quality of services** and **increase patients' and families' quality of life**
- **Making sure that as many social service providers as possible are habilitated to properly care for patients**
- **follow structures and requirements similar to those of other professional training programmes** existing at Member State level
- **implemented as part of a wider national cross-sector training programme for professionals** dealing with people living with a RD
- Trainings should be **appropriate and proportionate**
- **Continuity of training should be encouraged**

EURORDIS
Rare Diseases Europe

TRAINING AND THE NATIONAL PLANS/STRATEGIES

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

click here to read the document

April 2014

- When elaborating, evaluating or revising **National Plans/Strategies for RDs**, Member States should strive to **include a proposal for the training of social services providers,** in **cross-sector collaboration** between the Ministry of Health, the Ministry of Social Affairs, the Ministry of Education, Centres of Expertise, national Specialised Social Services and National Alliances for RDs.

- **National authorities** and ministries of Health, of Social Affairs and of Education should do their utmost to be **involved in the promotion or implementation of these training principles and programmes.**

FUNDING, EVALUATION AND ACCREDITATION

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD Joint Action Guiding Principles – Training Social Services Providers

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

1. Developing training programmes is essential to ensure that each Member State's social services

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES
PROVIDERS

TO THE EUROPEAN COMMISSION,
MEMBER STATES AND ALL
STAKEHOLDERS

click here to read the document

April 2014

- **Funding** mechanisms need to be **adequate and long-term**.
- It is then recommended that:
  - These programmes are funded by the **mechanisms normally used in each Member State** to support training of professionals
  - **Specific public funding** be mobilised **for the initial implementation phase**
- The **National Plans/Strategies for RDs allocate funds** to the initial implementation phase
- **Training assessment** is included in the internal and external evaluation of the services
- **System for accreditation** of the trainings is implemented, in order to evaluate and guarantee the quality of the training programmes

EURORDIS
Rare Diseases Europe

COLLABORATIVE, CROSS-SECTOR MULTI STAKEHOLDER HOLISTIC APPROACH

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES PROVIDERS

TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

click here to read the document

April 2014

- Trainings should be organised in **cooperation between all relevant parties** who can provide consultancy and valuable input such as:
- **Centres of Expertise**
- **Orphanet's national teams**
- **National Help Lines**
- **Patient Organisations**
- **Families and Patients**
- **International Professional Networks**

CONTENT AND ORGANISATION

Document copies available in this session room! Take yours, read it, use it, share it!


EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES
ON TRAINING FOR SOCIAL SERVICES PROVIDERS
TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

click here to read the document

April 2014

- Following the same principle of COE and ERNs, it is recommendable that training **programmes are organised by therapeutic domains or [groups of] diseases**
- Trainings should **provide professionals with information and tools**, **prepare them to act and** be able to **establish a follow-up and bi-lateral communication system between trainers and trainees**
- Training programmes should reinforce the promotion of an **ethical and non-discriminatory attitude/policy** amongst professionals of the social sector towards people living with a RD.
- Trainings should **promote RD specific tools** such as:
  - Orphanet Encyclopaedia;
  - Orphanet disability charts;
  - Orphanet **rare disease disability core sets** and an **online database crossing RDs and disability indicators;**
  - National helpline and other relevant support services and organisations
  - EURORDIS InfoHub

CONTENT AND ORGANISATION

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES
ON TRAINING FOR SOCIAL SERVICES PROVIDERS
TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

April 2014

click here to read the document

- Training programmes' contents should include:

i. Information on the disease/group of diseases, the **medical consequences** and **treatments**;

ii. Information on the **disabilities generated,** the **psychosocial consequences** and the **consequences on patients' daily lives, life paths and autonomy**;

iii. The importance of the **multidisciplinary and cross-sector work**;

iv. **National and international sources of information and support**, including Orphanet, EURORDIS, local and national patient organisations, help lines and other RD specific tools;

v. Communication and **cooperation with health care** providers, professionals involved in **education and other professionals involved in patient care**;

vi. **Communication** with **patients and families**;

CONTENT AND ORGANISATION

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

April 2014

click here to read the document

- Training programmes' contents should include:

vii. **Patients' and families' rights** and relevant legal frameworks;

viii. The importance of **individual care**;

ix. The importance of **peer support**;

x. Patients' **psychological and emotional features**;

xi. **Adaptation of the environment** to the needs of the patient (home, school, work);

xii. **Security** measures;

xiii. **Other relevant issues for the specific target** group (neuropsychology, behavioural issues, nutrition, transition from childhood to adulthood, etc.).

CONTENT AND ORGANISATION

Document copies available in this session room! Take yours, read it, use it, share it!

EUCERD Joint Action Guiding Principles – Training Social Services Providers

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

EUCERD

EUCERD JOINT ACTION
GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES
PROVIDERS

TO THE EUROPEAN COMMISSION,
MEMBER STATES AND ALL
STAKEHOLDERS

click here to read the document

April 2014

- Trainings should include **practical training** and preparation for real situations, via role playing or other methods deemed adequate
- Trainings should anticipate a model for **effective feedback and follow-up**, once the training is completed and the social service providers have to face real situations
- Trainings should make **the optimal use of information and communication technologies** in order to streamline resources and reach more professionals efficiently.

EURORDIS
Rare Diseases Europe

BEYOND THE POLICY DOCUMENT

How to make
Training for Social Services Providers
a Reality

Various stakeholders need to take action

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

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

Contents need to be refined: a **complementary document** will be prepared, on the more technical aspects of training shared by experts during the workshop in Copenhagen

Beyond the Policy document – The Technical Document

Based on the junction of:

- The workshop group discussions and draft document comments

+

- The collection of quotes and examples of actual training programmes for RD run by different providers - Frambu, Norway; Agrenska - Sweden; AFM - France; Edubolirare - Romania; Adapted Housing Prader-Willi Syndrome – Germany

Intended to focus more on technical aspects and less on policy

BEYOND THE POLICY DOCUMENT – THE TECHNICAL DOCUMENT

What makes sense to you as a patient?

What would be the level of detail you would need on…?:
1) Logistical issues (like rooms, steps to set up training, etc. and 2) content issues (subjects, examples of specific curricula)

Is your patient group involved in trainings in your country?
With what role?

Do you envisage to become a training provider?

Do you have any training curricula to share?

EURORDIS
Rare Diseases Europe

EURORDIS
Rare Diseases Europe

Berlin, May 2014
raquel.castro@eurordis.org